Understanding the journeys of Black Caribbean parents who have children with autism.

Karla Jane Bates

A thesis submitted for the degree of Doctorate in Child, Community and Educational Psychology

Tavistock and Portman NHS Foundation Trust

University of Essex

September 2024

39,987 words

CONTENTS

TABLES

FIGURES

ILLUSTRATIONS

ACKNOWLEDGEMENTS

Thank you to my friends and family for their love and support, and to everyone who supported this research from beginning to end; to Dr. Adam Styles, my research supervisor, for his invaluable guidance and encouragement; and lastly, to the incredible participants who made this research possible.

ABSTRACT

This qualitative study explores the journeys of Black Caribbean parents (BCPs) living in the UK who have children with autism. It focuses on the experiences, thoughts, and processes surrounding a BCP's child's autism diagnosis, and how cultural factors intersect with them.

This study contributes to a small but growing body of knowledge exploring both autism and culture. It elevates the voices of BCPs, who have not yet been exclusively represented in autism research. It also presents the perspectives of a group widely reported in education statistics (e.g., school exclusion and attainment rates), but often not heard themselves.

Six BCPs were interviewed using semi-structured interviews, who collectively had ten children with autism. A grounded theory methodology (Corbin and Strauss, 2015) was used to analyse the data, resulting in the development of the *essential super-advocacy theory*.

The essential super-advocacy theory proposes that BCPs who have children with autism are required to become *'super-advocates*' to provide the essential, fervent, and persistent advocacy that their children will need. It presents three '*essential super-advocacy factors*' needed to do this, which are a) *enhanced autism awareness and ongoing learning*, b) *the ability to overcome stigma and inner conflict,* and c) *connection and collaborative support*.

The essential super-advocacy theoretical model illustrates how these factors are developed over time and across three stages. These stages involve a series of events and processes shaped by the BCP's socio-cultural contexts and experiences.

The implications of these findings consider how Black Caribbean parents and their children with autism can best be supported by professionals who work with them, including educational psychologists.

1 INTRODUCTION

This qualitative research explores the experiences of Black Caribbean parents (BCPs) who have children with Autism. It pays particular attention to the processes and factors involved in identifying autism as well as parent experiences before, during and after diagnosis. This research uses a grounded theory (GT) methodology as the aim was to develop an explanatory theory to inform and improve the outcomes and wellbeing of this population group.

1.1 Research rationale

There is currently a gap in research that explores the views and experiences of parents in the UK from minority ethnic groups that have a child with autism (Desai et al., 2012; Edwardraj et al., 2010; Russell & Norwich, 2012). There are also currently no studies that focus on the experiences of BCPs who have children with autism in the UK. This knowledge is essential to improve understanding of culturally specific conceptualisations and experiences of autism, and to develop a culturally informed approach (Perepa, 2014; Slade, 2014; Theara & Abbott, 2015).

Key legislation, notably the Special Educational Needs and Disabilities (SEND) Code of Practice (DfE, 2015) and the Children and Families Act (2014) emphasise the importance of person-centred planning and a family-centred approach. Cultural awareness and sensitivity are a crucial part of this. The Equalities Act (2010) also highlights the responsibility of professionals to have an awareness of the prevalence of SEND across ethnic minority groups and the issues that might affect them. Seeking the views of and building positive relationships with individuals, families and professionals around the child is central to the work of the Educational Psychologist (EP). These aspects make this research especially relevant to the EP profession.

1.2 Why Black Caribbean parents?

Significant attention has been drawn to the current outcomes of Black Caribbean children in education, including high fixed-term and permanent exclusion rates (Department for education [DfE], 2023), comparatively low attainment levels (DfE, 2022), and being three times more likely to be identified as having social, emotional and mental health needs (SEMH) and moderate learning difficulties compared to White British children (Strand & Lindorff, 2018; 2021). Historically, during the 60s and 70s, when the British Government invited workers from the Caribbean to fill the post-war labour shortage, Black Caribbean children were overrepresented in schools deemed for those with ‘low intellectual abilities’ (at the time referred to as educationally subnormal schools) (Wallace & Joseph-Salisbury, 2021). In these schools, access to an adequate education and curriculum was low, as were expectations and opportunities for the children. In a landmark book from 1971, Bernard Coard discussed the issue. He stressed that many of the children who were new to the country did not have low intellectual abilities, but tests were culturally biased, and the trauma of immigration was not taken into account. Parents played a pivotal role in campaigning for a change in this system, and thereafter, the 1981 Education Act abolished the term Educationally subnormal and mandated the inclusion of children with special educational needs into mainstream schools (John-Baptiste, 2021). These examples begin to demonstrate the distinct and challenging current and historical circumstances of the Black Caribbean group in the area of education in the U.K. It is, therefore, necessary and important to build research that provides greater understanding and better knowledge to improve the support, practice and tools used to enable positive change. Elevating the voices of BCPs will be essential to help accomplish this.

1.3 Why autism?

Autism has become an area of increasing importance to professionals working with children and families, especially as the identification in school-aged children doubled in England between 2005 and 2014 (McConkey, 2020; Strand & Lindorff, 2019). Prevalence is currently predicted to be at 2.9% for 5–19-year-olds, over a 1% increase from the 2017 census data (O’Nions et al., 2023). Autism is also currently the most common primary need on educational health care plans (EHCPs) in England (Strand & Lindorff, 2018). There is growing research on the prevalence rate across ethnicities in the UK. A recent longitudinal study in the UK found a higher prevalence of autism among Black and minority ethnic children (Roman-Urrestarazu et al., 2021). Further research will be needed to better understand the prevalence rates of individual Black groups within the broader ‘Black’ category and important key information, including the age of diagnosis, events leading to diagnosis, and the support put in place post-diagnosis. Whilst the current research is not about prevalence rates, it provides valuable insight into the experiences and perceptions of autism from parents of the Black Caribbean group, which can make an important contribution to future research in this area.

The DSM-V identifies autism as a spectrum that can lead to varying levels of difficulty for individuals in the areas of social Interaction, communication and language, and repetitive patterns of behaviour and interest (2022). It is also defined as a complex and lifelong developmental disability that is difficult to accurately diagnose and can have a significant impact on individuals and their families (Ravindran & Myers, 2012). However, early identification and appropriate intervention have been found to facilitate positive outcomes for children and their families (Fernell *et al*., 2013; Freeman, 1997). Parents, educational psychologists, and all those working with children and families in education and healthcare are, therefore, ideally positioned to develop culturally specific knowledge. This research aims to contribute to that knowledge and inform the development of culturally sensitive recommendations and tools, and improved person and family-centred practice.

1.4 Autism terms

Different terms are often used by researchers to refer to autism. common terms used include autism spectrum disorder (ASD), and autism spectrum condition (ASC). The term chosen will often reflect the researcher's professional and philosophical orientation. The medical field typically uses ‘ASD’, but those that ascribe to the social model of disability (the theory that people are disabled by barriers in society, not by their impairment or difference) tend to avoid using language like ‘disorder’ as it is considered negative and a term focused on deficits. For this research, the term autism will be used which is also the preferred term used by the National Autistic Society. This reflects the researcher's view that it is important to speak about autism in a way that reflects the whole person, including strengths and abilities.

1.5 Culture and ethnicity definitions

As this research focuses on the experiences of a group that shares key aspects of cultural and ethnic identities, it is important to first define these terms and how they are conceptualised in this study.

Culture refers to the shared beliefs, values, norms, customs, and practices that characterise a particular group or society, that are socially transmitted from one generation to the next

(O’Hagan, 2001). These can include ways of dress, religious ceremonies, patterns of work, language and family life (Giddens, 1993).

Matsumoto builds on the above by providing a psychological perspective that views culture as a complex system of shared meanings, values and practices that shape how individuals interpret and interact with the world (2001). While recognising the universality of underlying psychological processes, his work focuses on how cultural influences shape the experiences and expression of emotion and psychological processes. This stresses the importance of cultural awareness, particularly in healthcare, mental health, and diagnoses.

Ravindran and Myers (2012), in their paper "Cultural Influences on Perceptions of Health, Illness, and Disability: A Review and Focus on Autism," adopt this definition to understand how cultural beliefs and attitudes influence understanding and help-seeking behaviours regarding autism. Their 2013 paper focuses on South Asian Parents and is, therefore, of similar interest to the current research.

Ethnicity refers more specifically to groups defined by shared characteristics, such as ancestry, history, language, traditions, and geographical origins (American Psychological Association, n.d.) Anthropologists have emphasised that ethnicity is less about biological or genetic similarities and more about the social constructs and collective experiences that create a sense of belonging (Perepa & Jordan, 2019). Therefore, in the same way that culture shapes the expression of universal processes and the interpretation and interaction with the world, so does ethnicity.

The concepts of culture and ethnicity are complex and multifaceted and cannot be fully explored within the scope of this research. However, based on the studies reviewed, the Matsumoto definition, used in similar studies as discussed, will be adopted. It recognises the role of culture and ethnicity in the conceptualisation and expression of emotions and psychological processes and is most relevant to the aims and field of this research.

1.6 Thesis structure

This thesis has five chapters. The current Introduction chapter outlines the research rationale with key background information. Chapter two is the methodology and outlines the methods of this research including epistemological and ontological position. Typically, the literature review would follow the introduction; however, in line with traditional GT methodology, the literature review was conducted after analysing the data and is, therefore, the fourth chapter. This is to help minimise the influence of literature on analysis and the concepts that derive from it (Corbin & Strauss, 2015). The post-analysis literature review compares, contrasts, enhances, and confirms findings. It also reviews the theoretical frameworks in the literature and their relevance to the current research. This might be typically seen in an introduction chapter, but as the GT methodology discourages using existing theories during analysis, it was reserved for the post-analysis literature review. The third chapter is the findings that present a detailed breakdown of the GT derived from analysis. The fifth and final chapter discusses how the findings can be used to support real-world change, including recommendations, limitations, and areas for further research. Both the findings and literature review chapters are substantial sections that provide detailed information to support an in-depth understanding of the theory. Furthermore, given the current contexts and the absence of research on BCPs who have children with autism in the U.K., it was important to amplify their voices as much as possible.

2 METHODOLOGY

2.1 Chapter overview

This chapter outlines the background and development of this research, including the theoretical stance and methodological approach.

2.2 Research purpose and aims

The purpose of this research was to attain a theory on the experiences of Black Caribbean Parents who have children with autism in the UK. The main questions it aimed to answer were:

1. How do cultural beliefs, values and experiences shape parents' conceptualisation of autism?
2. How are the processes of identification, diagnosis and intervention experienced?
3. How do ethnicity and cultural factors intersect with these experiences?

This research is exploratory and explanatory. Its main purpose is to explore the experiences of BCPs who have children with autism in the UK and analyse how culture and ethnicity intersect with them. In doing so and deriving a theory, this research also provides an explanation of BCPs' experiences.

These aims are important because no research is currently dedicated to this phenomenon. Therefore, it aims to provide new and valuable information to the educational, psychology, healthcare, and related fields to encourage culturally diverse and person-centred approaches to autism practice.

2.3 Research orientation, ontology and epistemology

From a cross-cultural viewpoint, this research adopts a universalist approach. This concept derives from the work of Berry and colleagues (2009), who identified four main perspectives when investigating phenomena across cultures. Universalism is situated between absolutism (the assumption that all human phenomena can be viewed and understood in the same way, irrespective of culture or environment) and relativism, which suggests that they are entirely shaped by cultural contexts (Berry, 2013). The universalist approach believes that basic human characteristics and psychological processes are universal; however, culture and environment impact the development, display and meanings attached to them. Therefore, what is understood and recognised as autism within one cultural context might not look the same or mean the same things in another. This position argues that gaining a better understanding of how behaviours and experiences are conceptualised cross-culturally (and the values and beliefs attached to them) is an essential and much-needed consideration in autism practice. This is to raise understanding and culturally sensitive support while validating the unique experiences and perspectives of people from different backgrounds (Ravindran & Myers, 2012).

The current research's ontological position is, therefore, critical realist, a perspective developed by Bhaskar (1975). Critical realism considers the existence of a fundamental universal reality, but how this is perceived and understood is shaped by contextual factors, i.e., time, place, gender, ethnicity, cultural, political and religious beliefs, etc.

This research aimed to qualitatively explore contextual factors and lived experiences by engaging with participants through semi-structured interviews. Different epistemologies can be adopted within the critical realist framework, but as this research seeks to explore lived experiences interactively through interviews, it aligns with the social constructivist epistemology.

2.4 Grounded Theory- ontology and epistemological considerations

Grounded theory (GT) is a qualitative research methodology developed in the 1960s by sociologists Glaser and Strauss. Their methodology allowed for the development of a theory grounded in the data by identifying concepts and processes that present new insight into the studied phenomena. '*Discovery of Grounded Theory'* (1967) provided a systematic and flexible procedure for analysing data the GT way. Their approach was considered groundbreaking due to the absence of a preliminary hypothesis and the emphasis on theory development (Charmaz & Thornberg, 2020).

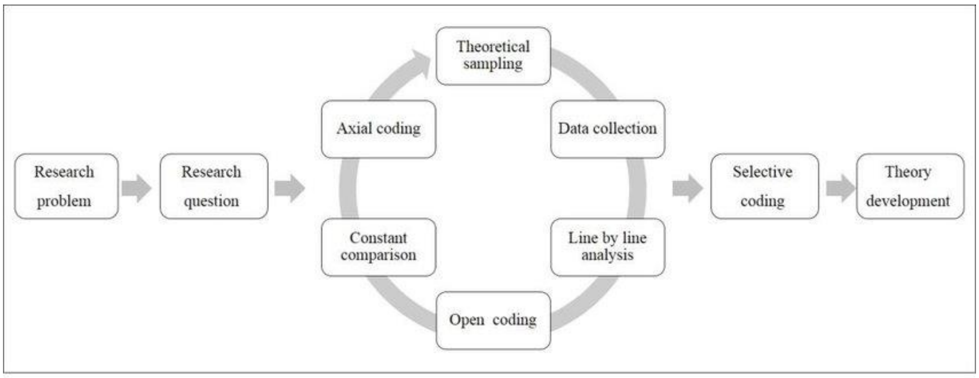


Figure 1. Grounded theory methodology flow chart

Further Key principles of GT include the iterative process, in-depth analysis and inductive approach. As Figure 1 shows, data collection and analysis happen in cycles rather than linearly. A set of data is analysed, and the concepts derived from it are used to guide further data collection. This is known as theoretical sampling and is used to develop the theory. The systematic process starts with line-by-line analysis where 'open codes' denoting meaning are assigned to small data sections. These open codes are then refined and integrated into categories (axial and selective coding) by 'constant comparison'- the repeated comparison of data to identify similarities and differences. These processes lead to deriving the core theme and theory. Conducting the literature review after theory development was also advised by Glaser and Strauss (1967) to reduce the influence of existing research on findings. This bottom-up approach made GT innovative and provided a rigorous methodology for qualitative research (Denzin & Lincoln, 2011).

An interactionist philosophy underpins GT and aligns with the current research's orientation and worldview. Mead (1932,1934,1938) and Blumer (1969), often considered the fathers of symbolic interactionism, assert that the meaning applied to knowledge, self and society is created through interaction between individuals within a social context using language and symbols. According to Interactionists, examining this action and interaction 'in routine as well as problematic situations' supports a better understanding of how they relate (Corbin & Strauss, 2015).

Qualitative methodologies such as GT allow for the in-depth analysis of actions and interactions and the meanings attached to them, producing a better understanding of participants' perceptions and life experiences (Corbin & Strauss, 2015). Furthermore, while Interactionism is a detailed and multifaceted philosophy, it aligns with the social constructivist epistemology at a fundamental level. Social constructivism relies on the collaborative construction of knowledge through shared language to interpret and understand social phenomena (Charmaz, 2014).

Generating theory grounded in data best suited the exploratory purpose of this research. The aim was not to test pre-formulated hypotheses but to explore and develop a deeper understanding of the voices and experiences of BCPs who have children with autism.

Grounded theory was developed to derive theory from complex real-world social interactions and processes (Tie et al., 2019), which was more appropriate for the current research than the more descriptive thematic analysis (TA) (Braun & Clarke, 2006). As developing a theory was a key aim of this research, interpretative phenomenological analysis (IPA) (Smith et al., 2009) was also not considered appropriate as it focuses more on the ideographic experiences of participants, i.e., the nuances of individual stories (Oxley, 2016), rather than the explanation and understanding of patterns and shared experience.

2.5 Rationale for Corbin and Strauss (2015) Grounded theory

Since the introduction of GT in the 1960s, new versions have been developed considering more contemporary philosophical paradigms, namely constructivism and postmodernism. Glaser and Strauss's GT, is often referred to as classical GT as it adopts a more positivist approach to qualitative research. This is the idea that the researcher is a detached observer, able to measure, record, and report qualitative information with little to no influence on the process or derived theory. However, constructivist and postmodern thought in GT considers the researcher to be the constructor of theory (using the data). It emphasises that the understanding and meaning of events can be interpreted in different ways (Farragher & Coogan, 2018). Constructivist GT, developed by Charmaz, is considered the contemporary version of GT with these philosophical underpinnings (Charmaz, 2014). Corbin and Strauss's 2015 *'Basics of Qualitative Research 4th Edition'* is often considered the middle ground. Historically, Corbin and Strauss primarily held an interpretive philosophical stance, which views the researcher as engaged and actively interpreting the data (Sebastian, 2019). However, in the 2015 4th edition of their GT guide, Corbin expresses close alignment with constructivism, marking a shift in epistemological positioning:

> *I agree with the constructivist viewpoint that concepts and theories are constructed by researchers out of stories that are constructed by research participants who are trying to explain and make sense out of their experiences and lives, both to the*

> *researcher and themselves. Out of these multiple constructions, analysts construct something called knowledge. (Corbin & Strauss, 2015, p. 26)*

What perhaps distinguishes the 2015 Corbin and Strauss GT from the Charmaz Constructivist GT, however, is Corbin's emphasis on the belief that constructed concepts and ideas correspond to real-world events and that through common culture, 'common meanings are arrived at through discourse' (Corbin & Strauss, p. 26, 2015). This would make it possible for research findings to be validated through different external perspectives, e.g., a literature review, which was an aim of the current research. Constructivist GT, on the other hand, does not emphasise validation, as the constructed theory is considered a unique interpretation that does not serve as a representation of reality (Sebastian, 2019).

Another distinguishing feature of the 4th edition of Corbin and Strauss GT is the apparent greater emphasis on 'teaching persons how to think more self-consciously and systematically about data' (Corbin & Strauss, p. 25, 2015). As Corbin writes:

> *I want to emphasize that techniques and procedures are tools to aid with analysis and not directives. … The analytic process, like any thinking process, should be relaxed, flexible, and driven by insight gained through interaction with data. (p. 26)*

This balance of using an established and systematic methodology in a flexible way appealed to the researcher. It provides rigour, which is important in GT research, while also recognising an insightful aspect of analytic processes.

Therefore, the Corbin and Strauss 2015 GT was chosen for this research. It aligns with the research's epistemological and ontological assumptions. It agrees that meaning and understanding of action and interaction are developed through common culture and dialogue. It provides a balance of structure and flexibility and can be used to inform positive, real-world changes.

2.6 The researcher

> *"An important consideration in theory building is what the researcher brings to the research process in terms of philosophies, experience, professional background, and interests. These factors influence the choice of topics, approach to analysis and where the emphasis is placed." (Corbin & Strauss, p. 29, 2015)*

The researcher's interest in working with children and families started in her own childhood, as her mother was a carer and playscheme leader for children with special needs and disabilities. The researcher went on to work in education for 11 years as a secondary school teacher in inner-city London and later trained in low-intensity cognitive behavioural therapy (CBT) for children and young people with the NHS. A large part of this role was working with parents and supporting them to implement CBT strategies at home with their children who were experiencing anxiety, behavioural challenges or low mood.

The researcher is currently at the end of her educational psychology training. Her first-year placement was with a Children and Adolescent Mental Health Service (CAMHS) Neurodevelopment Assessment Centre, where she worked as part of a multidisciplinary team to assess autism and deliver post-diagnostic support. The inspiration for the current research was developed while on this placement after working with a Black Caribbean mother and her 14-year-old son. He was at risk of exclusion from school, and his SENCO referred him for a neurodevelopmental assessment, suspecting that he might have autism. This work sparked many questions that eventually led to a research proposal.

The researcher is of Black Caribbean heritage and was born in the UK. Her experiences, interests, background, and profession led her to this research topic and population group. Also the desire to contribute new information to the field, promote enhanced cultural sensitivity among professionals, and support the wellbeing and care of children, young people, and their families.

2.7 Ethical considerations

2.7.1 Regulatory approvals

An ethics application was made to the Tavistock Research Ethics Committee (TREC), which was reviewed and approved on 6 April 2021 (see Appendix 1). Permission was also requested from the local authority (LA), where recruitment information would be shared and was granted (Appendix 2). The research design complied with the British Psychological Society (BPS) Code of Ethics and Conduct (BPS, 2021) and the Standards of Conduct, Performance and Ethics for Practitioner Psychologists (Health Care Professions Council [HCPC], 2008).

2.7.2 Consent

All participants were provided with written information about the research in a letter and consent form (Appendix 3). The text was written in plain English without technical language. If required, a video presentation with the same information in audio was made available. They were invited to contact the researcher if they had questions or wanted to discuss anything further. Table 1 outlines the details of the research information letter.

The research information letter informed all participants of the following:
• The research topic and purpose, and the criteria for taking part
• What participation would involve, including the forum (online) and how long it will take
• The interview would be audio recorded and stored securely on a password-protected computer
• All data, including the audio recordings and demographic information collected, would be stored according to the Data Protection Act (2018) and Tavistock TREC procedures
• All transcripts, notes, and memos would be anonymised, pseudonyms ascribed and made strictly confidential, with only the researcher and research supervisor having access
• The limits of confidentially, i.e., those who know them very well might recognise aspects of their stories even when anonymised
• Anonymised findings would be included in the research paper
• Recalling some experiences might be upsetting, so there would be a provided list of supportive services that might be helpful in that circumstance
• They have the right to withdraw from the research and have their data removed at any point up until data analysis starts, and this can be done without explanation, disadvantage, or consequence. The difficulty of withdrawing after analysis was explained
• They can contact the researcher or the Tavistock Trust Quality Assurance Officer if there are any problems or queries about the conduct of the research

Table 1. Details of the research information letter

Prior to participating, written voluntary consent was obtained from all participants.

2.7.3 Mitigating risk and promoting wellbeing

In line with the BPS code of ethics, the researcher considered the psychological wellbeing, mental health, personal values, and dignity of participants while aiming to mitigate potential risks. As mentioned above, due to the nature of the research topic, recalling and discussing some experiences might be distressing to participants. With this in mind, the researcher was attentive to the needs of the participants and made them aware of their rights throughout the research process. Table 2 outlines the measures taken to do this.

Measures taken to mitigate risk and promote wellbeing
• In the information letter, pre-interview email, and at the beginning of interviews, participants were informed that sharing some experiences might be distressing
• A list of therapeutic and relevant services was provided if they needed further support
• It was ensured that a time and date suitable for the participant was arranged
• Participants were reminded that they were free to take a break or end the interview at any point if needed
• The researcher, a trainee educational psychologist experienced in therapeutic work with parents of children with SEND, used a professional, nonjudgmental approach in all interviews
• Empathy and sensitivity were shown to the emotions expressed by the participants
• At the end of each interview, participants were signposted to information regarding relevant services, including national and local parent organisations, culturally specific support groups and health and wellbeing charities and helplines.

Table 2.Measures taken to mitigate risk and promote wellbeing

2.8 Validity and reliability issues

Yardley offered four ‘characteristics of good (qualitative) research’ (Yardley, 2000 p. 2019), a comprehensive and flexible set of principles to evaluate qualitative research (see Table 3).

Characteristics of good (qualitative) research. Essential qualities are shown in bold, with examples of the form each can take shown in italics.
Sensitivity to context *Theoretical; relevant literature; empirical data; sociocultural setting; participants' perspectives; ethical issues.*
Commitment and rigour *In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.*
Transparency and coherence *Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method; reflexivity.*
Impact and importance *Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers).*

Table 3. Characteristics of good (qualitative) research (Yardley, 2000, p.219)

The researcher used Yardley's approach to evaluate the current research (below) as it provides a set of important principles that fit well with Corbin and Strauss's (2015) GT in a clear, open-ended and flexible way.

2.8.1 Sensitivity to Context

Yardley suggests that there are different aspects of 'context' that are important for the researcher to be sensitive towards. One aspect is the context of theory and the 'understandings created by previous investigators' as this supports the 'sophistication of the interpretation of the data' (Yardley, 2000, p. 219). The current research has included a detailed literature review that examines both the theoretical contexts of previous studies and the findings. This has added depth and an enhanced understanding of how the current research fits within the current discourse. It has also supported the development of recommendations and implications for practice, as seen in the final chapter.

Another aspect of context sensitivity proposed by Yardley, is sensitivity to the data itself. One way of demonstrating this is through 'corroborating' theory with 'compelling empirical evidence’ (Yardley, 2000, p. 219). As there are no preliminary hypotheses in GT, the corroborating happens after the theory has been developed. The literature is therefore used as a source of empirical evidence to ‘validate findings and show how the theory supports, adds to, or amends other theories dealing with the same phenomenon’ (Corbin & Strauss, 2015, p. 371). As the ’Comparative Review’ section shows, there is a thorough demonstration of how each section of the current GT is validated and supported by the literature and also where there are differences.

Yardley also considers the awareness of the sociocultural setting of the study and participants crucial for having the sensitivity needed to understand and interpret the data. This includes the historical, ideological, and socioeconomic influences on beliefs and expectations (Yardley, 2000, p. 220). The researcher’s professional experiences and background (as outlined above) supported this sociocultural sensitivity. Additionally, self-reflection was practised as outlined by Corbin and Strauss (2015) to examine the influence of feelings, thoughts and assumptions on the research process. This was achieved by memo writing and reflection in supervision with an experienced senior educational psychologist and research supervisor.

2.8.2 Commitment and Rigour

Yardley explains that ‘commitment and rigour’ correspond to ‘the usual expectations for thoroughness in data collection, analysis, and reporting any kind of research’ (Yardley, 2000, p. 221). More specifically, commitment involves ‘prolonged engagement with the topic’, not just as a researcher, but also through professional/work or personal capacity (Yardley, 2000, p. 221). As explained above, the researcher has over 20 years of working with children and families, with an interest in autism and neurodiversity. However, engagement with the current research has been sustained and thorough to ensure full immersion in the data and rigorous, in-depth data analysis.

Rigour is referred to as the ‘resulting completeness of the data collection and analysis’, which should ‘ideally address all the variation and complexity observed’ (Yardley, 2000, p. 221). The main phenomenon of the current research’s GT, as will be explained, encompasses variation and complexity and explains the ‘why and how’, a characteristic of theory as opposed to description (Corbin & Strauss, 2015). The researcher acknowledges that the GT of the current research can be further developed as more research into the phenomena is conducted. The process of in-depth data analysis was followed however, and the researcher felt that ‘well-developed’ and ‘sufficient’ concepts for the purpose of the research were achieved that show variation and good integration (Corbin and Strauss. 2015, p. 135). The significant corroboration of the findings with the literature also provides some validation of the derived theory.

2.8.3 Transparency and Coherence

Transparency and Coherence refer to the ‘clarity and cogency’, of the research, the ‘fit between the research question and the philosophical perspective adopted’, the ‘presentation of the analysis and data’, and ‘openly reflecting’ on how different factors might impact the research (Yardley, 2000, p. 222). MAXqda, computer-assisted qualitative data analysis software, helped ensure and demonstrate transparency in applying the Corbin & Strauss 2015 iterative coding process and analysis. This was shared and discussed with the researcher’s supervisor. The presentation of the theoretical diagrams and illustrative use of quotes also aimed to provide further clarity and understanding of the research findings. The philosophical perspective fits the research question and aims as explained above.

2.8.4 Impact and importance

Impact and utility are suggested by Yardley as the decisive criterion for research. This involves achieving the objectives set out by the research and having an impact on the community that the research involved. Usefulness is also considered the ‘theoretical worth’ and being able to accurately explain and contribute a new perspective ‘which opens up new ways of understanding a topic’ (Yardley, 2000, p. 222). As explained earlier, the current research aims to support professionals in the psychology, education, and healthcare fields to better understand the target group and improve practice and care. The aim is also to support changes that consider the wellbeing and care of an underrepresented group in current research. As Corbin states ‘I am practical in what I want to accomplish with my research… I want to bring about social change and make persons’ lives better’ (Corbin & Strauss, 2015, p. 27). As there is currently no research on BCPs who have children with autism in the UK, the researcher hopes that this study will begin to achieve this.

2.9 Research method

2.9.1 Sampling

The aim was to recruit 6-8 Black Caribbean parents in the UK who have a child or children with an autism diagnosis. This sample size is considered adequate for a small-scale GT project using qualitative semi-structured interviews (Braun & Clarke, 2013). As the research question aims to explore a specific phenomenon about a select group, the size reflects this also (Morse, 2000). Sufficient analysis of the rich data would also be feasible during the research project's timeframe.

Initially, the research was going to focus on parents of children with autism who were diagnosed during mainstream education (between the ages of 5 and 18); however, the researcher decided, in discussion with their supervisor, that due to the small population group, it would be best to include parents of children diagnosed at any age, and/or at any educational setting. It took some time before parents began registering interest, and it was therefore important not to exclude those who were interested but did not fit the initial criterion. The amendment was submitted and approved by TREC (see Appendix 4). For full participant inclusion criteria, see Appendix 5.

Following permission from the researcher's LA, service professionals working with children and families were asked to forward the information letter, presentation and consent form to parents they knew who might fit the criteria. An information poster (Appendix 6) was also shared with relevant services and schools, including a summary of the research purpose, participant criteria, and researcher contact details.

Six parents responded to the research information (see Table 4) and returned a signed consent form to the researcher via email.

2.9.2 Participant information

Interview No. & early-diagnosed group (LDG) or later-diagnosed group (LDG)	**Parent Pseudonym & Background**	**Occupation or Occupational background**	**Place of birth**	**Caribbean Heritage**	**Child pseudonym**	**Age of autism diagnosis**	**Child's age at time of interview**
Interview 1 LDG	Sadé	Therapist	England, U.K	Jamaican	Danny Isabelle	15yrs 14yrs	19 17

Interview 2 EDG	Beverly	Full-time mum and SEND Support group leader	England, U.K.	Dominican	Isaac	2yrs	14
					Taylor	3yrs	13
					Ezekiel	20moths	10
					Shiloh	On diagnostic pathway	7
Interview 3 LDG	Marianne	Accountant	England, U.K.	Jamaican	Caleb	7yrs	7
Interview 4 EDG & LDG	Kate	Pensions Advisor	England, U.K.	Jamaican	James	4yrs	19
					Kyle	9yrs	23
Interview 5 LDG	Rachel	Youth Justice	England, U.K.	St Vincentian	Asher	8yrs	10
Interview 6 EDG	Elizabeth	Teacher	England, U.K.	Jamaican and Grenadian	Aiden	3yrs	4

Table 4. Summarised information about the participants and their children with autism

2.9.3 Interview schedule

Each participant was interviewed once using a semi-structured interview schedule. This partial structure allowed for pre-planned questions and themes to be raised while allowing flexibility in how they were asked and the order. This suited the exploratory nature of the research and ensured that the main topics were covered. Semi-structured interviews are also the most used form of data collection in qualitative research and GT (Creswell, 1998; Marshall & Rossman, 2006; Strauss & Corbin, 1998).

Each interview was conducted virtually using a secure online video conferencing platform. The researcher conducted the interviews in a private and confidential space and reassured the participants of this. The participants were also encouraged to participate in a quiet and private space. The interviews lasted between 80 and 120 minutes. Please see Appendix 7 for the interview questions.

2.9.4 Data transcription

The researcher transcribed all the interviews word for word using the denaturalised approach, which involves removing speech elements like pauses, stutters, and non-verbal language (Oliver et al., 2005). This approach was chosen to support clarity and easier reading for coding and analysis.

2.9.5 Data analysis

The data analysis was conducted following the Corbin and Strauss GT model (2015). Ideally, the researcher would have preferred to analyse each interview before moving on to the next. Due to practical constraints, however, this was not possible. One constraint was that many of the parents displayed interest at a similar time, and to ensure that interview opportunities were not missed, the researcher agreed to interview them at the soonest available time. Recordings were, however, transcribed after each interview, which started the analysis process by immersion in the data.

MAXqda, a computer-assisted qualitative data analysis software, was used to analyse the data. It provided an organised system that supported analysis, including assigning codes, colour coding, categorisation and memo writing (see Figure 2). Some key terms from the Corbin and Strauss GT methodology are outlined in Table 5.

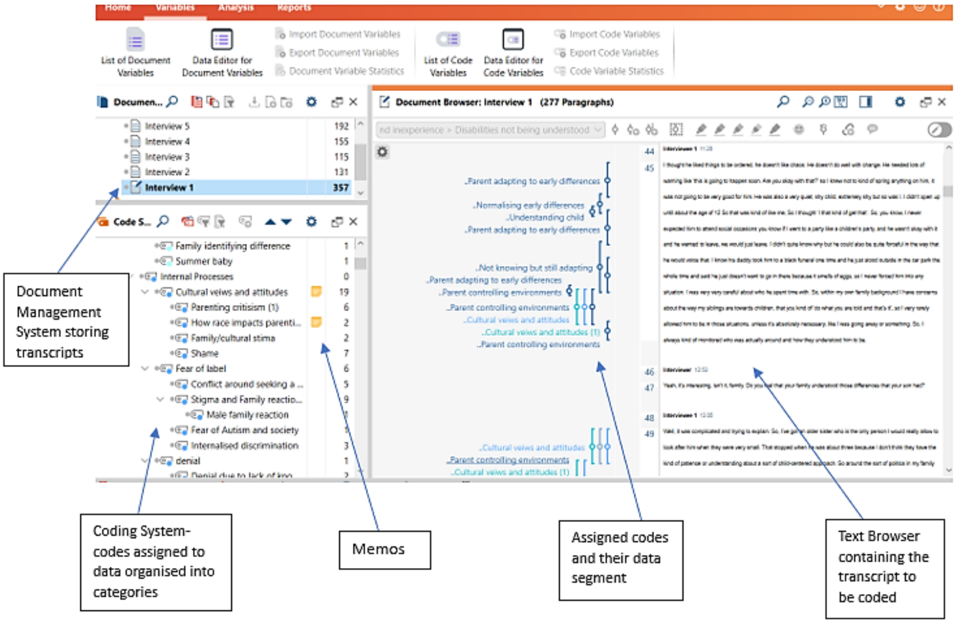


Figure 2. Basic features of MAXqda

Key grounded theory methodology terms (Corbin & Strauss, 2008, 2015)
Coding: Denoting concepts to stand for interpreted meaning of data
Concepts: Words used by analysts to stand for interpreted meaning of data
Properties: Characteristics that define and describe concepts
Categories: Sometimes referred to as themes, are higher-level concepts that group lower-level concepts that become sub-categories
Core category: A concept that is sufficiently broad and abstract that summarises in a few words the main ideas expressed in the study
Microanalysis: A form of open coding that is open, detailed and exploratory that develops concepts in terms of their properties and dimensions
Constant comparison- Data is compared with data to identify similarities, differences and consistency
Dimensions: The range over which a property can vary; an important concept in grounded theory because it accounts for differences and brings density to the theory
Integration: Linking categories around a central or core category to form a theory
Memos: Written records of analysis
Theory: A set of well-developed categories that are related by statements of relations that are used to explain the phenomenon
Theoretical model: A visual representation of the theory
Integration: Linking categories around a core category and refining and trimming the theory
Saturation: When no new concepts are emerging

Table 5. Key grounded theory methodology terms (Corbin & Strauss, 2008, 2015)

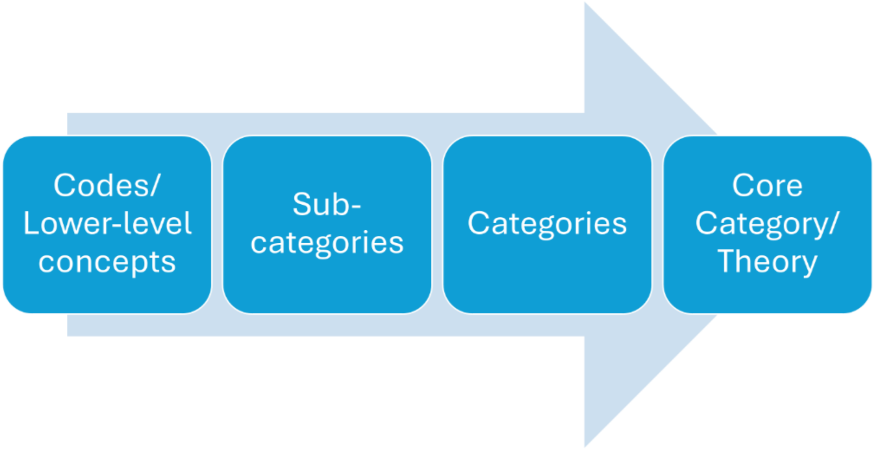
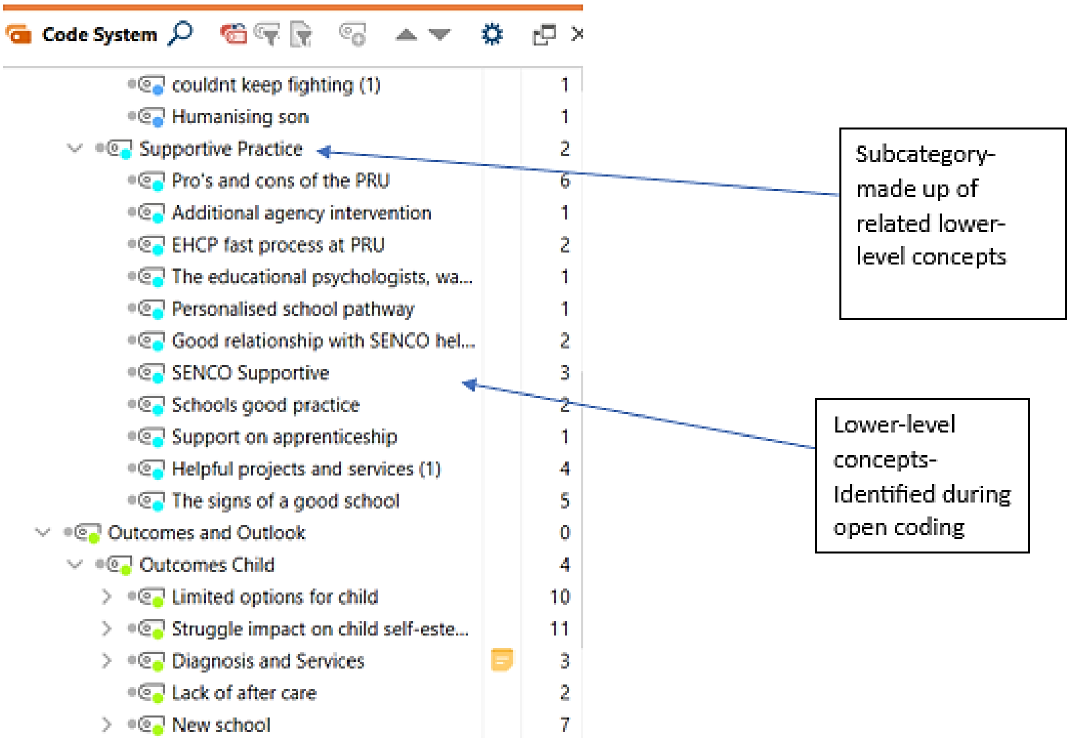


Figure 3. Grounded theory concept development

2.9.6 Open coding/microanalysis

Each transcript was listened to at least three times during the transcription process. This supported familiarisation and immersion in the data, both important aspects of GT data analysis (Corbin & Strauss, 2015). Each transcript was analysed using line-by-line coding- a very close examination of the data, starting with the transcript from interview 1. Codes were assigned to the data to denote meaning as interpreted by the researcher. The data sections from the transcripts that codes were assigned to could be a line, one or two sentences, a small paragraph or a few words. This was an open and exploratory stage of analysis, which ‘generates possibilities and tests out those possibilities against the data’ (Corbin & Strauss, 2015, p. 71). All transcripts were microanalysed, with new codes assigned or data that confirmed existing codes given the same label. These formed the lower-level concepts of the theory (see Figure 3. for the GT concept development diagram).



couldnt keep fighting (1)	1
Humanising son	1
Supportive Practice	2
Pro's and cons of the PRU	6
Additional agency intervention	1
EHCP fast process at PRU	2
The educational psychologists, wa...	1
Personalised school pathway	1
Good relationship with SENCO hel...	2
SENCO Supportive	3
Schools good practice	2
Support on apprenticeship	1
Helpful projects and services (1)	4
The signs of a good school	5
Outcomes and Outlook	0
Outcomes Child	4
Limited options for child	10
Struggle impact on child self-este...	11
Diagnosis and Services	3
Lack of after care	2
New school	7

Subcategory- made up of related lower-level concepts

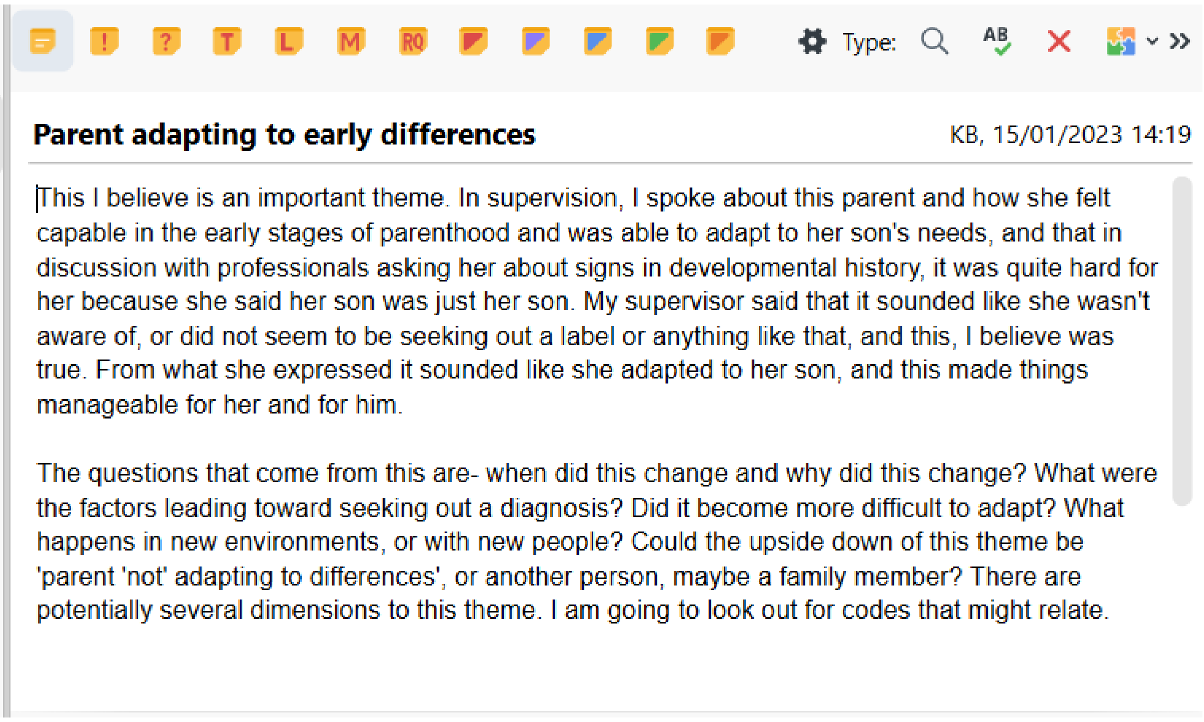
Lower-level concepts- Identified during open coding

Figure 4. Excerpt of coding hierarchy: lower-level concepts and subcategories, MAXqda

2.9.7 Forming subcategories

A constant comparison process was continued to identify similar or contrasting concepts. This involved re-reading transcripts, identifying confirmation of existing codes, and asking further questions of the data. Lower-level concepts that were conceptually related were grouped together to form subcategories (see Figure 4). Some of these subcategories had dimensions which gave further depth to the sub-categories. These began to form the basis of the theory's higher-level concepts or main categories. Please see Appendix 8 for the full code system.

The researcher interacted with the data using memos, which involved asking questions, recording thoughts, and suggesting possible relationships between concepts. This supported analysing and identifying the properties and dimensions of concepts (Corbin & Strauss, 2015).



Parent adapting to early differences KB, 15/01/2023 14:19

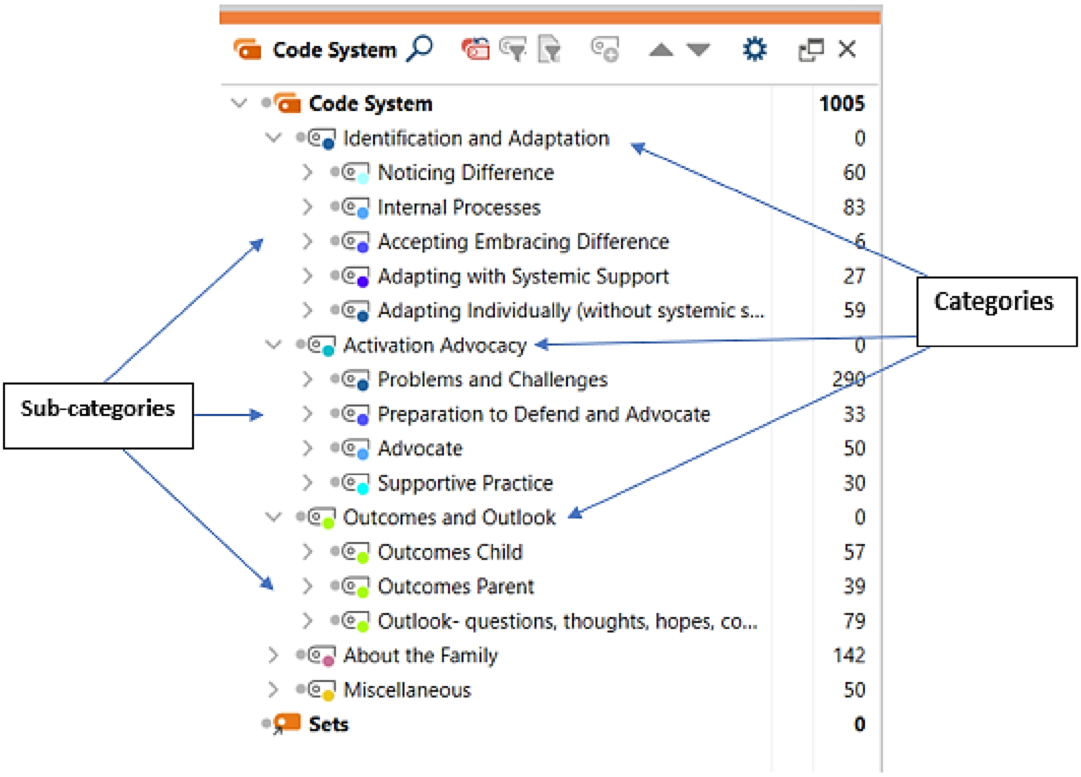
This I believe is an important theme. In supervision, I spoke about this parent and how she felt capable in the early stages of parenthood and was able to adapt to her son's needs, and that in discussion with professionals asking her about signs in developmental history, it was quite hard for her because she said her son was just her son. My supervisor said that it sounded like she wasn't aware of, or did not seem to be seeking out a label or anything like that, and this, I believe was true. From what she expressed it sounded like she adapted to her son, and this made things manageable for her and for him.

The questions that come from this are- when did this change and why did this change? What were the factors leading toward seeking out a diagnosis? Did it become more difficult to adapt? What happens in new environments, or with new people? Could the upside down of this theme be 'parent 'not' adapting to differences', or another person, maybe a family member? There are potentially several dimensions to this theme. I am going to look out for codes that might relate.

Figure 5. Memo 5 from Interview 1, MAXqda

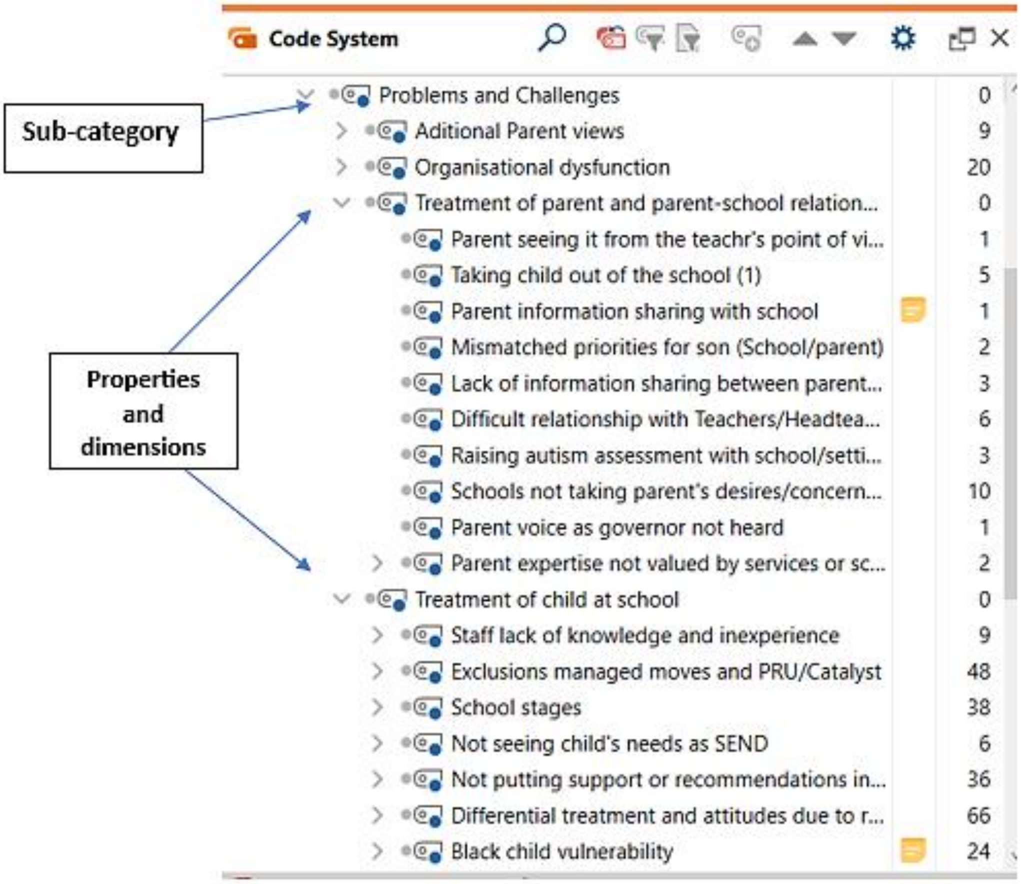
2.9.8 Developing categories

The code system created on MAXqda was printed out, and highlighters were used to colour-code sub-categories with conceptual similarities. These categories were then labelled and became the theory's higher-level concepts/ main categories. The codes were then organised on MAXqda accordingly. Several dimensions and properties were identified within these main categories, e.g., in relation to the above memo, (Figure 5) two types of 'adapting' were identified. One type related to *'adapting with systemic support'*, and the other type *'adapting without systemic support'*. These dimensions show variations in the parent experience, all included in the theoretical model presented in the findings chapter. Because of the depth of properties and dimensions within each category, contradictions/ or 'negative cases' were often accounted for e.g., *'problems and challenges'* with schools became a significant subcategory (see figure 6), but there were some cases where there were positive experiences with schools. There is, therefore, a subcategory called '*supportive practice'*. This is a much smaller category and added dimension to the concept of experiences with schools.



Code System			**1005**
	Identification and Adaptation		0
		Noticing Difference	60
		Internal Processes	83
		Accepting Embracing Difference	6
		Adapting with Systemic Support	27
		Adapting Individually (without systemic s...	59
	Activation Advocacy		0
		Problems and Challenges	290
		Preparation to Defend and Advocate	33
		Advocate	50
		Supportive Practice	30
	Outcomes and Outlook		0
		Outcomes Child	57
		Outcomes Parent	39
		Outlook- questions, thoughts, hopes, co...	79
	About the Family		142
	Miscellaneous		50
Sets			**0**

Figure 6. Excerpt of coding hierarchy: categories and subcategories, MAXqda



```
Problems and Challenges                                 0
  Aditional Parent views                                 9
  Organisational dysfunction                            20
  Treatment of parent and parent-school relation...      0
    Parent seeing it from the teachr's point of vi...    1
    Taking child out of the school (1)                   5
    Parent information sharing with school               1
    Mismatched priorities for son (School/parent)        2
    Lack of information sharing between parent...        3
    Difficult relationship with Teachers/Headtea...      6
    Raising autism assessment with school/setti...       3
    Schools not taking parent's desires/concern...      10
    Parent voice as governor not heard                   1
    Parent expertise not valued by services or sc...     2
  Treatment of child at school                           0
    Staff lack of knowledge and inexperience             9
    Exclusions managed moves and PRU/Catalyst           48
    School stages                                       38
    Not seeing child's needs as SEND                     6
    Not putting support or recommendations in...        36
    Differential treatment and attitudes due to r...    66
    Black child vulnerability                           24
```

Figure 7. Excerpt of coding hierarchy: sub-categories and dimensions, MAXqda

2.9.9 Theoretical saturation/sufficiency

No new concepts were identified after the microanalysis and constant comparison cycles of the transcripts. Concepts were thoroughly developed by the identification of properties and dimensions (see figure 7), illustrating depth and variation within the concepts and, therefore, the participants' experiences.

2.9.10 Integrating categories

Integration of the categories to form the grounded theory required a detailed reviewing of the coding system and previous thoughts and questions. This was to understand the core concept that was being communicated through them and ensure that it was an accurate reflection of the data. This was a lengthy and involved process. It was recognised that this theory was one of process and development that comprised different stages. Each stage was met with a challenge of some form, requiring participant adaption, development and preparation. The second stage (which consists of the concepts and events from the second category) was the largest and included many concepts around development. This stage appeared to be the main event, or the epitome of the data. Once these aspects of development became clear, the following questions were asked: What is the ultimate purpose of this development? What is the ultimate driver of this development? Answering these questions led to identifying the core category and forming the theoretical model, which will be outlined in detail in the next chapter.

3 FINDINGS

3.1 Chapter overview

This chapter presents the findings of a GT analysis on the journeys of BCPs who have children with autism. The study aimed to gain insight into the experiences, processes and events surrounding a BCP's child's autism diagnosis and how cultural factors might interplay with them.

The theoretical model will first be presented, outlining the overarching categories of the theory. This will then be broken down to discuss the main categories that make up each stage of the model in detail.

3.2 The essential super-advocacy theory (ESAT)

The essential super-advocacy theory proposes that BCPs who have children with autism are required to:

a) Become '*essential super-advocates*' to provide the fervent and persistent advocacy that their children will need, and to:
b) Attain the *essential super-advocacy factors* to help them provide the level of advocacy needed in an effective and timely way

The essential super-advocacy factors identified are:

1) *Enhanced autism awareness and ongoing learning*
2) *The ability to overcome stigma and inner conflict*
3) *Connection and collaborative support*

Where these are absent or underdeveloped, greater difficulties are experienced by both parent and child. Conversely, where the essential factors are present and at an earlier stage, the levels of difficulty are reduced, and outcomes are improved.

The theoretical model (see Illustration 1) illustrates how these factors are developed over time through a series of events and processes shaped by the BCP's socio-cultural contexts, experiences, and belief systems. This happens across three proposed stages:

Stage 1- *The identification and adaptation stage*

Stage 2- *The activation advocacy stage*

Stage 3- *The outcomes and outlook stage*

The final feature of this theory relates to the variation in experience throughout the stages between the parents of children who are diagnosed *before* five years old (the 'early-diagnosed group' or the EDG) and the parents of children who are diagnosed *after* five years old (the 'later-diagnosed group' or the LDG).

BCPs and the children within the LDG were found to encounter an additional and distinct set of challenges and complexities across the stages. These were found to correlate with:

a) An initial delay in the parent attaining the essential super-advocacy factors
b) A series of crisis points or *'activators'* calling for immediate and rigorous parent advocacy
c) These activators acting as catalysts for the development and execution of the essential super-advocacy factors

By 'the outcomes and outlook stage', the final stage, parents from both groups have confronted, challenged, and, in some cases, overcome the internal, familial, and organisational hurdles experienced on their journeys. They have developed the essential super-advocacy factors needed to help them support their children effectively. This grounded theory, therefore, proposes that BCPs who have children with autism are required to work exceptionally hard to become the advocates that they are needed to be.

The following sections of this chapter will provide a breakdown of the ESAT and explain the processes of each stage in detail.

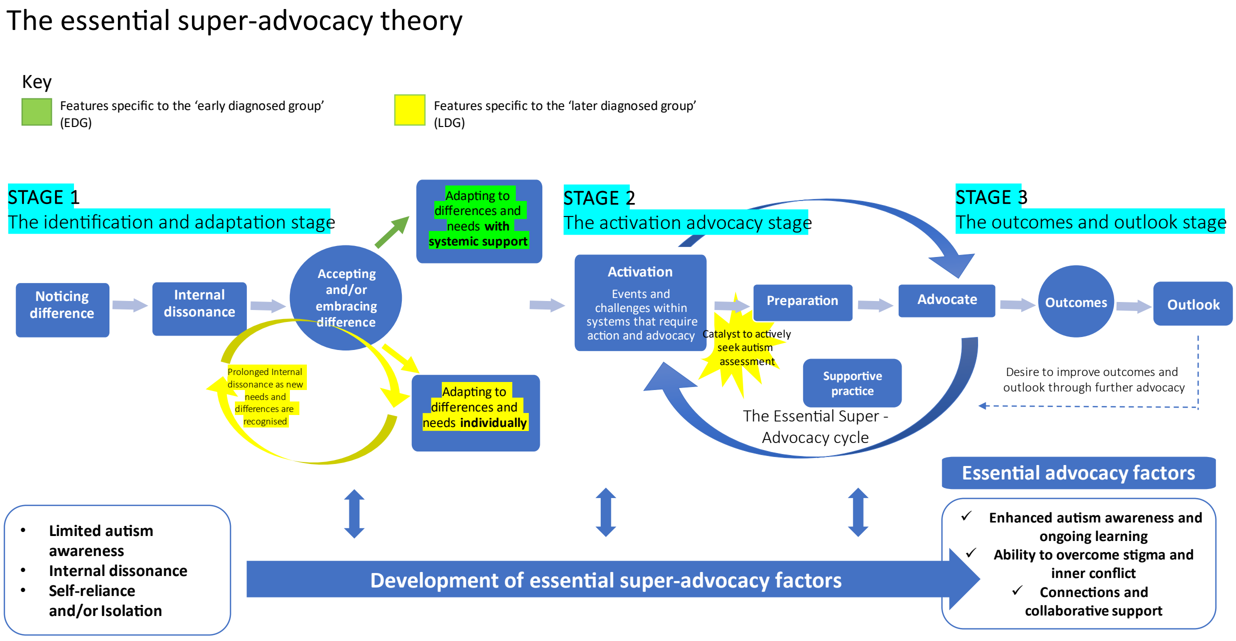
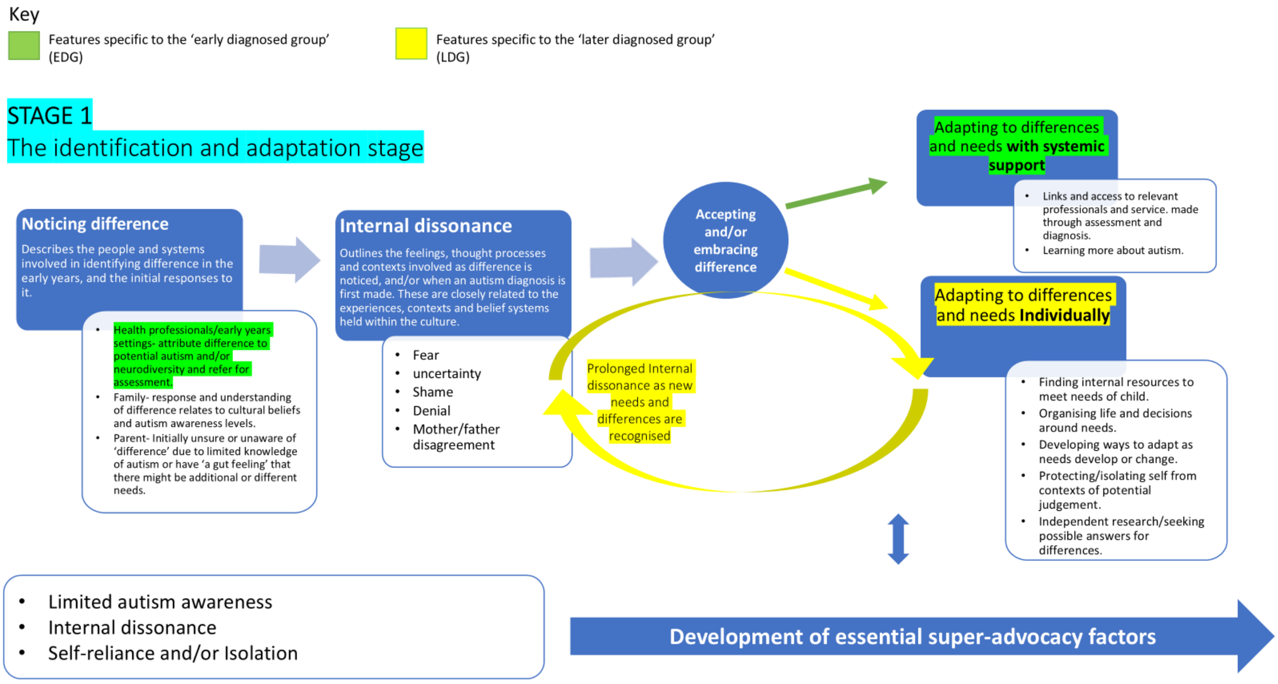


Illustration 1. The essential super-advocacy theoretical model

3.3 Analysis of the theory

The essential super-advocacy theoretical model illustrates how BCPs develop the proposed essential super-advocacy factors to support their children who have autism. It is, therefore, a theory of process and development and highlights the drivers and inhibitors of this development on their journeys. There are three main stages of this theory, and although all parents move through these stages, distinct aspects are unique to the EDG and the LDG. For this reason, throughout the analysis, there will be stages where these groups are discussed separately. This is a significant part of the findings, drawing attention to the diversity within BCP's experiences. It will be helpful while reading this section to reference the participant information in the methodology section. This provides contextual data about the participants and their children.

3.4 Stage 1- The identification and adaptation stage



Key

🟩 Features specific to the 'early diagnosed group' (EDG)

🟨 Features specific to the 'later diagnosed group' (LDG)

STAGE 1
The identification and adaptation stage

Noticing difference

Describes the people and systems involved in identifying difference in the early years, and the initial responses to it.

- Health professionals/early years settings- attribute difference to potential autism and/or neurodiversity and refer for assessment.
- Family- response and understanding of difference relates to cultural beliefs and autism awareness levels.
- Parent- Initially unsure or unaware of 'difference' due to limited knowledge of autism or have 'a gut feeling' that there might be additional or different needs.

Internal dissonance

Outlines the feelings, thought processes and contexts involved as difference is noticed, and/or when an autism diagnosis is first made. These are closely related to the experiences, contexts and belief systems held within the culture.

- Fear
- uncertainty
- Shame
- Denial
- Mother/father disagreement

Prolonged Internal dissonance as new needs and differences are recognised

Accepting and/or embracing difference

Adapting to differences and needs **with systemic support**

- Links and access to relevant professionals and service. made through assessment and diagnosis.
- Learning more about autism.

Adapting to differences and needs **Individually**

- Finding internal resources to meet needs of child.
- Organising life and decisions around needs.
- Developing ways to adapt as needs develop or change.
- Protecting/isolating self from contexts of potential judgement.
- Independent research/seeking possible answers for differences.

- Limited autism awareness
- Internal dissonance
- Self-reliance and/or Isolation

Development of essential super-advocacy factors

Illustration 2. Stage 1: The identification and adaptation stage

The identification and adaptation stage demonstrates the initial processes involved in the BCP's journey. It starts with '*noticing difference'* and then describes the feelings and internal processes experienced by the parent. The baseline position before developing the essential super-advocacy factors begins at the start of stage 1. It will become clear that not all parents begin in the same position, i.e., with the same level of autism awareness, *internal dissonance*, and self-reliance/isolation. However, degrees of each aspect are commonly experienced, particularly at the beginning of the stage. The final parts of this stage outline how the BCP begins to meet and adapt to their child's needs, marking the start of the development of the essential super-advocacy factors.

In discussing the theoretical model, reference to 'difference', 'differences' and 'types of difference' primarily refers to the two main areas of difference recognised in autism and their associated traits and characteristics. The two main areas are social communication and social interaction and restricted and repetitive patterns of behaviour and interests. The latter includes sensory interests and/or sensitivities. These areas of difference are defined in the DSM-5 and the International Classification of Diseases 11th Revision (ICD) and used as part of the diagnostic criteria. They are also used more widely and sometimes broken down into smaller subcategories to support the understanding and awareness of autism.

Area of difference becomes important during this stage, as the children who present with verbal communication differences (specifically with speech and language delay) were more likely to be identified by a professional and referred for an autism assessment before the age of 5. This becomes significant in the course of each parent's journey and is illustrated in the theoretical maps and explanation in this chapter.

3.4.1 Noticing difference

Noticing difference is the first part of the BCP's journey in the essential super-advocacy theory. It describes the people and systems involved in noticing and responding to difference in the early years. These people and systems include family, staff from early years settings, health professionals and the parent themselves.

3.4.1.1 The parent

Parents discussed noticing behaviours and characteristics from when their children were young, initially seeing these as part of their child's individual character or as a typical stage in child development. These parents did not relate these characteristics to autism or any other type of neurodiversity.

> *So, I had Isaac, and I used to go to a local playgroup, and I just thought he was excitable because he was a little boy.*
>
> *Ezekiel my youngest son, at this time, was about 20 months old. After about 45 minutes of me talking to her [the portage worker], she'd been watching Ezekiel, and she said, Is it normal for Ezekiel to do that? And I said, yeah, that was just Ezekiel being Ezekiel.*
>
> *Beverly*

> *I would put it down to terrible twos. If you said no, and Asher couldn't do something, there'll be this long excessive crying for quite a long period of time. … As he got a bit older, his memory for things was outstanding, remembering bus routes and bus numbers. … He would build elaborate train tracks, and again, I just thought, well, you like trains. But he would get very, very distressed if the train line broke and then it'll take a long while to sort of settle down.*
>
> *Rachel*

Some parents explained that although they began to notice more differences and needs, they did not make the connection with autism because they did not have a good understanding of what autism was. There is an implication here that if they had known more about autism at this stage, they would have had a knowledge-base or framework to support understanding of some of the behaviours they noticed.

> *So, from a very young age, I kind of thought it was 'autistic' without really knowing what autism was. Because he would do things like I used to have flowers outside, and they'd been in a bit of a cluster, and he'd always line them all up, so, I knew there was something about him needing things a certain kind of way.*
>
> *Sadé*

> *The only thing that related to me in regard to autism was the film Rain Man … that's the only recollection I had of it, but then I thought, well, he's nothing like that.*
>
> *Beverly*

> *James had no interest in what was going on around him or anybody else. He just wanted to do his own thing. …I had suspicions, but I didn't know what autism was.*
>
> *Kate*

One parent, however, did have prior knowledge and awareness of autism and had worked as a teacher at a school with an autism base.

> *Aiden wasn't giving much eye contact. He wasn't responding to his name. He would often look at the light, like if I'm putting him to sleep, he'd stare at the light. And I was constantly online and looking up red flags for autism and all the rest of it. Aiden ticked a lot of the boxes.*
>
> *Elizabeth*

3.4.1.2 Professionals

All the children diagnosed with autism before the age of 5 in this study (the EDG) had a professional involved in identifying difference and suggesting a referral for assessment.

Some of these referrals were not specifically for autism but to explore and assess some observed behaviours and traits that indicated potential additional needs.

> *“One of the workers said oh, we've got a speech and language therapist in to just look over the kids, … you don't mind if he has a chat with you. And again, Isaac was just the hyper 18-month-old boy. … he wasn't very vocal. He was googooing and gagaing and stuff, but very advanced physically for his age. … then the speech and language therapist just said to me, 'We've arranged for an appointment for you to go and see a paediatrician at the our hub Children's Centre. … I still didn't have a clue about anything; I was just like, okay, if it's what I've got to do, it's what I’ve got to do.*
>
> *Beverly*

> *James went to an early years nursery, and they picked it up very quickly that he was playing by himself and wasn't interested in what everybody else was doing. He was lining toys up … He just wanted to do his own thing. So, they suspected, and they're the ones who referred him for assessment.*
>
> *Kate*

> *The lady said to me that she thinks I should get James referred or see an audiologist at Guy's Hospital because that’s the standard; to eliminate.*
>
> *Elizabeth*

Professionals played an essential role in identifying signs of autism or speech and language delay and suggesting a referral for assessment in the EDG. Their support appeared to be through direct discussion with the parent about the signs observed and information about a referral. Early signs of speech and language delay was an aspect of all referrals in this group, and perhaps the absence of speech and language delay in the LDG during the early years is a factor in their later diagnosis. Either way, all but one parent could recognise that verbal and social communication and interaction differences and repetitive and restricted patterns of behaviour and interests are traits of autism and neurodevelopmental differences. This left parents of five children unable to understand and contextualise the behaviours that they and others were beginning to identify.

3.4.1.3 Family

The wider family response to signs of difference in both the EDG and LDG was found to be an important part of how parents began to process and conceptualise their child's differences. The theme of family noticing difference in the early years was more prevalent in the LDG, and family response to diagnosis is more prevalent in the EDG at stage 1. The latter is discussed in further detail in the internal dissonance section, as it is more a response to the diagnosis than traits and characteristics. There is a lot of overlap between family response and cultural beliefs and attitudes, which will also be explored further in the next section of this stage.

Parents, particularly from the LDG, felt that their children's differences were viewed by the family as a result of 'bad' parenting. This created a sense of being negatively judged for differences that they had tried to understand and adapt to. Discomfort was also expressed when family members tried to correct or discipline their children for behaviours that were viewed as incorrect in some way. This led to some parents avoiding family situations, e.g., gatherings. Some also stopped leaving their children with family members for childcare. Therefore, the support network usually provided by extended family was minimised, leading to the parents mainly working on their own to raise their children.

Parents also explained that it was hard helping their family to better understand their child's needs and differences because they didn't fully understand them at this time. This led to a type of double isolation, i.e., not having the practical and emotional support and understanding helpful when raising a child. Parents from this group spoke of internalising the judgement and questioning their own parenting abilities.

> *In the early times, I felt alone, just me, and not just alone, but almost like I was fighting against or protecting against incorrect expectations and assumptions. My parents, quite outwardly, would talk about my son being naughty and things like that. No one understood him, really. ... So it's almost as though I've kept him to myself. So, let's say we would visit, but I wouldn't leave him there, or I would make sure I'd have to be present. But a lot of the time, we just didn't go.*
>
> *Marianne*

> *I was just like, what have I done wrong? Where have I gone wrong? Is this my fault? Am I not believing all the things that people are trying to say to me about how I should parent? Or having my own sister say to me you need to do x, y and z with him... and all these opinions. You don't have the answers, and you don't have a point of reference to understand the behaviour. You're then going inward, and you're sort of thinking, Is it me? What have I done wrong?*
>
> *Rachel*

> *I've got an older sister who is the only person I would really allow to look after him when they were very small. That stopped when he was about three because I don't think they have the kind of patience or understanding of a child-centred approach.*
>
> *Sadé*

Some parents also expressed the feeling of there being stricter behavioural expectations of children in Black Caribbean families, especially from their own and their parents' generations. Many referenced the 'do as you're told' rule and the difficulties encountered when their children did not comply.

> *In terms of being Caribbean... children should just be well-behaved and should just do what they're told and all those kinds of things, and when your child is not being that person, sometimes, we're not open about what's going on. Other people have the same experiences and have the same struggles, but we're insular about it. So, we're here sort of trying to deal with it ourselves, not realising that actually, this is not just a 'you' thing.*
>
> *Rachel*

> *I always used to find that, If, say, for example, we were at something and James was not keeping still, I would have to adjust other people trying to discipline him because they were not understanding what's actually going on. So I've had to keep telling people don't do that.*
>
> *Kate*

> *So, within my own family background, I have concerns about the way my siblings are towards children, that you kind of 'do what you are told and that's it', so I very rarely allowed him to be in those situations. … I got a lot of criticism from my sister about my parenting because it wasn't like hers. I had the children quite late. I was very laid back. I think she was waiting for me to be that kind of shouty, angry person that I have never been.*
>
> *Sadé*

Sadé, however, expressed that the perceived 'harsher behavioural expectations' of children in Black Caribbean families is a complex issue due to there being 'a bigger issue at stake'.

She spoke of ‘living within a context that you know you're going to be judged based on the colour of the skin’, and parents not wanting their children to be ‘bringing the police back to their door’. Nevertheless, she recognised that her ‘laid back’ parental style was judged negatively by her family as well as her son’s behaviour.

On the other hand, one parent shared that her mother did not criticise her parenting, but mentioned that there might be more to some of her child’s behaviours, e.g., ‘excessive crying when told no’, but she decided to dismiss this and assume it was just her mother’s traditional expectations of how children should behave.

> *I remember my mum saying to me that something isn't right. She said I have had four children and something's not quite right. But again, I kind of thought, well… I put it down to her being sort of old-school.*
>
> *Rachel*

3.4.1.4 Noticing difference summary

The parent, their families and professionals were all involved in noticing traits and characteristics of autism but attributed them to different things. Overall, the parents were more likely to attribute differences to the child’s character or stage in development. Family were more likely to see the behaviours as a sign of inadequate parenting, and professionals in early years settings as a potential neurodevelopmental or additional need. The BCP, at this stage of The essential super-advocacy theory overall, has limited awareness of autism. Their child’s differences, especially before diagnosis, begin to make some parents feel judged or blamed in the family context. This led some parents to feel isolated and withdraw from family settings.

3.4.2 Internal dissonance

This part of the identification and adaptation stage feature the feelings and thought processes involved as parents begin to recognise more differences and/or when an autism diagnosis is first made. Some of these relate to cultural beliefs and attitudes held within the family and the perceived stigma within Black and Black Caribbean communities. The ‘dissonance’ aspect refers to the tension expressed by some parents wanting to recognise, accept and support their child's needs while also fearing what a label and having differences might mean for their child in future. These feelings were often described by parents as something they had to manage on their own, further emphasising the isolation and difficulty felt at this stage.

3.4.2.1 Grief, fear and shame

> *There's frustration, upset, there’s, I suppose, maybe a lack of feeling supported, there’s shame, and I am referring to the shame because you have a child, and you have all these dreams and aspirations for them. … Because I knew academically, he was able, I would have said that I want him to do the 11 plus and go to grammar school or get a private school place, and then go off to a Russell Group university, but I had to I suppose, realign my vision in some respects.*
>
> *Rachel*

> *I just remember going back to my husband and saying, if I'm honest, I would rather he be deaf than be autistic, you know? So that's when I knew within myself that I had a big issue with autism. … At the time, I just figured if he was deaf, you've got the sign language. It’s more visible as well. I thought it'd be better. So when he was all cleared and his hearing was fine, I just knew from then. … I remember I cried for a good day or two.*
>
> *Elizabeth*

> *There's an issue around being autistic, which I didn't know at that time, and being trans. We got to the point where Isabelle was eight or nine and still struggling in school, still not doing well academically, really struggling with identity as a boy or a girl. She was scared to go to bed at nighttime. She was just really struggling. In the mix of this now was gender identity, and I thought, why me? I really struggled a lot with a kind of sense of loss and grief and really trying to manage that.*
>
> *The difficulty for me was that me and my partner are both mental health activists around diagnosis and all those things. So, we absolutely don't do diagnosis at all for anybody on any level; they don’t need to kind of be part of a very dirty sort of oppressive system.*
>
> *Sadé*

Feelings of fear, especially around the misuse of labels, are discussed further in Stage 2- the activation advocacy stage.

3.4.2.2 Suspicion or distrust

Some parents raised being unsure or sceptical about autism and where it ‘comes from’. The measles mumps and rubella (MMR) vaccine was referenced once, and some parents also felt that more Black boys were being diagnosed with autism. No specific theories were raised, but there was the presence of some suspicion or distrust as to why this might be the case by some parents.

> *With both of my pregnancies, I didn't want the MMR vaccine. And it was mainly because of the associations or the, you know, history that they say.*
>
> *I do find that more Black children are being diagnosed. … So, I do wonder, is there something in our makeup, or something that’s been put? Like conspiracy theories, they do run wild. I’m not gonna lie. I try not to dwell on that, but it does make me wonder.*
>
> *Elizabeth*

> *As a community, many have these experiences with the system and even the use of SEND to sometimes diagnose or claim that there is a need when there isn’t one; the inappropriate use, should I say, of SEN, to actually discriminate and hold back as opposed to actually support. Our resistance can come from that.*
>
> *Rachel*

3.4.2.3 Father disagreement

Two parents from the LDG also raised difficulties that they encountered when trying to talk to the child’s father about the things that they had noticed. In these examples, the mothers explain that their concerns were met with disagreement, resistance or dismissal, which appears to have exacerbated feelings of isolation and dissonance.

> *My husband wasn’t engaged. When I started to learn things, I sent him videos and articles and things like that. I was met with the response, ‘Don’t send me this rubbish’. So, throughout the whole time, he has not been supportive at all. … He still doesn’t acknowledge it.*
>
> *Marianne*

> *And then there are all the other elements, in terms of disagreements between me and my son's dad. Some of it, he believed, was just, 'he doesn't behave like that with me, so it's you'. He'd say, essentially, there is no issue. And in some ways, that was right; he wasn't behaving the same in all places.*
>
> *Rachel*

> *I'd been left to deal with this by myself. Every time I brought it up, I started getting all teary-eyed and everything else. … I was with their dad as well at home during this whole time. He didn't really take much interest in finding out more about it. It was like everything was left to me, to be honest.*
>
> *Kate*

> *I would tell my ex-husband, and he was very much the complete opposite. He would say things like, you know, 'there's nothing wrong with Aiden' and 'every child develops in their own way'. So, me being the person that I am- a natural worrier, I thought maybe he's right. Maybe I just need to relax, and maybe in time, he will do certain things and talk and all the rest of it. But at the same time, my gut instinct just knew I needed to be on top of it.*
>
> *Elizabeth*

3.4.2.4 Internal dissonance and family

Family reaction to the news of an autism diagnosis appears to contribute to the internal dissonance experienced by parents of the EDG. There are links between this and the previous section on family response to difference, but the latter refers to responses to the child's behaviours rather than the diagnosis. Family reactions of blame, dismissal, and sadness were raised, as well as how this brought on further feelings of isolation for the parent.

> *I called my big sister, and I said they think Isaac is autistic. My sister cried on the phone to me. Like I told her that Isaac had died. … I was a bit shocked because my sister is quite an academic. She's got several degrees and a master's, and she's quite academically clever… So when she reacted like that, I instantly thought, why are you crying? Why? Why is it so bad? Isaac is still Isaac.*
>
> *I've even had some of my in-laws, you know, say it must be me because that 'bad gene' doesn't come from my husband's side.*
>
> *Beverly*

> *When I mentioned it to [ex-husband's] mum, she was like, 'Oh, he'll grow out of it'. There was no mention of it ever again, despite the fact that he has needs. So I've just felt like I was just really dealing with it myself.*
>
> *I remember getting a leaflet or pamphlet about autism and giving it to my dad when I went to visit him, and he just took it and put it down. I thought, wow, okay. I have never got into a conversation with my dad about it either. … I feel it was something that was kind of swept under the carpet.*
>
> *Kate*

Parents felt that some of their own reactions and the reactions of their families were a 'cultural thing'. Reasons as to why these feelings might exist, especially among Black and Black Caribbean people, was also raised.

> *Culturally, it's not fashionable to have a diagnosis of any of this stuff. And yet, moving around the world just in a normal way, what I'm finding is that there's just ignorance, the expectations that everything is correct, you know, from other people. It's really sad, that that's how people are.*
>
> *Marianne*

> *It's hard to accept, especially in the Black community, to be honest. There's a lot of denial that goes on.*
>
> *Elizabeth*

Beverly reflected on her sister's reaction of crying when sharing the news that her son Isaac was diagnosed with autism. She also suggests that the tendency of some parents to ignore signs of difference is to avoid feelings of blame or 'failure'.

> *It was her naivety; it was her lack of understanding and a cultural thing as well. … What I struggle with is a lot of parents of colour or of a similar background; they don't want to address it. It's more about failure; it's more about because the child's got an ailment, it must be their fault.*
>
> *Beverly*

3.4.2.5 Internal dissonance summary

Parents express feelings of grief, fear and shame when learning of their child's diagnosis or when identifying more traits and characteristics. Feelings of shame appeared to be linked closely to denial and cultural views perceived within the family context and broader Black and Black Caribbean communities. Some parents put this down to a lack of knowledge. Others felt that denial might be a form of fear or resistance to labels and diagnoses that could be used to perpetuate discrimination and oppression. This further illustrates the weight of the issue for these parents, all mothers, who expressed feeling isolated at this stage when managing these thoughts and emotions.

3.4.3 Accepting, embracing, and adapting to child's diagnosis and/or needs

Parents, during the final part of stage 1, go through a process of accepting, embracing, and adapting to their child's autism diagnosis and differences. This sees parents take new and decisive actions to support their child's needs and adopt an approach that fully acknowledges their child's differences. Most started this by educating themselves about autism and/or seeking greater knowledge and understanding of their child. Parents from the EDG were found to adapt and develop knowledge with systemic support deriving from the services involved and signposted to during their child's assessment. They also appear to challenge some of the internal dissonance experienced and cultural stigma around autism. This shows that with systemic support, these parents were able to begin to develop the factors found to be essential to advocate for their children, especially during the later stages of the essential super-advocacy theory. Parents from the LDG did not have external systemic support at this stage but took steps to adapt independently with the resources they had access to. Feelings of isolation and dissonance were found to continue in this group while trying to adapt on their own. What both groups had in common, however, was the desire to learn more and better understand their child's needs.

3.4.3.1 The early-diagnosed group

Parents from the EDG reflected on the support that they received leading up to and after their child's diagnosis. It was found that for most children, support was put in place before the official diagnosis was made. Parents explained that the support they received allowed them to learn more and research autism. The EDG also illustrate how a network of support was built that gave them access to useful information and services that would help them adapt during the crucial years of their child's development. This included children receiving personalised support at their settings and being able to experience successes as a result. It involved home visits and practical and emotional support for the parents, courses delivered by relevant professionals, and help to access the resources they were entitled to.

3.4.3.1.1 Adapting with systemic support

> *Isaac started nursery just after he turned two. … They were extremely good as well. They got in an early intervention team and got him some extra support. In that year of not having his diagnosis, I literally should have a degree in autism, with the amount of research, the amount of looking up autism. … Because there was funding, we had [home London borough] autism support, which is an organisation through the National Autistic Society. They literally did home visits, and ran through everything, what I'm entitled to, what help I could get, and so on … Also, we had a portage worker who again, was phenomenal.*
>
> *Beverly*

> *James was diagnosed with autism when he was four, and he was still in nursery, who, meanwhile, had already put things into place for him before he even got diagnosed. They had speech and language with him weekly, and they set up a table where they have an inbox and an outbox of tasks for him to do, and they said that it works really well. … So, looking at transitioning to school, we invited the head teacher to come to the nursery to discuss him and what his needs were, et cetera.*
>
> *Kate*

> *Sleep has been an issue, to be honest, but we're getting there. He's getting support from the sleep clinic at the minute, and she checks in on us, like regularly. You know, it's nice. They give you little tips and stuff. And compared to last year, I can say, he sleeps through the night at least five nights a week. .*
>
> *Elizabeth*

3.4.3.1.2 Reflecting, reconciling, and challenging internal dissonance and stigma

This was something that the EDG also appeared more able to do after their child's early diagnosis and the systemic support that followed. These appear to have provided a means to better understand and explain their child's needs, not just to others but to themselves.

One parent described this as taking ownership of the situation, which also seemed to provide the space to reflect and, in some cases, challenge some of the difficult emotions and experiences leading up to their child's diagnosis. The following examples illustrate this, and the groundwork and empowerment needed to provide the essential advocacy that their child will need, as will be seen further in stage 2.

> *When I got the diagnosis for Aiden, I felt really comfortable just saying oh yeah, he's on the spectrum. Whereas before, because I hadn't had that diagnosis, I didn't feel I could own it, if that makes sense. It made it a lot easier once he had his diagnosis to own it and just to say, he has autism, and that's that.*
>
> *My approach is, I just look at him now. Whereas before, I'll be honest with you, I was thinking more about the autism, and now I just see him. Autism is just a part of him if that makes sense. But again, not many or not everyone thinks that way.*
>
> *Elizabeth*

> *I do find with people of our culture, instead of doing things like take the child to the cinema and take them out, they hide the child away. And that to me is extremely scary because that child is not given the opportunity to be included in normal situations or know if they do or don't like something, or know if they can handle a situation, because the parent is too scared to be outside, to have to deal with a meltdown.*
>
> *Don't get me wrong, I understand that when a child gets diagnosed, there's a lot of grieving that takes place, but ultimately, it's about the child, their child. Nothing changes in regards to who their child is.*
>
> *Beverly*

One parent, Kate, described her approach when seeking a neurodevelopmental assessment for her eldest son, just after her youngest was diagnosed at age 4:

> *I knew there was an issue. So I wanted it to be referred. I wanted these things to happen so that it wasn't awkward and find out what it is and what needs to be done… . But other people were like, we don't want to be labelling our children. I was thinking, if you're concerned about labels, that's ridiculous because there's going to be people out there that are not getting help, and that makes no sense to me.*
>
> *Kate*

One parent of this group shared that she wanted to make a point to herself and others that she was not going to use autism as ‘an excuse’ for behaviours such as hitting or pushing. She explained that she has seen other parents do this and does not agree. When asked why she thinks that some parents might do this, she replied:

> *Parents who are unaware or naive, that's what they see as an excuse for their child's behaviour. And if not, the behaviour gets to that because of the lack of interaction and intervention before that behaviour.*
>
> *Beverly*

Although only one parent raised this in the group, this point was important to include, as it sheds light on some of the advantages of early diagnosis. It shows a level of empowerment that enabled parents to establish certain expectations of their children. This is from a position of having better knowledge and understanding of why their children might exhibit these behaviours to begin with. Having a network of systemic support might also have helped to establish this, along with the parent’s character and parenting style. The quote above becomes relevant when seeing the impact of limited knowledge and specialised intervention for the LDG due to unidentified autism.

From this early stage of the essential super-advocacy theory, parents of the EDG have already begun to develop advocacy skills, i.e..., taking steps to empower, believe in, and educate others about autism on behalf of and for the benefit of their children.

3.4.3.2 The later-diagnosed group

The LDG found ways to adapt to the needs of their children without the systemic support that the EDG had as a result of early diagnosis. Parents of the LDG sought ways to help and understand their children with some of the difficulties they faced e.g., with sleep or certain sensory environments. Some parents expressed a continued sense of isolation and the need to further withdraw their children from situations for fear of not knowing how they might react. Parents were also made to make some major lifestyle decisions, e.g., reducing hours at work, withdrawing their child from school (discussed in more detail in stage 2), and, in one case, deciding that one child needed to move in with his father. Some parents expressed regret over some of the decisions made in hindsight, now knowing that their child had undiagnosed autism at the time. Others accepted that it was the best they could have done under the circumstances. The experiences of parents in this group illustrate a prolonged sense of dissonance and isolation. The children of this group also appear to have encountered escalating difficulties not just at home but also at their educational settings. Although stage 1 of the essential super-advocacy theory is mainly based around the early years, ‘adapting without systemic support’ crosses over into school-age years for the LDG. A suggested reason for this is the continuation of isolation and limited autism awareness and support. This will be demonstrated in the following categories identified.

3.4.3.2.1 Adapting without systemic support

In an effort to avoid putting the child in stressful or unpredictable situations, parents of the LDG were found to carefully control where their children went, and who they could be around. In relation to the internal dissonance discussed, some parents expressed not fully understanding the behaviours of their children, which appears to have had an impact on their parenting confidence. Limiting or controlling their environment may also avoid the blame or shame previously discussed. Parents however tried to find ways to understand their children and make things work i.e., by studying patterns of behaviour, changing their own mindset, and using resources that they had.

> *He liked things to be ordered, he doesn’t like chaos. He doesn’t do well with change. He needed lots of warning like ‘this is going to happen soon. Are you okay with that?’ so I knew not to kind of spring anything on him, it was not going to be very good for him.*
>
> *He was also a very quiet, shy child… I never expected him to attend social occasions. If I went to a party like a children’s party, and he wasn’t okay with it and wanted to leave, we would just leave. I never forced him into any situation. I was very very careful about who he spent time with.*
>
> *Sadé*

> *Even when it came to childcare for me to be able to do something, I didn’t feel comfortable leaving my children anywhere. But then, I also kind of took comfort in just feeling like, well, you know, that’s my main job, anyway, so to speak, and I just kind of got on with it.*
>
> *Marianne*

> *What I have is a child who has no diagnosis and also who is behaving in ways that I couldn't understand and deal with myself. I just didn't know what was going on. I knew my child was distressed. I knew that he needed help, but I didn't have the tools or the resources to be able to get him that help. I tried and he did a course of play therapy that I paid for myself.*
>
> *Rachel*

The emotional burden on the mothers in this group is evident, particularly as many shared that they did not have support or agreement from the child's fathers during this time. The decision to homeschool instead of work and pay for private therapy also implies financial consequences.

3.4.3.2.2 Independent research

Parents of the LDG also spoke of independently looking for answers and information about their children's needs and finding ways to best support them.

> *I've learned about the circadian rhythm and all sorts of other things about how our bodies work, which has been really helpful in terms of explaining, even for me, why certain things felt really difficult. I was ensuring that he had adequate sleep, cutting out certain things out of his diet, got rid of the microwave. I wanted to go more the natural way.*
>
> *Marianne*

> *We knew she was really affected by noise in the classroom so she couldn't really concentrate. She had a screener for dyslexia, which they said she doesn't appear to have. …, we weren't getting anywhere, so eventually, I found out about visual stress. So, through the assessment, they were very clear: that's what it is, and she needs overlays.*
>
> *Sadé*

Parents of this group were self-motivated to find ways to help their children despite not being aware of autism and being without additional systemic support.

3.4.3.2.3 Big decisions

For some parents of this group, big decisions were made in regard to their children, when they felt they had no other option or way to resolve a situation.

> *There have been a couple of instances at home where he was sort of getting really aggressive with his sister, and I had to be really clear and say nobody gets smacked in this house. Nobody hits in this house. So, I said you know what, you're going to your dad's, I'm not tolerating this. I wanted to make a big statement. It was the worst thing I ever did, I think.*
>
> *Sadé*

> *I did what I could. I'm not a teacher. I went into the whole homeschooling, but I went in on the back foot. Most people, when they choose to homeschool, it's a choice they've made, it's something they've paid for, and it's something that they've psychologically taken the time to make a commitment to. They've been empowered to do it. I wasn't empowered. I was literally doing this because I had no other choice.*
>
> *Rachel*

Rachel decided to homeschool after repeated incidents were reported by the school regarding her son's behaviour. More on schools is discussed at stage 2.

3.4.3.2.4 Accepting, embracing, and adapting to child's diagnosis and/or needs summary

All parents were found to adapt, accept, and embrace their children's differences in different ways. The EDG had support with this and were able to process and reconcile some of the dissonance experienced around diagnoses, and gain empowerment to begin advocating for their child and also for themselves. The LDG, however, experienced extended dissonance while trying to navigate supporting their child independently while feeling isolated. Some felt forced to make big decisions without the knowledge needed to fully understand what might have been happening. During stage 2, *the activation advocacy stage*, the LDG encounter a series of events that accelerate and intensify their search for answers and support, which leads them to actively seek an autism assessment for their children. There is also an acceleration in the development of the three essential super-advocacy factors: enhanced autism awareness and ongoing learning, ability to overcome stigma and inner conflict, and connection and collaborative support. What was discovered, however, is that parents in both the EDG and the LDG would need to exercise these persistently throughout their children's school years.

3.5 Stage 2- The activation advocacy stage

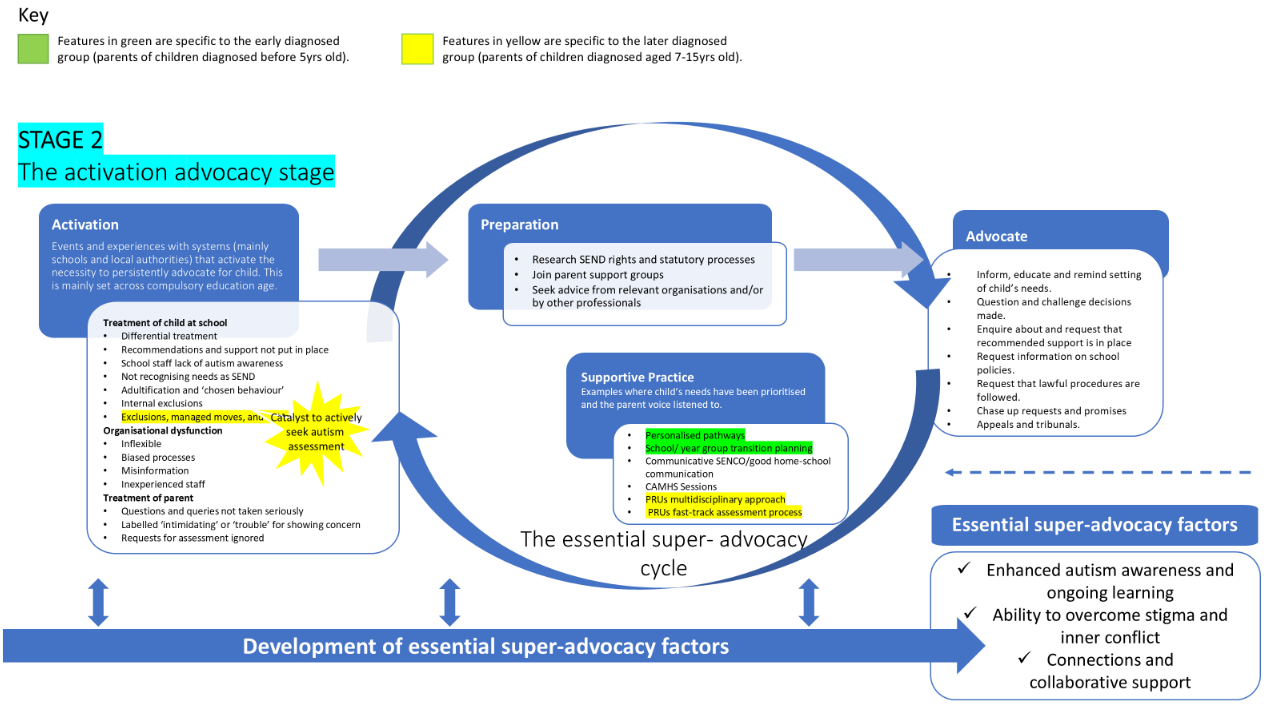


Illustration 3. Stage 2: The activation advocacy stage

The activation advocacy stage is the critical stage of this theory and is characterised by events with, and within systems (particularly schools and local authorities) that activate the necessity for persistent advocacy by BCPs to support the needs and wellbeing of their children who have autism.

This stage consists of three main categories: activation, preparation, and advocacy (see illustration 3). *Activation* describes the event or situation that activates parental response and advocacy. Preparation outlines what the BCP does to equip themselves to advocate effectively. Lastly, *advocate* explains how the BCPs advocated in response to the activation events. *The essential super-advocacy cycle* represents the ongoing nature of preparing and advocating in response to new events and challenges that arise during the school years. A smaller category called *supportive practice* was also found which includes services and settings that supported the parent and child during this stage.

The EDG and the LDG will be discussed separately during parts of this stage. Whilst there are similarities and overlap, there are marked differences in the experiences of these groups. These differences appear to relate to the effect of undiagnosed autism within a mainstream setting.

During this stage, all parents undergo an acceleration in the development of the essential super-advocacy factors (enhanced autism awareness and ongoing learning, ability to overcome stigma and inner conflict, and connections and collaborative support). The LDG, however, appear to have a steeper learning curve, as early diagnosis supports development as demonstrated by stage 1.

3.5.1 Activation

The events and experiences that activate an advocacy response by the BCP are mainly related to the difficulties that arise for the child at school, and how the school responds to them and treats the child. Organisational dysfunction at the setting (or local authority) and attitudes towards the parent were, however, other categories closely related to this.

3.5.1.1 The later-diagnosed group

Treatment towards the child at the setting, organisational dysfunction and attitudes towards the parent

Parents of the LDG discussed the challenges that their children faced at mainstream school. At the beginning of this stage, none of the children had been assessed or diagnosed with autism, but with the persistence of the parents, each child was eventually assessed by the end. The challenges faced usually involved their child's more 'challenging' behaviours being attributed to deliberate or 'chosen' behaviour instead of being recognised as a potential sign of undiagnosed special educational needs (SEN) or autism. Parents felt that their children were often treated differently with harsher rules compared to other pupils. They also felt that there was a general lack of curiosity by schools and a reluctance to investigate what might be going on for their child.

> *By year nine they were saying this is really serious. He is getting out of hand; he won't stay in class. He's not doing his work; he's not doing homework, and he's being disruptive, all without anybody considering what's going on.*
>
> *He's never been physical with anybody, but there were teachers making remarks about him, and of course, he reacted. There was one particular time that this teacher*

> *said something like, 'If I was anywhere else, I'd knock you out,' and then lied about it. So, the trauma just never stopped, and you're just constantly undermined and attacked really badly in school... So, in terms of what that does to your sense of who you are. It's just horrible, really horrible.*
>
> *Sadé*

> *A parent who volunteered at the school said to me, whatever Asher tells you about how he is treated, you need to believe him. She said he was being shouted at. He was being made to face the wall; he has been made to miss his play. This is a child that is 5 years old.*
>
> *I asked the school what's going on. I am told, 'Well, you know, there's all these problems, and we don't know what's going on'. I kept asking, what is the antecedent? They would always say, 'Oh, It happens very quickly', but then also be coupled with language like, 'You know, he's just going to waste his life'.*
>
> *Rachel*

Parents said that when they began to raise with schools that they felt undiagnosed autism might be the cause of some difficulties, their concerns were not taken seriously, or were ignored. Parents also felt that schools began to label them as difficult or angry, making it harder for them to communicate with them about their children.

> *At the end of the school day, I would ask Caleb's teacher how he got on, and the headteacher would call me and say, 'The teacher doesn't have time to be standing there talking to you'. … His attitude and his demeanour towards me was disgusting. I just thought to myself, what did I do that was wrong?*
>
> *From September to July, I kept having all these meetings and kept having all these complaints. … I mentioned that I would like him to have an assessment for autism because I was noticing certain things. The school were not very helpful and were very slow about things. The consultant that we see for Caleb's epilepsy actually did the referral. So it was from her referral that we eventually were seen.*
>
> *Marianne*

> *Kyle started to struggle at school, and school would put it down to behaviour and say he wouldn't do this and that, and I was thinking, but I've done a referral; you are aware. I had suspicions about him being on the spectrum, and I told the school all this, but they weren't interested in listening.*
>
> *Kate*

> *He had a number of fixed-term exclusions. I said, Let's get an Educational Psychologist because clearly something's not okay; let's find out what that is. I said he might be autistic again. But they refused to do an assessment; the reason they gave was that there was not enough time because he's 14 years old. … We got to the point where his behaviour was serious enough that they wanted to permanently exclude him.*
>
> *Sadé*

The difficulties experienced by the child at school were found to often result in internal exclusions, managed moves, permanent exclusions, and moves to Pupil Referral Units (PRUs). This escalation led many parents to contest the judgements, with many leading to tribunals (discussed further in the preparation and advocate section).

Parents felt that some of these difficulties and challenges were partly due to a lack of experience and awareness about autism and SEN. Some also mentioned organisational dysfunction, including relevant information about the child not being disseminated to teachers, and schools employing inexperienced teachers. All parents, however, felt that race and racism were factors in the way that they and their children were treated by schools.

> *I feel that there was a lot of 'oh, he's Black '. 'Oh, he's just defiant' and this, that and the other; despite the fact that I thought he might be on a spectrum, they didn't want to hear anything about it. I've always had this thing where I'm very conscious of the way some teachers will look at Black children, and they have this either unconscious or conscious bias or assumption, which I wasn't happy about.*
>
> *Kate*

> *My daughter was allowed to wear glasses in school, and trainers, for medical reasons. Both my children were challenged for wearing trainers, even though they had medical notes, and they were saying things to my son like 'where's your note then? Where's the medical note?'. And it's already in the school system. So, they'd have to argue in the corridors with teachers who were just rude to them.*
>
> *Outright, all the Black kids have been excluded; I mean, all the Black boys are excluded. That's what happens. You're gone. Any sign of trouble, you're out of there, never mind about unmet needs. You're Black, you're trouble, you're gone. We're not having it, we're a white Catholic school, we're not having it.*
>
> *Sadé*

> *I know there are other parents who have children who are very similar. Oftentimes, you know, a white child will receive compassion. Those steps will be taken to understand something as a need as opposed to just being pure defiance. … This is the message they're getting consistently. You are not good enough for here; you are a problem.*
>
> *I need them to see that this is a little child. Right? It's not some adult who has the ability and the mental capacity and emotional capacity to, you know, make decisions because sometimes it feels like that's how you're treated. Adultification, that's what it was.*
>
> *Rachel*

> *She couldn't be in the classroom. People were bullying and clicking pens behind her head and she'd get very angry and upset, but then she'd get in trouble.*
>
> *Sadé*

Two out of the four boys in the LDG were permanently excluded and sent to PRUs. This was after parents raised with the schools that they thought their child might have autism and wanted the assessment process to take place.

Catalyst to seek assessment

These activation events appear to present an urgency to readdress the internal dissonance experienced during stage 1 around diagnoses, difference and autism. Parents expressed that seeking a diagnosis had become an issue of protecting and defending their child within an education system where they seemed particularly vulnerable (especially the boys) to certain biases and exclusion. Parents also expressed the feeling that a diagnosis might give their children access to the resources and support that they needed to navigate education and life with potential autism. This activation stage, therefore, appears to facilitate the ability to overcome or reconcile the inner conflict and associated stigma experienced at stage 1. This development of an essential advocacy factor is accelerated by the events that highlight the difficulties and vulnerabilities of a child with undiagnosed autism, but more specifically, a Black Caribbean child with undiagnosed autism. Some parents still acknowledged having conflicting feelings around diagnoses and labels but decided to actively pursue an assessment for their child as a way to safeguard them.

> *So here I am now faced with this situation, where I want to get my son a diagnosis, and my partner was furious. I had to read up a lot of stuff in terms of getting my head around this to be able to hold my arguments. And what we came to is an agreement. We still really struggled with it. The agreement was that I'm going down this route because I've got no choice; it gives them a protected status in any school environment, and that is the reason I'm going to do this. I was very clear about what I think autism isn't; it is not a psychiatric disorder. It's a difference.*
>
> *Sadé*

> *I still do question that earlier stage when he was being perceived as disruptive and stuff. Was it really that he was being disruptive or was it actually that they weren't meeting his needs academically because they wouldn't see that he was a child that is capable? Because of this we sometimes resist, or there is denial. … There needs to be an understanding of resistance coming from our experiences of discrimination.*
>
> *Rachel*

3.5.1.2 The early-diagnosed group

Parents from this group faced similar challenges during the activation stage of the essential super-advocacy theory but of a slightly different nature. Parents of the EDG tended to describe difficulties related to ensuring that their children received the funding and support that they were allocated and/or entitled to. This was through the EHCP or (in one case) the SEND statement process, involving schools and local authorities. Problems related to organisational dysfunction (i.e., errors with data protection, information sharing and misinformation) caused delays and mistakes in the process. This often left their children without the support and recommendations that they were recommended.

> *It was very simple to get Isaac's statement at the time, extremely simple. So, when it came to Taylor I thought it was going to be the same, however, it wasn't. The local authority had turned me down for a statement. So, I fought them.*
>
> *Nobody actually trusts or has any faith in the local authority because of these kinds of mistakes. This is sensitive information in these reports; if I've been sent someone else's report, who's got my report? And yes, human error, but my children's details are on there. It's a massive breach.*
>
> *Beverly*

> *You’re being misinformed. I was. ... I say misinformed, but on some occasions, you’re just being lied to. Just last year, I was told by the case manager, that the statutory school leaving age was at 16. And I said no, it isn’t, it changed. I said you have to be in education unless you’re going into employment or an apprenticeship. And they said, Well, no, that’s not statutory. I said under which law are you referring to? And she couldn’t respond.*
>
> *Kate*

There were some closer parallels with experiences of the LDG in relation to the treatment of the child at school. James attended a specialist speech and language school before his mother Beverly eventually withdrew him and moved him to a specialist autism school.

> *I found out after he left there, that other children who happen to be on the autistic spectrum left for the same reasons. It felt like they were not interested in finding out what was wrong [when he started to have ‘meltdowns’] and what was causing these things to happen. Because I started to get phone calls… talking about exclusions and stuff.*
>
> *Beverly*

Elizabeth’s son Aiden was only 4 at the time of the interview so had not entered compulsory education, but she reflected on her experiences and impression of schools’ provision for autistic children:

> *I worked in a school that had an autism resource base. … the teachers didn’t ill-treat them, but I would hear conversations in the staff room and just how they were spoken about. I just remember thinking, wow, like, that could be my child that they’re talking about.*
>
> *Elizabeth*

3.5.1.3 Activation summary

A difference noticed between the activation events of the LDG and the EDG was that there were fewer references made to race and racism as a factor by the EDG. This could be due to the events being mainly in relation to the local authority rather than day-to-day and face-to-face interactions involving the child, e.g., with schools. In general, however, the EDG had more positive experiences with schools and settings than the LDG, likely due to their child receiving more appropriate provision and also parents having a greater understanding of their children's needs at an earlier stage. They were, therefore, able to begin to develop the three essential super-advocacy factors ahead of compulsory education age. Both groups nevertheless had to expand connections and collaborative support to effectively prepare and advocate for their children during this stage.

3.5.2 Preparation and advocacy

Parents from the LDG and EDG, seek advice and make important connections following the activation events of stage 2. This expands their knowledge and support network regarding SEND laws and processes (namely the statement and EHCP process) and provides important advice from relevant organisations and professionals to defend and advocate for their children.

It is during this stage that parents prepare for and attend meetings with headteachers or tribunals, learn more about what is available to support them and their children, and also how to access it. This stage also involves continual contact with settings and services to ensure the correct provisions are being made or to understand and investigate the frequent issues being raised about their children. Parents also develop their knowledge and awareness of autism and neurodiversity as they learn more about their children and their needs and advocate for them.

3.5.2.1 Building connections and ongoing learning

Parents describe reaching out to make new connections, build a support base, and continue learning to better advocate for their children:

> *With the support from a person from [organisation], who I contacted, she attended all the meetings that I had with the schools. She told me that I had the right to actually make the [EHCP] request and I didn't have to wait for the school to make it. [Organisation] covers all subjects to do with special educational needs and a lot of information in regard to the legal side of things.*
>
> *Kate*

> *I'm now around people who are in this kind of SEND world, and it's completely different now; I'm learning things about the system.*
>
> *Marianne*

> *Everything that I learned and all the information I got came from being really proactive, but also from having some connections in my network because my sister is a teacher, and I had an advocate from the centre; they were really helpful.*
>
> *Rachel*

> *I'm still learning as well; I am constantly going on courses just to be more informed. I think when it comes to autism, knowledge is everything; knowledge, patience, and understanding.*
>
> *Elizabeth*

> *I can't go down the road of a medical disorder, I'm not having that. So, I then went off and did a Post Graduate Certificate in autism, which gave me a completely different perspective; it's a more activist perspective that fits in with my values.*
>
> *Sadé*

3.5.2.2 Seeking specialist advice

Parents independently sought out specialist support to help them advocate for their children when they were at risk of being permanently excluded from school. These appeals were not found to be very successful and often led to further action being taken by parents.

> *I bought in a behavioural specialist. … He came and did the ABC chart thing with the school, but the school were not filling the chart in properly. He said obviously, there's something happening that is setting him off at school, but the school clearly has no interest in finding out or working on that.*
>
> *Kate*

> *We happened to have as an expert witness a Black Educational Psychologist who suggested possible ADHD and autism; she wasn't sure but said that it should be looked into. They upheld the school's decision, and therefore, he was permanently excluded. It was just horrendous, it was heartbreaking.*
>
> *Sadé*

3.5.2.3 Appeals and tribunals

Five of the parents of this study went through the school appeal process and/or went to tribunal. The sixth parent's son was only 4 years old at the time of the interview and had not entered statutory education. The experiences of the parents show that appeals to the school, especially around decisions to exclude, were not very successful and often led to the child going through a managed move, being transferred to a PRU, or being taken out of school to be homeschooled by the parent. Parent's who escalated cases to tribunal level were found to be more successful.

Other tribunal cases directly against the LA, were for decisions made in regard to the statement or EHCP process and provisions made for the child.

Rachel appealed the decision to exclude her son from the independent school he was attending but it was unsuccessful.

> *I submitted a full report. I asked them questions in terms of their behaviour policy for example, if there are early indicators of low-level disruption, What steps did you take at the earliest point? … no one's denying what the behaviours are, but what did you do before it got to that point? Of course, they didn't follow the steps that they should have. They didn't make any real effort.*
>
> *Rachel*

Danny, was sent to a PRU after being permanently excluded from his secondary school. After the board of governors refuted an appeal, the case was taken to tribunal:

> *They were absolutely appalled. I've never been anywhere where I've been so listened to and so respected, so considered in terms of what we've been through. I expected them to be a bit adversarial or a bit difficult, but they were just lovely. When they looked at these behaviour points- [they said to the school] this child's got 170 points, at what point where you going to raise this with parents? My son is the only child in [home city], who got back into his old school to date.*
>
> *Sadé*

Kate’s school choice for her youngest son, James, was turned down by the local authority. She wanted him to go to a specialist school, and the LA allocated him the local mainstream. She planned for tribunal, but the LA ‘backed down at the last minute’. James was then able to attend the specialist setting.

Beverly went to tribunal 3 times in total. The first was regarding a blue badge application. Her paediatrician advised that she should apply for one for her first son, Isaac, when he was first diagnosed aged 2. This was due to his limited sense of danger, and tendency at the time to run out into the road. When it was rejected by the LA, Beverley went to tribunal and waited 18 months for the date:

> *They had two judges and two doctors, and they asked me loads of questions. They then said we are going to award it to you. They apologised and said the Department of Working Pension was saying they see Isaac as ‘a normal five-year-old’, and I said to the woman, can I ask, do you know anything about autism? She said she did a one-and-a-half-day course, and I said, well, I tell you what, come and live in my house for a half-day.*
>
> *Beverly*

The second time was related to advised provisions being removed from Isaac’s statement by the LA, and the third, when the LA said that they did not need to update Isaac’s EHCP post 16. Beverly won each of these cases.

3.5.2.4 ‘Non-stop fight’

The ‘essential super-advocacy cycle’ of stage 2 illustrates the continual nature of advocacy that is needed by BCPs of children who have autism. One parent described this as a ‘non-stop fight’.

> *I nearly went on to have four years of fighting, nonstop, every single day, not just for my son but for my daughter also. I never had a minute’s peace, I’ll say over a day, there was probably about half an hour a day where I wasn’t challenging the school’s behaviour. It was horrendous.*
>
> *Sadé*

> *I'm confident at challenging, but I always say thank you and appreciate that this is not personal; it's just about me getting what I need for my son, and I think people kind of accept that and recognise it.*
>
> *Rachel*

> *I've learnt that I can fight in the name of my children. … I didn't know that I had the strength and versatility to be able to push and fight the way that I have; it's so much.*
>
> *Beverly*

3.5.2.5 Preparation and advocacy summary

The 'preparation' and 'advocate' categories of stage 2 characterise the role and importance of BCPs in advocating for their children who have autism. They illustrate the necessity for BCPs to be ready and able to constantly defend and be the advocate. They also demonstrate the challenges faced when trying to do so. Children from the LDG required the most advocacy from parents in relation to their time at school. All these children were undiagnosed at the time of entering mainstream education. Appeals and tribunals were common against school decisions to exclude. This was often after parents raised with schools that they thought their child might have additional needs. Parents from the EDG appeared to have more direct issues with Local Authorities and their advocacy often involved challenging decisions made regarding access to resources and provisions for their child. During stage 2 of the essential super-advocacy theory, the development of the essential super-advocacy factors is accelerated to equip and sustain parents with the knowledge, tools and support that they need.

3.5.3 Supportive practice

There were examples of good practice by some schools and services that BCPs of this study found both helpful and supportive. These were often practices that the parents felt prioritised the needs of their child, developed their knowledge and understanding of their child's needs, and valued their voice as parents.

3.5.3.1 Good practice by schools and educational settings

Parents discussed parent-headteacher and SENCO relationships at a school as an important indicator of the support the school would give their child. Trying to foster a positive relationship was something parents felt was their duty, but a positive and responsive SENCO and headteacher was considered good practice and had a positive effect on their child's experiences and treatment.

Another example of good practice valued by parents was schools considering the unique needs of their child and personalising educational pathways in a way that nurtured strengths while supporting areas for development.

> *Although Isaac was nonverbal and had social, emotional, and social communication difficulties, He was extremely academic, so the majority of special schools turned him down because he was too academic. So what the resource base did was they assigned him a specialist one-to-one, and he just stayed travelling from the base to the mainstream. He couldn't do that in secondary, though, so the mainstream secondary school he's at has specialist skills, so he actually has no more than six kids in his class. … I have quite a good relationship with the current SENCO, and the resource base team as well.*
>
> *Beverly*

> *My daughter is in year six at the moment and next year, she'll be going to secondary school. In July, I had a meeting with her SENCO, because I said to her that I would like an assessment for my daughter. So she gave me the initial paperwork and things like that and we started having conversations, and yeah, she sent off a referral for my daughter already. The SENCO was very supportive. … I'm still finding support and as a school, the class teachers, I feel like I'm working better with them.*
>
> *Marianne*

> *What was brilliant about this new head teacher is that he brought in SEN consultants. One of them specialised in autism and taught all the teachers how to do an IEP properly and then made sure that every single classroom had a visual timetable as well in the class and that was in Kyle's final year of junior school, and I noticed a difference instantly. He got back to enjoying going to school.*
>
> *Kyle did the apprenticeship. He worked in something to do with commercial housing, but it was like more the administrative side of things. He got a lot of support, and I was so shocked. They put in an Access to Work assessment and everything like that. They actually got funding to help him with his confidence.*

Kate

3.5.3.2 CAMHS

Despite waiting times, the post-diagnostic sessions offered by CAMHS for parents were considered a good space to learn more about autism and neurodiversity and the different professionals involved in supporting children and young people with autism. This appeared to be especially important for parents of the LDG as the EDG received similar support during stage 1 when their child was first diagnosed.

> *They had four parent sessions that were run consecutively over four weeks, and they were helpful. After the first session, which was very much the kind of medical stance, the three sessions were just very helpful, very practical. We had Paediatrics, Speech and Language, so it was the other people who are going to support you, and the Occupational Therapist. To me, they are the more reasonable people, not so coming from that sort of diagnostic perspective.*

Sadé

3.5.3.3 Pupil referral units

The parents of children who were excluded and sent to PRUs expressed feeling distraught about the decision, often referring to the high numbers of Black boys sent to PRUs who rarely make it back into mainstream education. These parents said they were adamant that their child would not stay at the PRU, and in the cases of this study, all children were eventually transitioned back to mainstream education. Parents, however, found that there were systems and practices at the PRU that supported them and the needs of their children, namely a fast-tracked neurodevelopment assessment for the children who had not been referred by the schools that had excluded them. Parents also referenced the multidisciplinary approach and them being able to play an active role in decision-making for the benefit of their child.

> *We got an awesome assessment, all completed in six weeks. I think there was a kind of understanding that this is probably quite urgent given that he was out of school and could potentially get involved in low levels of criminality or something, there was a bit of a push. … The Early Intervention Team made the referral.*

Sadé

> *The PRU had a dedicated CAMHS person who was obviously able to circumvent the system. Children in the PRU would be prioritised. … The PRU, with all the perceptions that come with it, I will honestly say now that there are some good people who fight for the cause of our children there, but again, the setting is not right. … it gave us the ability to identify a school that can best suit his needs. The school that my son is at is actually the school that I originally wanted him to go to, but back then, he didn't get in because we weren't in the catchment area.*

Rachel

3.5.3.4 Community services

Parents mentioned projects or services within the community that helped them in their time of need or offered their children new and fun experiences.

> *He had a chance to try archery at the Inclusion sports day run by the [organisation]. They do like an inclusion sports day for eight to 25-year-olds, sometimes during the half term or during the summer holidays where you can try lots of different sports. One time, he tried archery, and he was really good.*

Kate

> *The church had been quite supportive. They were able to give us some vouchers for food during the pandemic and things like that. So they were quite supportive.*

Marianne

3.5.3.5 Supportive practice summary

The supportive practices discussed above were found to be helpful to parents and beneficial to the child. They were practices that considered the unique needs of each child, offered multidisciplinary support, valued the voice of the parent and offered new and funded experiences for the child and/or family. It is, however, important to consider that these practices delivered by some schools and PRUs, services, and the community were relative to the overarching experience of parents as outlined by stage 2.

3.6 Stage 3- The outcomes and outlook stage

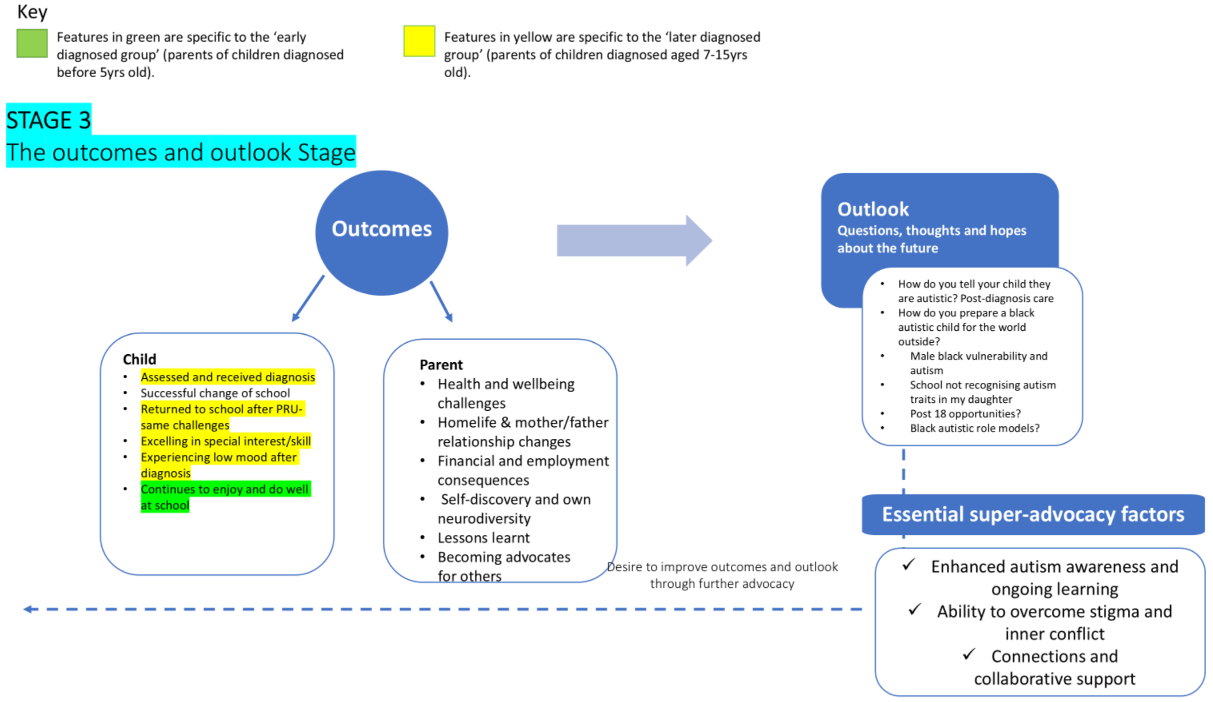


Illustration 4. Stage 3: The outcomes and outlook stage

Stage 3 of the essential super-advocacy theory (see illustration 4) evaluates the outcomes and outlook of BCPs and their journeys so far. It identifies categories regarding outcomes and also the hopes, thoughts and ideas that they have about their children's futures.

3.6.1 Outcomes

3.6.1.1 Post diagnosis

It was found that the fervent advocacy provided by parents achieved some of the desired aims as outlined in stage 2, e.g., all children from the LDG were eventually assessed and received a diagnosis, which confirmed and validated parent queries. All children who were transferred to PRUs also returned to mainstream settings, but the success of reintegration was, however, mixed. Some families were also able to gain access to helpful services after the diagnoses were made.

> *He’s now in a mainstream school, he has an EHCP, and he has a diagnosis which means that his needs can be viewed in that context. As a symptom of his disabilities. It feels like as a school, they have better resources and their TAs, for example, are much more skilled and have that practical experience. In general, the quality of staff is better.*
>
> *Rachel*

> *For my son, since now having the diagnosis, I was able to access a charity who do junior respite sessions and also family holiday clubs that we were all able to go to over the summer. At one of the family sessions, he met a friend.*
>
> *Kyle really enjoyed maths. He did really well in maths. He actually got a B. He wanted to do maths at A level and even passed the pre-test. … he did level three BTEC ICT Level Three Media Studies and he got a merit in one and a distinction in the other.*
>
> *Kate*

> *I managed to get him back into school but he didn’t last very long in the school environment because they hadn’t put any support in place and they hadn’t worked on anything. To be honest that kid is now, you know, after having this experience, he’s really angry with everybody.*
>
> *He got 5 GCSEs. He got his French; he did French for 15 months and got his French. He could have got a 9 in maths, that’s what this kid was predicted to get, but he got a five, so he passed.*
>
> *Sadé*

3.6.1.2 Successes

Children and young people who went to specialist settings and had access to the provision that their parents fought for, were overall reported to have done (or be doing) very well. Children who also had opportunities to develop their individual gifts and talents were said to be excelling in them.

> *Taylor got his EHC. Isaac was at his school’s base, and they are both in secondary school now. They both are doing phenomenally. … Isaac does animation and voiceovers in Japanese. I want to see him working for a gaming company or an animation company.*
>
> *Beverly*

> *She's a very talented [team sport] player, a very unusual player because she's autistic, and she does all this stuff that other people don't do. … She's an elite player because she was chosen for the [elite sports team] talent pathway.*
>
> *Sadé*

> *He was lucky enough to take part in the para-London youth games. … We took the day off school because we had to travel up to East London on a Wednesday to compete. James didn't train or nothing. He just turned up and he ran and won a gold medal. … He does basketball now and started Saturday club and he used to do racquet sports, but now he does basketball.*
>
> *Kate*

3.6.1.3 Continued challenges

The LDG appear to continue to face a distinct set of challenges throughout the stages of this theory mainly due to their child's diagnosis coming at a later age. A question that was raised by many parents of this group was how to support their child or teenager to understand and process their new autism diagnosis. Some parents explained that the diagnosis was not easy for their child to accept. One parent had not yet told her son who was recently diagnosed aged 7, as she did not want him to immediately associate it with behaviours that he had witnessed at the PRU.

> *The message my son is probably getting all over the place is that he doesn't get anything right, and so that has a knock-on effect in terms of his confidence and how he sees himself. So, for me, that is why I was very clear: I am not going to tell him until he is in a better space to hear that there will actually be more challenges and that autism doesn't mean that he is going to stay in a pupil referral unit or always going to be permanently excluded. … I didn't want him to make that association with autism because that's not what autism is. That's what the system is. So that is the reason I decided not to tell him, but I have decided to tell him very soon.*
>
> *Rachel*

> *Yeah, it's been a rough time; I mean, there's no doubt these kids have had a tough time from being quite young just grappling with all the school stuff and, you know, overcoming lots of difficulties and low self-esteem. … I'm working with children who are depressed, and they got depressed when they heard that they got the diagnosis, and I'm talking about depression, not feeling a bit fed up.*

Sadé

The parents with children who were 18+ at the time of the interview, shared concerns about limited opportunities and support available for their children during this stage of their lives, and that it feels like they are almost forgotten by the system at this age.

> *It was just a fixed-term apprenticeship. So, he was there for a year. The manager said they were looking to help him to find somewhere else to go and he wasn't really finding anything. But they kept him on for another six months but only part-time because they can only fund so much. Then after that, that was it. He's basically been at home in his bedroom ever since.*
>
> *Kate*

3.6.1.4 Parent outcomes

When looking at outcomes for the parents, they all expressed that their journey and the 'non-stop fight' had been very stressful and had impacted health, work and relationships, as discussed in stages 1 and 2. Many, however, now support other parents who have children with SEND and autism so that others can benefit from their hardship and learning. Some parents also shared that their journey included valuable growth and self-discovery with some recognising neurodiverse traits in themselves.

> *I requested part-time. I said my son has an autism diagnosis now, I've split from my husband, and I'm now a single mum. Help me out, you know. They were like flat out, 'No, it's full-time or nothing', and that was it for me. I left, and I don't regret it to this day. … It's daunting because I'm on my own, but my children are happy despite not having money like I used to.*
>
> *I always say that if I had neurotypical children though, then I wouldn't be the person that I am today. You know, because Aiden's taught me a lot in a very short space of time. It's been hard, not gonna lie, but yeah, he's taught me a lot.*
>
> *Elizabeth*

> *You could imagine the levels of stress, anxiety, upset and shame and despair that we were under. I still get teary about it now because I feel like it was a clear injustice. … I also had to give up my job at that time as so often I'd be in meetings and I'd be triggered by conversations around me about the sort of thing that I'm going through,*

> *almost feeling like I'm now allowing my personal experiences to interrupt my professional experience. … it's a journey and I feel like I want to share with others but it just feels like- did it have to be so traumatic?*
>
> *Rachel*

> *Now that I know about neurodiversity, I can see it in my family members, even within myself.*
>
> *Marianne*

> *I got assessed privately and was diagnosed. … now I can understand and manage and regulate what I need to regulate to function as a mother, a wife and an advocate as well.*
>
> *Beverly*

> *I think I spent a long time as an activist and I'm kind of coming to the point in terms of my own health and wellbeing that I just want to chill out a little bit. … I was trying to work at the same time, I mean, I hardly could work. The level of stress, I'd say it's really weird now but it used to feel like my chest was being sat on and I was going to collapse. I had to start my own therapy because it was just so awful, but I needed to stay strong.*
>
> *Sadé*

3.6.2 Outlook

Categories concerning the outlook of BCPs, reveal concerns around 'how you prepare a Black autistic child for the world outside. These fears were around navigating racism in society while being autistic, and the vulnerabilities it might pose, especially for sons. Some parents, however, were beginning to find that it was harder for professionals to recognise autistic traits in their daughters, which raised concerns about different challenges in future for them. More 'positive Black autistic role models' was also raised by parents who felt this would support their children to have greater confidence, while also challenging the stigma that exists within Black Caribbean cultures. Parents also raised that there was a lack of specific support regarding the culturally specific issues that Black parents and people face in relation to autism, neurodiversity, and assessment.

3.6.2.1 Black role models, professionals, and tailored services

Parents raised the idea of a need for Black autistic role models for their children and also Black parent role models who have children with autism.

> *Like any child you want them to have aspirations. We want them to have positive role models and see people who they can see themselves in.*
>
> *Rachel*

> *There needs to be a lot more people of colour standing up and saying it's okay if your child is on the spectrum. We see all the time with, you know, Paddy McGuinness and Katie Price and all of these people of colour with children with SEN they're not standing up. A prime example, she annoys me, Toni Braxton, her son is on a spectrum, and suddenly now he's 'grown out of it'. It's things like that that drives me crazy.*
>
> *Beverly*

> *I think every Black family should see Stephen Walsh's story. So, this is a kid if you listen to him speak, he's got quite stilted speech, so he's obviously different. He also talks about the fact that he was nonverbal until he was about the age of nine, and then it quickly moved forward so they can see the gallery itself; his stuff is selling for about a million pounds.*
>
> *Sadé*

Some parents also expressed a feeling of safety or reassurance when working with Black professionals regarding their child, and that more thought needs to be given to provide safe spaces for the concerns of Black parents to be discussed.

> *It was great that we went to do a neurodiversity pathway assessment, one of the psychologists was a Black woman actually. So you know, seeing that felt a little bit assuring.*
>
> *Rachel*

> *There was a brilliant Black family worker. He was just like an angel there to protect us. He was so supportive and so lovely and handled things well.*

Marianne

> *Provision specifically as a Black person dealing with a child with autism, having space that is specific to my race and my culture that provides that safe space to be able to explore and talk about those issues. Because in the back of my mind, I'm always thinking of how what I'm saying might look to the school.*

Rachel

3.6.2.2 Black vulnerability and intersectionality

There was a deep fear and concern expressed by some of the parents that the risks posed by being a Black child, (or more specifically a Black boy) with autism were not fully acknowledged or understood by those who need to understand them i.e.., the education and legal system. Parents felt that more needed to be done in this area.

> *I think it is really necessary to understanding the complexity, the uniqueness, and the various aspects of a child, a boy. A Black boy with additional needs, and what that means in terms of their experiences of going to school and not just going to school but living their lives and accessing services.*
>
> *Another part that I worry about because the whole sort of not always being able to navigate social rules, unspoken social rules, or conversations and that sort of thing that I sometimes think to myself, we get drawn into unnecessary disagreements because he has just simply said it as he sees it, and that being perceived from others in the wrong way may it be authority, or peers.*

Rachel

> *My husband previously worked at a young offender's Institute as a prison officer. He knew, coming from our family, that at least 70% of children of colour in there were undiagnosed ADHD or ASD. And, you know, for me, it's scary because I don't want my boys to be that statistic, I don't want them to have to be institutionalised for them to realise that if something was put in place when they're in reception in school, they wouldn't be locked up.*

Beverly

3.6.2.3 Daughters' autism traits not recognised

Some parents found that when they started to recognise traits in their daughters, professionals were reluctant to investigate them. Some professionals said that they felt these traits were 'learnt behaviours' due to growing up with a brother on the spectrum. Others felt that there was no need to assess as the daughters 'enjoyed learning' and were conscientious and helpful in the classroom. More study is needed in this area, as it appears that experiences gaining access to services might look quite different to that of boys, especially if she has other autistic family members known to the school, or she is doing academically well with no 'behavioural' difficulties in the classroom.

> *I realised that my daughter was exhibiting traits as well. I did not have the space to start a process of referral, but at one point in 2019, I did go to my doctors and ask, and that's like a whole other story, the incompetence and ridiculous way that that's been handled.*
>
> *Marianne*

> *I picked up a lot about Shiloh being on the spectrum, but she's very, very good at masking. I took her to the drop-in sessions at the Children's Centre. All they saw was a young, bossy girl who wanted to learn. The OT basically said to me, 'Oh no, no, it's just learnt behaviour; you know she'll be alright.'*
>
> *With all the parents I support with girls, they find that their daughter is on the spectrum after they've self-harmed. … with girls, it usually comes in adolescence with the transitions, puberty hormones, and secondary school. It comes out in a mental health issue. I don't want that for her.*
>
> *Beverly*

3.6.2.4 Outcomes and outlook summary

The parents of this research stress the need for more work in the area of providing culturally specific autism support for BCPs and their families. They desire a safe space to discuss the issues they face at the different stages of their journey, as many felt isolated and lost, particularly during stage 1 and the beginning of stage 2 of the ESAT. More professionals and advocates who are passionate about the unique needs and concerns of Black families was also a strong recommendation, especially more Black professionals and role models to encourage parents to seek support and to help newly diagnosed Black children know that they are not alone.

As outlined above, there are some ongoing systemic concerns, particularly around the safety of the Black Caribbean autistic child out in the world. Parents expressed wanting to do more about this, while also recognising the scale of the problem. Many of the parents, however, now advocate for other parents who have autism or work with young autistic children, e.g., in creative therapy. They continue to contribute towards positive change using the skills and knowledge developed on their journeys.

This final stage of the ESAT lastly summarises the accomplishments of these BCPs. In the face of fierce challenges, they showed resilience, fervour, strength, passion, and love for their children with autism.

3.6.3 Chapter summary

The ESAT demonstrates that these parents are indeed super-advocates, providing the advocacy essential for their children to acquire the support, protection, and resources that they need. The next chapter will examine how these findings relate to existing literature.

4 SYSTEMATIC LITERATURE REVIEW

4.1 Chapter overview

This chapter aims to explore:

- How The ESAT fits in with what is already known about the experiences of BCPs who have children with autism
- How extant literature supports and enriches the current theory and vice versa

To do this, the search strategy and search results will first be outlined, followed by a discussion of the relevant theories stemming from the literature and their significance to the ESAT and BCP's experiences. An integrated review of the literature, structured and analysed according to the stages of the ESAT, will then be presented to further demonstrate how the current theory connects, supports, and enriches what is already known and vice versa.

4.2 Literature search

4.2.1 Initial literature search and change of literature population group

Fifteen databases on EBSCO host were searched for relevant literature. After searching key terms in varying orders (*'Black Caribbean or West Indian AND parents or caregivers or mother or parent AND experiences or journeys or perceptions or attitudes or views or feelings or perspectives AND child with autism spectrum disorder or autism or ASD'),* It was found that there was no existing research dedicated to the experiences of BCPs who have children with autism in the UK. The results rendered 363 papers (reduced to 283 papers once U.K. or British limiters were applied). Most papers were related to one of the search terms and sometimes loosely; however, none were related to the experiences of BCPs who have children with autism in the UK. Most papers on Black parents' experiences were US-based on African American (Black American) parents.

A constructive decision was therefore made to conduct a literature search on the Black American population. This group has been used comparatively in British educational research and longitudinal studies due to the similarities with the Black Caribbean population in the U.K. This includes very similar trends in academic achievement and SEND disproportionality..

4.2.2 Rationale for change of literature review population group

It might initially seem more appropriate to conduct a literature review on an alternative Black British group or use the more general 'Black British' category instead. However, there are more similarities, particularly in educational statistics, between Black British Caribbean children and Black American children than there are between Black British Caribbean children and children from the Black African and Black Other groups in the UK. British statistics often do not report on specific Black ethnicities, preferring the broader 'Black' category, which can create the impression of homogeneity. However, the statistics suggest otherwise when the ethnicity is specified (usually as Caribbean, African and Black Other). This indicates important differences in the societal challenges and cultural contexts between them.

As mentioned in Chapter 1, a reason that drew the researcher to seek the experiences of BCPs specifically was the statistics involving black Caribbean children within the education and SEND systems. The largest UK study to date on ethnic disproportionality and SEND by Strand and Lindorf (2021) highlighted some of the differences seen between the statistics on Black Caribbean and Black African children. They found a significant over-representation of Black Caribbean children being identified as having SEMH, even when controlling for age. This was not the case for Black African children, who were underrepresented. Government statistics have further reported that Black Caribbean and White and Black Caribbean mixed children are twice as likely to be permanently excluded than their White British counterparts, even after controlling for gender, age, SES, and prior attainment (Department for Education, 2023). This was, however, not the case for Black African children, who are half as likely to be permanently excluded than their White British counterparts. Additionally, despite an overall improvement in attainment by Black Caribbean students at GCSE with a 52% standard pass rate in English and Maths in 2022, it was still below the national average of 65% and the 69% pass rate by Black African pupils (Roberts & Bolton, 2023). These examples begin to highlight the importance of understanding the distinct cultures, trends, challenges, and experiences of each ethnic group, even while recognising shared issues that also exist.

The differences between Black Caribbean and Black African students in the educational statistics above have been understood in many ways. Some researchers have stressed the difference in immigration patterns. The majority of Caribbean people arrived in the UK as a part of the Windrush generation in the 50s and 60s, which makes many parents and children of this group today second or third-generation UK-born. Whereas larger immigration from

West Africa began mainly in the 1990s and continues to this day (Strand, 2015). This makes it more likely for Black African families to be newer immigrants. Some researchers have proposed that newer immigrants have a stronger focus on academic achievement to improve social mobility (Kao & Thompson, 2003). In fact, Black African students (alongside those from Chinese, Indian, and other ethnic backgrounds) are more likely to attain a university degree than White British and Black Caribbean students from similar socio-economic backgrounds, although this does not always lead to better job outcomes (Social Mobility Commission, 2023).

It is, however, very important to consider the experiences of the Caribbean Windrush generation on arrival to the UK during the 50s, 60s and 70s, particularly within the education system. These experiences highlight the severity of systemic barriers from the outset, e.g., being labelled as ‘educationally subnormal’ and sent to schools for children deemed as such (Coard, 1971/2021). This provides some context as to why obtaining a higher education degree (for example) would be significantly more difficult for this group. Therefore, the generational experiences and availability of opportunities play a significant role in the disproportionalities discussed.

Going back further, despite Black Caribbean people making up a part of the African diaspora, their more recent histories resonate more closely with Black American groups due to transatlantic slavery. It was between the 15th and 19th centuries that men and women were forcibly taken from West and Central Africa to the Americas (including the Caribbean) by European slave traders. African traditions, culture, family structures, and way of life were dramatically disrupted and altered, and living within a system of subjugation and dehumanisation became the norm. Despite progress since the abolition of slavery and the development of new and distinct cultural expressions, similarities in the challenges faced by both groups today can be traced back to the impact of this shared history, as well as the underlying systemic structures and beliefs that have persisted (A. Missouri Sherman-Peter, 2022).

As mentioned earlier, Black American students currently exhibit trends similar to those of Black Caribbean students in the UK, particularly in areas such as academic attainment, SEND (Special Educational Needs and Disabilities) disproportionality, and exclusion rates (Chapman & Bhopal, 2019; Strand & Lindorff, 2021). As a result, researchers have used data from the Black American population to draw comparisons with the Black Caribbean group in the UK.

While it is important to respect the differences between the groups, there are recognised and significant socioeconomic, cultural, historical, and racial identity similarities. This makes studies with the Black American population a relevant and suitable group to review.

4.2.3 Literature search strategy

Two literature searches were conducted using EBSCO host and fifteen databases. The following key terms were used for Search 1: '*Black American or African American AND parents or caregivers or mother or parent AND experiences or journeys or perceptions or attitudes or views or feelings or perspectives AND child with autism spectrum disorder or autism or ASD'.* For Search 2, the terms 'advocacy or Advocate or Advocating' were added to ensure any papers including the key theme of advocacy were also identified. The terms for both searches were also run through Google Scholar as an additional search method.

The inclusion and exclusion criteria for the literature can be found in Table 6, and the identification and screening process on the PRISMA flow diagram (Figure 8).

Inclusion and exclusion criteria	**Exclusion criteria**
Papers on Black American Parents or mothers of children with autism*	Papers where Black American parents are not the main group of the study
Papers referring to parent experiences and perceptions related to: - Before, during and after diagnosis - The diagnostic process - Accessing services - Relationships with schools, services and community	Papers that focus on a very specific aspect of the parent's experiences, e.g., autism and religion
Peer-reviewed qualitative studies	Papers that focus on the impact of specific interventions
PhD Theses	Studies that focus solely on the father experience
	Books and conference materials

Table 6. Inclusion and exclusion criteria

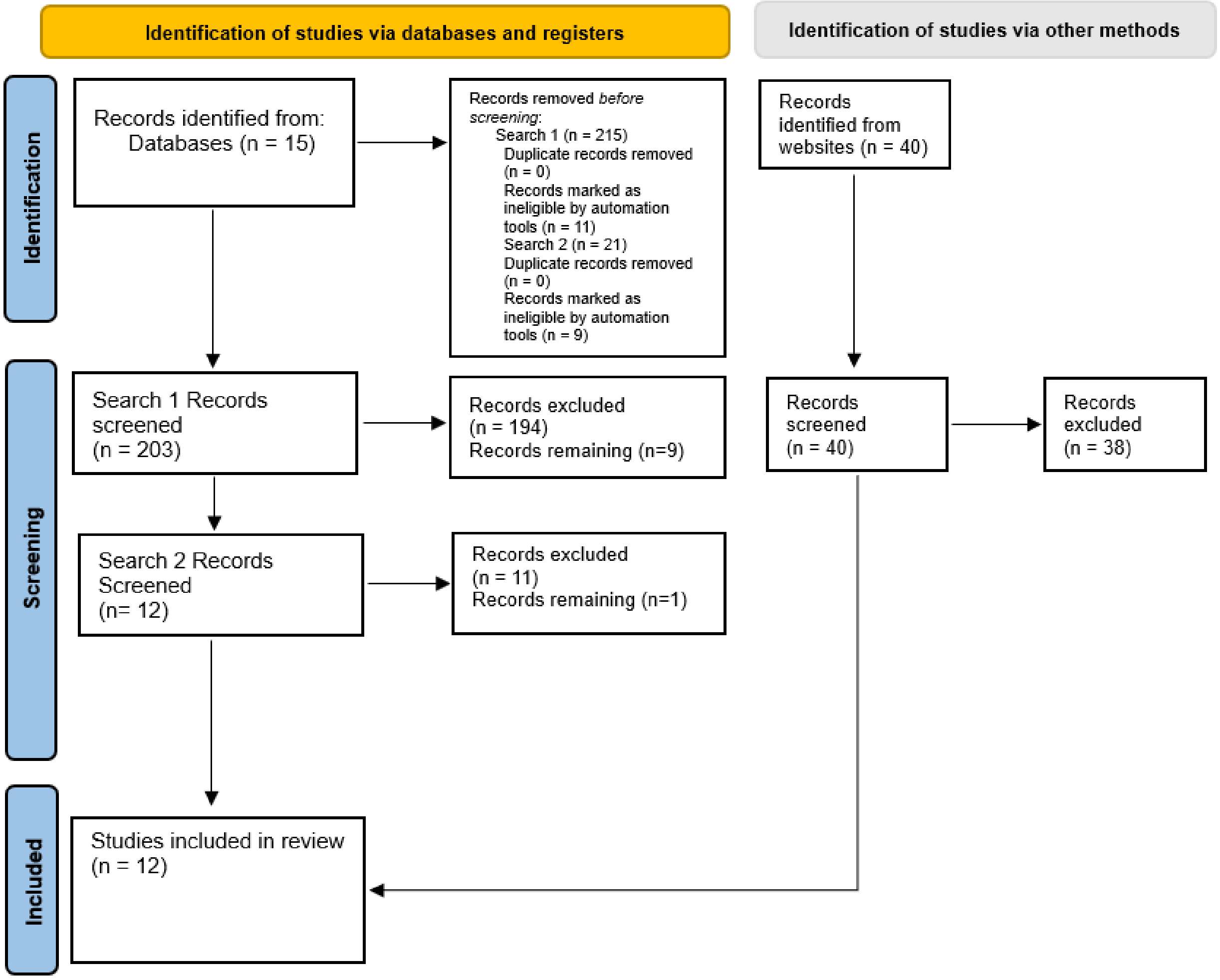


Figure 8. PRISMA Flow Diagram (Page et al., 2022) Illustrating the identification and screening process

4.2.4 Literature search results

Twelve papers were identified, including seven peer-reviewed published studies and five Doctoral Theses. Table 7 provides an overview of these results.

	Author/s year of publication and title	**Main research question/s**	**Type of source**	**Research design**	**Participants**	**Conceptual/ theoretical framework/s**

Paper 1	Hetherington (2012) *"They think we don't have the knowledge:" The Intersection of Autism and Race*	How do the dual oppressions of race and disability impact Black American mothers of children with autism and their relationship with the schooling process?	Doctoral Thesis Education	Qualitative Semi-structured Interviews, a focus group and field notes Grounded Theory analytical process	5 Black American Mothers of 7 children with autism	Feminist Disability Theory
Paper 2	McNair (2015) *My life, my son, our journey*	What roles must Black American parents play to access appropriate classroom accommodations, modifications, and support services for their sons?	Doctoral Thesis Leadership for Education Justice	Qualitative Narrative inquiry Online questionnaire and interviews	5 families, all of whom include a biological parent and a son with autism (from preschool to 8th grade/13 years old).	Critical Race Theory (CRT) (Delgado & Stefanic, 2001) Social Justice
Paper 3	Debabnah et al. (2018) *"We Had to Keep Pushing": Caregivers' Perspectives on Autism Screening and Referral Practices of Black Children in Primary Care*	What are the barriers and facilitators to ASD screening and referrals in primary care? Are there socioeconomic differences in primary caregiver-reported experiences?	Peer-reviewed paper	Qualitative Semi-structured interviews 'Grounded Theory approach' (Strauss & Corbin, 1990)	22 female caregivers (18 mothers, 4 'other' including grandmothers) of Back American Children with autism	Public Health Critical Race Framework (PHCRF) (Ford & Airhihenbuw, 2010)

Paper 4	Lovelace et al. (2018) *Experiences of African American Mothers of Sons with Autism Spectrum Disorder: Lessons for Improving Service Delivery*	What is the impact of race on the lived experiences of African American families who have boys with ASD? What caregiving experiences do participating African American Mothers of children with ASD attribute to race? Do participant reports provide evidence of a unique experience for African American families of children with ASD?	Peer-reviewed paper	Narrative Inquiry Grounded Theory Framework Codes were identified from existing literature and used as initial codes to start the analysis. Prospective codes from the data were then added and included in emerging themes.	3 Black American mothers of sons with autism	None Specified
Paper 5	Pearson & Meadan (2018) *African American Parents' Perceptions of Diagnosis and Services for Children with Autism*	What are the perceived factors that facilitate and impede early diagnosis and access to services among African American parents who have children with ASD?	Peer-reviewed paper Office of Special Education Programmes, U.S. Department of Education, funded	Qualitative questionnaires and semi-structured interviews Grounded Theory	11 Black American mothers of 13 children aged 4-11 with autism	None Specified
Paper 6	Hong & Singh (2019) *Contextualising the social and structural constraints of accessing autism services among single Black female caregivers in Atlanta, Georgia*	What are the social and structural factors that place children and their families with limited resources at risk of delayed ASD diagnostic services and limited therapeutic services?	Peer-reviewed paper	Qualitative, Semi-structured Interviews	21 single Black American female caregivers of children with autism who rely on state Medicaid health Insurance in Atlanta 16 mothers 5 Grandmothers	Adapted 'Cycle of Environmental Health Disparities Framework'

Paper 7	Morgan & Stahmer (2020) Narratives of single, Black mothers using cultural capital to access autism interventions in schools	What forms of cultural capital are used by single Black mothers to advocate for their children with autism in schools?	Peer-reviewed paper	Qualitative Semi-structured interviews Thematic Analysis	10 Single Black Mothers	Critical Race Theory (CRT) Community Cultural Wealth Model (Yosso, 2005) Bourdieu's 1973 Theory of Social Reproduction Cultural Capital Theory (CCT)
Paper 8	Brown & Mortier (2021) "Watch Your Tone" The Experiences of African American Parents of Students on the Autism Spectrum in Parent-School Partnerships	What are the experiences of African American parents of children on the autism spectrum within the family and community? What are the experiences and needs of African American families with children on the autism spectrum while navigating school communities?	Peer-reviewed paper	Qualitative Semi-structured interviews with parents Focus group with cultural brokers	7 Black American mother and 2 couples 6 Cultural Brokers 3 of which have children with autism	Communities of Practice (Wenger-Trayner, E. & Wenger-Trayner, 2002)
Paper 9	Jones (2021) African American Parents' Experience Accessing Support Services for Their Autistic Child	What are the experiences of African American parents in Philadelphia accessing and maintaining autism services for their child (barriers and facilitators)?	Doctoral Thesis	Qualitative generic study (Cooper & Endacolt) used to explore attitudes, beliefs, and experiences	10 Black American parents/ 5 Mothers and 5 fathers of children with autism	Resilience Theory (Zimmerman, 2013) Behavioural Health Model (Anderson, 1995)

Paper 10	Morgan (2021) The Developmental Process of Parent Advocacy for Black Mothers of Children on the Autism Spectrum	What are the pathways to becoming an autism parent advocate? What variables are associated with parent advocacy?	Doctoral Thesis	Mixed methods, surveys, focus groups and interviews. Thematic Analysis Narrative enquiry Phenomenological qualitative methods Self-Portraiture	7 Black mothers across 4 states of children with autism. Also Parent-peer coaches trained in advocacy	Critical Race Theory (CRT) Double ABC-X Model
Paper 11	Quinn-Lunny (2021) *A Phenomenological Study: Lived Experiences of Black Parents Through the Autism Spectrum Disorder Identification Process*	What are the lived experiences of Black parents through the ASD identification process, including barriers and facilitators? What are parent training needs to assist in effective identification?	Doctoral Thesis Education	Qualitative Semi-structured interviews, questionnaires, and parent journalling Phenomenological	16 Parents 15 mothers, 1 father 11 Black American 1 Jamaican 1 Haitian 1 Native American	None Specified
Paper 12	Lewis et al. (2022) The creator did not give me more than I can handle: Exploring coping in parents of Black autistic children	What coping strategies are used by Black parents who have children with autism? What role does culture play in the use and effectiveness of coping strategies?	Peer-reviewed paper	Mixed Methods Questionnaire and semi-structured interviews Grounded Theory Methods	Twenty parents of Black American children, all women. Children aged 3-17 All boys	Black Family Stress and Coping Model (BFSC) (Murray et al., 2018) ABC-X Model (McCubbin & Patterson, 1982) Mundane extreme environmental stress (Peters & Massey, 1983)

Table 7. Literature search results overview

4.3 Relevant Theories

To contextualise the literature review, the relevant theories and conceptual frameworks used or developed by the included studies will be outlined in terms of their significance to the current research and findings.

Nine of the 12 included studies explicitly use theoretical concepts to design and interpret their research and findings. To discuss these, they have been grouped into five categories: critical race theory (CRT) and intersectionality, strength-based theories, process theories, disparity analysis frameworks, and collaborative theories. Themes of intersectionality, however, are present in all theoretical frameworks, and so will reoccur.

4.3.1 Critical race theory (CRT) and intersectionality

Critical race theory (CRT) examines the intersection between race, systems, and institutions and explores how these contribute to the maintenance of racial inequalities. It acknowledges that systems and institutions were not created with marginalised groups in mind and, therefore, inherently disadvantage them.

Critical race theory was first developed by Black American legal scholars in the 1970s (most notably Derrick Bell), who were active in the civil rights movement. Since then, Kimberly Crenshaw’s work has been foundational in CRT, especially around the concept she coined ‘Intersectionality’- “a metaphor for understanding the ways that multiple forms of inequality or disadvantage sometimes compound themselves and create obstacles that often are not understood among conventional ways of thinking.” (Crenshaw, 1989). Education Professors Daniel Scolorzano and Dolores Bernal (2001), also prominent in CRT research, state that CRT mainly comprises five main elements (1) The centrality of race and racism and their intersectionality with other forms of subordination; (2) The challenge to dominant ideology; (3) The commitment to social justice; (4) The centrality of experiential knowledge (5) The transdisciplinary perspective.

Themes from CRT and intersectionality are prevalent in all of the literature review studies, with many adopting frameworks that consider overlapping identities and their interactions with systems (i.e. the health disparity analysis frameworks that are later discussed). The papers by Hetherington (2012), McNair (2015), Morgan & Stahmer (2020) and Morgan (2021), however, more explicitly use CRT and Intersectionality theories (including feminist

Black theory and feminist disability theory) within the design and interpretation of their studies.

The relevance of CRT and intersectional theory ties strongly to the disparities found within autism statistics at the time of their publishing. Black American children were less likely to receive an ASD diagnosis than their white American counterparts and, when diagnosed, were more likely to receive a diagnosis on average 2 years later (Debabnah et al., 2018; Jones, 2020). Access to services and intervention was also significantly delayed for the Black- American population (Liptak et al.; Mandell et al., 2009). These studies aimed to understand these disparities through the lens of the Black American parents' lived experiences. As CRT is closely related to social justice, understanding these experiences also aims to promote the necessary change.

A poignant example of a study that explores the intersection of race, disability, and gender is the doctoral thesis by Hetherington (2012). It focuses on the experiences of Black mothers of children with autism within the special education system.

Hetherington found through her qualitative study that the intersection of 'Black American mother' and 'child with autism' presents a 'complex labyrinth of hazards' within institutional structures and the special education system. The hazards and obstructions were found to be 'regulatory', i.e., through the power of knowledge required to navigate complex systems, and 'interactional', i.e., through the treatment they and their child received, including microaggressions and more overt forms of discrimination.

Hetherington's findings state that to overcome these hazards and obstructions, mothers need to learn the system, resist the system and exercise maternal agency. These closely align with the essential super-advocacy factors of the ESAT and suggest that there is an important and specific skill set that these Black mothers with autistic children require to successfully advocate for their children within educational systems. One of these skills (learning the system) is based on the central CRT concept that 'knowledge is power' and that this power is typically held by policymakers who acquired it from those who constructed systems historically. In the US (and the U.K.), this group predominantly comprised White Anglo-Saxon middle/upper-class protestant men.

According to the findings, for Black, working-class mothers to obtain a voice and agency within these systems, becoming learners of the system is crucial. Interestingly, however, knowledge was found to be insufficient on its own. The Hetherington study and the current study assert that resilience, resistance, and exercising maternal agency are also essential to overcoming the hazards and obstacles that these mothers face. The current research (and other studies later discussed) also goes further to suggest that collaborative support is additionally necessary for overcoming obstacles and advocating for your child.

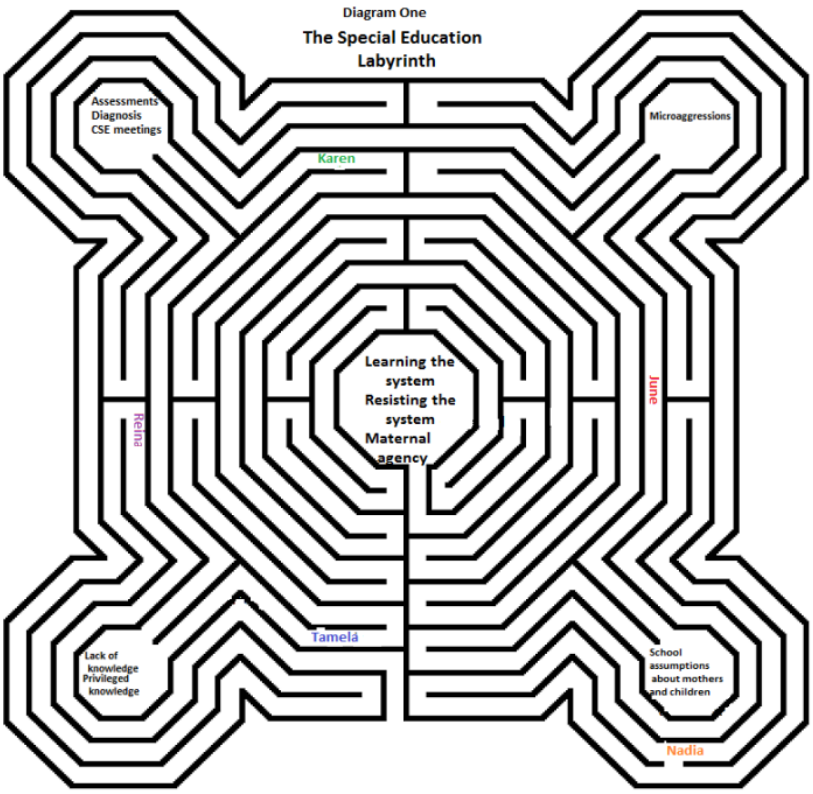


Figure 9. The special education labyrinth (Hetherington, 2012 p. 134)

The labyrinth diagram above from the Hetherington study (Figure. 9) illustrates the hazards and barriers each mother faced by the positioning of their names relative to each hazard, i.e., Nadia (bottom right of the diagram) mainly experienced barriers related to school assumptions about herself and her child, whereas Tamala (bottom middle-left of the diagram) experienced problems related to lack of knowledge and some regarding school assumptions also. This visual representation conveys the variability and complexity of the parent experience.

4.3.1.1 Critical race theory, intersectionality and the essential super-advocacy theory

The ESAT predominantly demonstrates process and the stages involved in overcoming barriers and developing successful advocacy skills; however, complexity and variation are similarly illustrated, particularly in the unique experiences of the EDG and LDG. Overall the ESAT demonstrates that BCPs' experiences and interactions with systems are based on a complex interweaving of intersecting identities that must be fully explored to understand how best to support them. Critical race theory and intersectionality are, therefore, very relevant to the current research.

4.3.1.1.1 Age of diagnosis and visibility of autism needs

In addition to presenting the BCP’s experiences with systems and internal processes, The ESAT also considers the child's age of diagnosis and the intersectional impact that this can introduce. It considers that differences in the visibility of certain autism traits and the age of diagnosis can present nuanced challenges and experiences for both the parent and child.

As discussed in the findings, children who accessed mainstream education before they were diagnosed encountered many difficulties in relation to assumptions and treatment by school staff and governing bodies. Exclusions, managed moves, referrals, board meetings and tribunals were all features of parents who had children diagnosed after 5 years old. Additionally, the parents experienced more overt interactional barriers and hazards with school staff than the parents of children diagnosed before 5 years.

It is important to note that parents from both groups experienced multiple barriers (with the EDG predominantly facing challenges with the local authority); but the intersection of the age of diagnosis and the visibility of needs clearly presents different barriers and hazards, with apparent prolonged internal dissonance, delayed parent empowerment and greater interactional difficulties with schools for the LDG, according to the ESAT. A U.S. study also states a likely underdiagnosis of Black American children with ‘milder forms’ of autism, suggesting a need for better expertise and knowledge among professionals in assessing less visible traits in young Black children to help counteract these problems.

4.3.1.1.2 Education, gender and black autistic sons

The intensity of hazards and barriers in interacting with mainstream schools that the LDG experienced can also relate to a further intersection factor—the child's gender. Three of the four children who were diagnosed after 5 (aged 15, 14, 9 and 7) were boys. Two of these boys were excluded or transferred from their schools after parent requests for an autism assessment and further investigation into their son's needs were dismissed.

The girl diagnosed at 14 (Isabelle) had difficulties at school before diagnosis, with one incident escalating into a physical altercation. This, however, did not result in exclusion. Her mother (Sadé) made a series of complaints about the incident, and it did not lead to an exclusion. When Sadé’s son Danny, however, found himself in a similar circumstance at the same school, Sadé’s interventions, complaints and requests for help for Danny were ignored, and he was eventually permanently excluded. This was only reversed after Sadé escalated the case to tribunal. Sadé felt that her son’s race, gender, height, and appearance made him more susceptible to harsh judgement and treatment at school, which had a negative impact on his overall wellbeing.

McNair’s Study ‘My Life, My Son, Our Journey’ (2015) found that the parents of Black autistic boys were pressured to accept ‘self-contained’ learning placements for their sons by the school district, which were non-inclusive placements for children with a very high level of additional needs. Many of the parents did not feel like these placements were appropriate for their sons. They also felt that these placements were non-compliant with the U.S. ‘no child left behind’ legislation passed in 2001 that advised that the ‘least restrictive environment’ or LRE be assigned for each child with special needs to enable the most inclusive environment wherever possible.

This finding appears to parallel the exclusion of Black Caribbean autistic boys from mainstream education in the current study, as in both studies, parents felt that placement decisions were inappropriately harsh and failed to acknowledge their son’s individual needs and abilities. The actual experiences at PRUs in the current research did accelerate the pathway to assessment and diagnosis, which can ultimately be seen as a positive outcome; however, had the mainstream setting been able to identify the needs of the students at an earlier stage and/or listen to parent concerns, exclusions and the impact on the child and parents might have been avoided.

In contrast, one mother in the current study (Kate) felt that because her son was quiet and rarely found himself in trouble at his school, the support he was allocated was often used for other children in his classroom, and he was often without the help he needed to progress in his learning. Beverly also found that schools (both mainstream and specialist) struggled to support her son Isaac because he was both non-verbal and academically advanced. Differentiating learning and catering to his individual needs and strengths was something that she reported did not happen despite recommendations for him. She had to fight and advocate for him so that schools could recognise his academic ability.

4.3.1.1.3 Societal vulnerability and black autistic sons

The Intersection of Black autistic male also presented specific fears and concerns for mothers in the current research as outlined in the outcomes and outlook stage, especially around their son's vulnerability and safety in society. This centred around fears of racial profiling, unfair treatment by police and arrest. These fears are consistent with current statistics. In the UK, males aged 15-19 have the highest rate of stop and search; the highest rates are with the Black Caribbean, Black Other and Asian Other ethnic groups (out of 19), with the Black groups most likely to result in arrest (GOV.UK, 2023).

These concerns were also raised by parents in the literature. In the Morgan study (2021), for example, the mothers feared for their autistic Black sons due to anti-Black violence in the U.S. One mother in this study, Ola, explained:

> *As a Black mother raising a young Black boy. We go out every day, and there are things that can occur. You need to be willing to defend him in that. ... my oldest son says he has a target on his back every day he leaves his house. (p.96)*

The intersection of race, gender and autism is, therefore, highly relevant in the current research. Anello et al. (2009) discussed that some autism traits, particularly those around social communication, i.e. difficulties recognising and /or understanding social cues and less variability in facial expressions, can resemble assumed or stereotyped behaviours of Black children (especially boys). This is a critical point as it begins to explore the underlying mechanisms of this apparent double societal risk that Black autistic children can face. It is clear that raising awareness of these particular autism traits and the bias that can occur without enhanced understanding is crucial, especially for educational settings and law enforcement.

This intersection strongly relates to the 'activation' category of stage 2. Harsh treatment of children at school, particularly boys in the LDG, was often perceived by parents as being related to their ethnicity and gender. This treatment (including exclusion and reluctance to investigate additional needs) was the main catalyst to BCPs actively seeking an autism assessment and diagnosis. This highlights that the function of a diagnosis acted as more than a way to better understand their child's needs. Instead, it suggests that BCPs urgently seeking a diagnosis were driven by a desire to protect their child from racial stereotypes and assumptions. Parents aimed to reframe both conscious and unconscious racial biases by obtaining 'proof' that their child has neurological differences understood as autism that need to be acknowledged and understood.

4.3.1.1.4 Black mother of black child with autism

It is not just the gender and race of the child that causes unique intersectional barriers but also the gender and race of the parent. As discussed in the findings chapter, mothers of the current research reported that they were often labelled as difficult or aggressive when advocating or showing interest or concern for their child's education and wellbeing. This would often result in being reprimanded by a senior member of the school or institution, as discussed in the findings. The mothers who experienced this felt that this was a symptom of negative racial assumptions made about Black women.

For 8 of the 12 studies, all participants were mothers or female caregivers, e.g., the grandmother, so the majority of the findings speak to the mother's experience. All of these studies raised this experience, with 7 referencing negative racial assumptions and microaggressions while trying to acquire the support needed for their child with autism. In the Quinn-Lunny study (2021), a mother expressed that her 'passion is seen as anger'. Examples of this can be seen in Brown & Mortier's study (2021). A mother reported being told to 'watch her tone' when enquiring about a literacy intervention for her son. Another mother from the same study noticed that police or security were always present when she requested an IEP meeting with her child's school. This is further illustrated by a conversation that June, a mother from the Hetherington study (2012), reported after asking the principal at her daughter's school when her daughter would receive the assistive technology that she needed:

> ***June:*** *Sir, what are you saying? My daughter has an IEP,*
> *she's entitled.*
> ***Principal:*** *Entitled? Entitled? She is not entitled to anything!*
> *That's what's wrong with you people…*

> ***June:*** *See, my husband, should have come…*
>
> ***Principal:*** *And what would your husband have done?*
>
> ***June:*** *Sir, I refuse to speak to you any longer.*
>
> ***Principal:*** *Well, let me escort you out.*
>
> ***June:*** *I don't need you to escort me anywhere. (p.159)*

Mothers of these studies raised other common assumptions made about them, including being a 'welfare mum' (Quinn-Lunny, 2021) or 'uneducated with no knowledge' (Hetherington, 2012). Interestingly, the Debabnah et al. study (2018) found that the economic and educational status of the parents did not determine or predict how parents were treated by professionals and the specific assumptions made about them. Parents from both higher and lower economic status and educational backgrounds reported ill-treatment, negative assumptions made and dismissal.

Another paper's findings, however (Pearson & Meadan, 2018), did not appear to have any explicit mention of perceived racism or racial assumptions as a barrier to diagnosis and accessing services. This was one of two papers out of the 12 with no explicit mention of perceived racism as a barrier in the findings (although acknowledged in the discussion of extant literature). Little information about the authors is given, but, it is specified that the study was funded by the Office of Special Education Programmes, U.S. Department of Education.

4.3.1.1.5 Single black mothers

The intersection of 'single' ', Black', and 'mother of child with autism' was found to compound barriers and introduce new ones.

Hong and Singh (2019) interviewed 21 single Black mothers for their study '*Contextualising the social and structural constraints of accessing autism services among single Black female caregivers in Atlanta, Georgia'*. A significant finding of this study was that single parenthood compounds the energy, time and knowledge required to navigate services. The authors draw attention to the burden of both 'unwaged and waged labour'. They explained that the unwaged labour involves the constant 'navigating and bureaucratic processes needed to obtain ASD services in addition to all the other caregiving work required to raise a child with special needs', which has a significant impact on the physiological and psychological of the parent. This is supported by the mundane extreme environmental stress theory (Peters & Massey, 1983), also cited in the Lewis et al. study (2022), which refers to the serious cumulative effect of chronic exposure to environmental stressors on health over time. The impact of these compounding pressures was also found to have a direct impact on the economic security of the families due to the problems obtaining or maintaining employment. Janice, a parent from the study, explained:

> *If [my child] has a big meltdown, nobody could control him, so I had to leave work and go see him. My supervisor sat me down, and she was like, "You've been taking a lot of days off." I told her what was going on, but she said, "You can stay, or you can leave." I had to leave because this is my son, and I left that company. … I don't want to ever feel like I'm neglecting him because I'm trying to go to work." (p.372)*

The 'waged and unwaged labour' can be seen in the stages of the ESAT, particularly in the essential super-advocacy cycle of stage 2, which illustrates the intense and ongoing involvement needed by the BCP.

The McNair Study (2015) supports Hong and Singh's findings and found that the stress experienced by a Black American single parent raising a child with a disability is greater than that of a married Black American parent with a child who has a disability because of the reduction of support at home- both practical and emotional. The authors emphasise that single mothers are not only trying to navigate the complex school systems on their own but also 'coming to the realisation that their sons would always be different'. The latter point resonates with the internal dissonance of stage 1 of the ESAT. The complexity of the new reality and practicalities of a child's autism diagnosis (or potential autism diagnosis) mirrors the complexities of the internal processes that the single mother must work through, often on her own. As outlined in the ESAT, these internal processes include feelings of fear, grief, guilt, and denial.

This study also found that while single mothers need more support from schools and services, they face the greatest resistance and/or isolation. This is demonstrated in the Lovelace study (2018). Tasha, a participant in this study, explained that services rarely consider the needs of single parents, e.g., she felt 'out of place' at parent support groups, as she was often the only single parent there. She explained that 'their problems were not her problems', which felt awkward and isolating. Another single mother, Latisha, stressed the practical implications of being a single parent of a child with autism and keeping up with appointments and interventions;

> *I have no one to get my kid on and off the school bus, so I cannot work during the week. I'm going to school during the week so when he's in school, I'm in school. And then, when he comes home, he has his TSS, PT, OT, and speech and then on the weekends, I'm at work all weekend. I have absolutely no life. Ever. (p. 10)*

Morgan and Stahmer's paper (2020) is the third to focus on the experiences of Black single mothers. The aim of this study was to explore single mothers' use of cultural capital in accessing school autism interventions for their children. The authors used many theories, including CRT, the community wealth model (Yosso, 2005), and Bourdieu's theory of social reproduction (1973) in the formation of their study and findings. Their findings in relation to cultural capital will be explored further when discussing strength-based theories. Their main finding, however, which is in line with CRT and intersectional theory and further supports the findings discussed, is that Black mothers, especially single Black mothers who have children with autism, 'must engage in systems that are structurally and systemically racist, sexist, and ableist', leading to higher risks of misdiagnosis, deferred diagnosis and poor quality of service. The strength-based theories section spends more time discussing how these are overcome, as does the ESAT.

Four of the mothers from the current research were single parents, and their experiences support the findings of these studies. The ESAT outlines the ongoing and intense advocacy of the parents and the impact on their lives, work, and wellbeing. In the area of employment for example, this is seen clearly. Rachel left her job to homeschool her son, as she feared for his wellbeing and safety at school. Kate said her life was consumed by caring and advocating for her two sons with autism after she was made redundant, so she had to become a full-time mother. Elizabeth became a single mother during her son's autism assessment process and had to leave full-time teaching when her school did not accept a request to go part-time – (similar to Janice's story from the Hong & Singh study). Another aspect seen in the ESAT is the feelings of emotional isolation that the single mothers felt, especially during the internal dissonance stage.

The parents who were married or in a long-term relationship, however, also expressed overwhelm and stress on seemingly similar levels. One also detailed significant disagreements with their partner around the subject of diagnosis. Nevertheless, this could be for many reasons. Beverly for example, who was married, also had the most children. She had three young boys with autism. It could be argued that the number and gender of her children multiplied the work, commitments and challenges. The other mother (Sadé), who had the support of a long-term partner, had a teenage girl and boy diagnosed at 14 and 15, which findings also show present intensified challenges due to their age and the delay to their diagnosis. Therefore, although the current research did not explicitly find that single mothers experience greater hardship, 67% of the participants were single mothers, so the ESAT and the parent super-advocacy needed widely represents their story.

Understanding the experiences of single mothers of children with autism is particularly significant to the current UK study for an additional reason. An independent family review by England's Children's Commissioner in 2022 found that 23% of families in the UK were headed by single parents, with 90% of these being mothers. There were large differences by ethnicity, with the Black Caribbean group having the largest proportion of single-parent families (57%) (compared to 44% in the Black African group and 22% in the White British). This stresses the significance of recognising intersecting factors that are more likely to affect Black Caribbean parents. Although it is crucial to avoid making assumptions, it is important that services and professionals understand the extent of compounding factors that single Black Caribbean mothers of children with autism are at a greater risk of experiencing.

4.3.1.1.6 CRT and intersectional theories summary

Critical race theory and intersectionality are key to understanding the experiences of BCPs of children with autism. Race, gender, visibility of needs, and age at diagnosis have all been identified as significant intersecting factors in the ESAT. The race and marital/relationship status of the mother also. It is important to note that the ESAT is not just about Black mothers but Black Caribbean mothers and aims to shed light on the uniqueness of their experiences within the context of UK society. There are striking parallels with the U.S. studies but also differences that have been discussed. These differences, however, still fit within the CRT and intersectionality frameworks.

It is also important to recognise that the experiences of Black Caribbean fathers are not represented in the current research, and only four of the 12 literature review studies had a small number of fathers. Additionally, the majority of parents in the current research and the literature had sons with autism rather than daughters. It will, therefore, be important to explore the experiences of BCP fathers and BCPs who have daughters with autism in future research.

4.3.2 Strength-based theories

All studies of the literature review have identified the strengths and skills executed by Black American parents to advocate for their children with autism. These will be examined in further detail later. In terms of strength-based theories, three were identified in the literature that provide a framework to help understand the parent factors that promote success. These strength-based approaches are relevant to the current research, as the ESAT also identifies strengths and success-related factors.

4.3.2.1 Community cultural wealth model (Yosso, 2005)

The community cultural wealth model, developed by Professor of Education Tara Yosso (2005), applies the concept of cultural capital to ‘communities of colour’. Traditionally, cultural capital is understood as a group of social assets that enable social mobility and status. These social assets include things like knowledge, education, style of speech, dress, and intellect (Bourdieu, 1973). Cultural capital was first defined by sociologist Pierre Bourdieu in his theory of social reproduction (1973), which theorised that those with higher cultural capital have greater advantages and social mobility in society. Bourdieu’s theory, however, is widely based on the cultural capital of western White culture, so it does not necessarily apply in the same way to different groups within the same society, i.e., minority ethnic groups. As seen in the studies discussed above, for example, it was not enough for Black American mothers to possess ‘knowledge’ of the special education systems (a key form of cultural capital). They needed additional skills that were not a part of Bourdieu’s original theory in order to be successful in these systems.

Yosso’s community cultural wealth model reconceptualises cultural capital to recognise these skills and the important social assets that help ethnic communities survive and thrive. This model, grounded in CRT, is a crucial strength-based theory that aims to promote culturally specific strengths that are otherwise overlooked. Table 8 shows the six types of cultural capital presented in the community cultural wealth model.

Name of capital	Definition
Aspirational capital	The ability to maintain hopes and dreams in oppressive environments
Linguistic capital	The intellectual and social skills attained through communication experiences in more than language and/or style

Familial capital	The cultural knowledge from family or kin that carry a sense of community, memory, and cultural intuition
Social capital	The networks of people and community resources
Navigational capital	The ability to navigate systems not built with a marginalised population of people in mind
Resistant capital	The ability to oppose and challenge inequality

Table 8. The community of cultural wealth model cultural capital definitions (Yosso, 2005)

Three of the papers reference Bourdieu's concept of cultural capital and that mothers with some aspects were at an advantage compared to other mothers who were without (Hetherington (2012); McNair (2015); Brown & Mortier (2021)). However, a key aim of Morgan and Stahmer's study (2020) was to investigate the forms of Yosso's cultural capital used by Black American Single mothers to advocate for their children with autism in schools. They found that there were two dominant forms used: resistant capital (the ability to oppose and challenge inequality) and navigational capital (The ability to navigate systems not built with a marginalised population of people in mind).

The literature review studies and current research support that these two skills are essential and demonstrated by most, if not all, of the Black parents advocating for their children with autism. Although the Morgan and Stahmer study is the only one that used the community of wealth cultural capital concept, skills associated with resistance and navigational capital, particularly persistence and resilience, are seen throughout all studies.

The ESAT, by nature, demonstrates the BCP's resistance and navigational power. It demonstrates the 'super' levels of advocacy needed and what it takes to accomplish them. The ESAT's version of cultural capital can be seen in the 'essential super-advocacy skills', i.e., the skills it would be impossible to successfully advocate without. The 3 identified in the current research are enhanced autism awareness and ongoing learning, the ability to overcome stigma and inner conflict and connections and collaborative support. It could be argued that these encapsulate aspects of Bourdieu's cultural capital and Yosso's cultural capital while introducing new ones.

An additional skill found in the ESAT is 'the ability to overcome stigma and inner conflict'. This allowed the BCPs the ability to advocate within complex systems with the conviction and persistence needed. A series of factors supported the development of this skill, including early diagnosis and systemic support. Nevertheless, it was led by a deep concern and realisation that without their advocacy, their child would not get the support that they urgently needed. Aspects of the internal dissonance stage were identified in ten of the twelve literature review papers, which will be addressed further in the next section.

The forms of Yosso's cultural capital that are perhaps less explicit in the ESAT are linguistic capital and familial capital. However, had Yosso's framework been used to inform the interview schedule, further information might have been provided in this area.

The community wealth model in the Morgan and Stahmer study emphasises Black parents' strengths and skills. This is very important, especially for considering ways to support and prepare other Black parents to advocate for their child with autism.

The ESAT demonstrates that many parental strengths are, however, developed under the most stressful of circumstances, which cannot be ignored. Ways to support parents to develop these skills at the earliest stage possible, to prepare and try to prevent escalation of crises and stressful circumstances, is therefore a key area for further research.

4.3.2.2 Resilience theory (Fergus and Zimmerman, 2005)

The Jones study (2021) uses the resilience framework to help understand the experiences of Black American parents accessing support services for their child with autism. The resilience framework, originally developed by Fergus and Zimmerman (2005), aimed to provide a strengths-based approach to understanding child and youth development. Identifying 'promotive factors', which they describe as 'contextual, social and individual variables', was an important part of their research to help develop strategies to mitigate the impact of risk factors (Fergus & Zimmerman, 2005). Resiliency has also been studied in family research and has been described as the ability to adapt or 'bounce forward,' i.e., learn to function and move forward despite stressors or crises (Walsh, 2002;2003).

The Jones study identifies some of the ways that Black American parents adapt and utilise promotive factors to support their child with autism. These included seeking support services, reframing negative feelings, self-efficacy, religious or spiritual beliefs and optimism (Jones et al., 2022).

Faith in God was also a prominent theme in 5 of the 12 studies where parents shared the strength it gave them while advocating for their child (McNair, 2015; Pearson & Meadan, 2018; Morgan, 2021; Quinn-Lunny, 2021; Lewis et al., 2022). Faith was not an explicit theme in the current research which might indicate a cultural difference e.g., in how open people are discussing religion and faith, or that the participants of the current research needed more explicit opportunities to discuss faith-based support.

The ESAT suggests that resiliency is a necessary strength for BCPs when advocating for their children with autism. Without resilience, developing through the stages and participating in the ‘non-stop fight’ would not be possible. This is reflected in the name of the grounded theory.

4.3.2.3 Black family stress and coping model (BFSC) (Murray et al., 2018)

The BFSC model explores the cultural and contextual factors of stress and coping in Black families. It takes into account socio-historical contexts (e.g. racism, discrimination and prejudice) as significant stressors while also considering culturally specific coping strategies that are protective factors for Black families (Murry et al., 2018). Similar to The Resilience Theory, The BFSC identifies 4 key ways that Black families cope under crises and stressful circumstances. These are optimism, kinship support, church involvement/spirituality, and collective socialisation.

Lewis and colleagues (2022) used the BFSC framework to help understand the coping strategies of 20 Black mothers who have sons with autism. They identified seven main coping strategies: planful problem-solving, self-control (or ‘professional persistence’), seeking social support, informal support, formal support, positive appraisal, and self-care. Four of these, in particular, are demonstrated clearly in the ESAT and will be discussed further in the comparative review section.

The paper provides important insights into coping and how it can manifest in different ways. It discusses the difference between ‘emotion-focused’ coping, which aims to reduce stress, and ‘problem-focused’ coping, which aims to solve problems or eliminate sources of stress. The latter involves careful planning and problem-solving actions, which can be seen throughout the ESAT, particularly during stage 2, where the mothers respond to injustices by actively seeking help and educating themselves about systems.

Aspects of coping not expanded on in the Lewis study findings were the more maladaptive emotion-focused types, such as avoidance and denial. This was potentially to focus on the strengths of Black parent coping. Avoidance and denial, however, were significant features of stage 1 of the ESAT, as well as the findings of 10 of the 12 literature review studies.

Denial and avoidance in the ESAT were associated with perceived cultural stigma, fear and distrust of systems, and a lack of autism awareness among family and members of the community. This denial led to feelings of shame and then isolation, delaying some parents from confidently seeking support for their child. This way of coping, therefore, acts as an internal barrier that needs to be better understood and supported.

However, it is important to recognise that a primary strength of BCPs in the current research was their ability to overcome denial and internal dissonance, develop the necessary skills and knowledge, and build the necessary connections. This is significant, as it illustrates how a coping strategy that initially acted as a barrier can be overcome with the help of the other cultural strengths and strategies identified in this group.

4.3.2.4 Strength-based theories summary

Strength-based theories serve an important purpose in this area of research. Instead of just focusing on disadvantage and hardship, they elevate the assets, skills, and resources within a people group that are otherwise overlooked. They also provide direction for the development of culturally specific interventions, which many participants felt was necessary.

There are some points of caution about a purely strengths-based approach however. First, it might potentially downplay or underestimate the harm that this level of ‘strength’ can have over time on the physical health and psychological wellbeing of the parent, as mentioned earlier. This is likely why the studies discussed use them in conjunction with other frameworks, such as the mundane extreme environmental stress framework (Peters & Massey, 1983), which recognises the impact of multiple ongoing stressors.

Linked to this, a strengths-based approach can, therefore, put an unhealthy amount of the onus on the parent. In the current research, their super-strengths were developed by necessity rather than choice, and while this is a strength, it is not known what happens to the children of BCPs who are not able to develop and maintain super-advocacy. Does this mean they are lacking in strength? Or does this mean that the system must also be thoroughly examined and developed so that parents can be supported in their advocacy instead of fought against?

The final caution is the risk of missing factors that might contribute to undesirable outcomes for the parent and/or child, such as denial, fear, avoidance, or cultural stigma, as well as the skills and strengths needed to overcome these. Understanding these is equally important so that the parent can be fully supported and empowered on their journeys.

4.3.3 Process theories

4.3.3.1 The double ABC-X model

This section will explore the background and purpose of the double ABC-X model and its applicability to the ESAT. This model was used in the Morgan study (2021) to explore the pathways that Black American mothers used to become autism parent advocates. Due to the similarities in the main focus of both studies, it presents a relevant framework that can enhance understanding of the current findings.

The double ABC-X formula and the ESAT

The double ABC-X model is rooted in the family stress theory developed by social scientist Reuban Hill (1949). The family stress model suggests that to ‘reduce adverse family outcomes, families must be supported to develop skills and strategies to help them cope with stressors’ (Hill, 1941). Hill was, therefore, concerned with supporting families in adapting and coping with stressors and crises. He went on to develop the original ABC-X model (1958), which studies the precipitating factors of a crisis (see Figure 10). By identifying these factors, Hill aimed to measure families ‘crisis proneness’ or ‘crisis proofness’ and help determine the important resources needed for family coping. This theory has been influential in fields that support families including social work, counselling, psychology and sociology (Rosino, 2016).

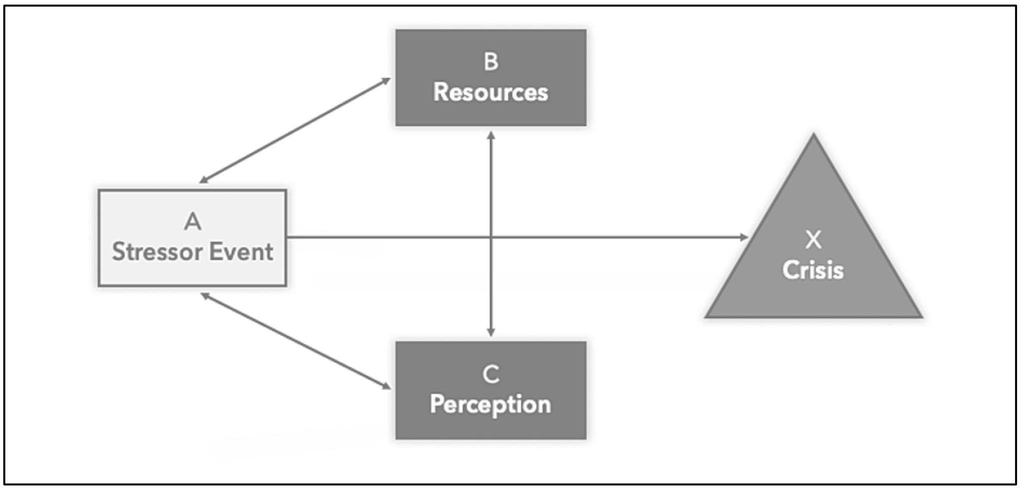


Figure 10. ABC-X model (Hill, 1958)

The variables of the ABC-X model can be applied to the ESAT as Table 9 demonstrates. This is a helpful tool to identify the resources that can minimise the 'crisis proneness' and has the potential to be used as an assessment aid to determine the targeted support a BCP family might need.

	ABC-X variables	**ABC-X variables from the essential super-advocacy theory (ESAT)**
Pre-crisis	**A- The stressor** A situation for which the family has had little or no prior preparation.	Noticing difference • Child's behaviours not understood, misunderstood or dismissed • Behaviours interpreted by some as a result of bad parenting • Socially excluded from some events • Withdrawing from some social events and settings • Emotional and social isolation
	B- Existing resources	• **Autism knowledge and understanding?**

	Protective factors within and around the family that can help prevent crises and/or improve coping.	• **Family support (extended and immediate, e.g., spouse/partner)?** • **Family autism knowledge and understanding?** • **Supportive and informative professionals, services and educational settings?** • **Knowledge of SEND systems and processes?** • **Access to systemic support, i.e., relevant services and Therapies?** • **Access to collaborative support with experienced parents of children with autism and support groups?**
	C- Perception of (a)? The definition that the family makes of the event. The more negatively the family define the stressor, the less able they are to adapt and cope with crisis, and vice versa.	Internal dissonance? • Fear • Uncertainty • Denial • Shame Accepting and/or embracing difference?
	X- The crisis The event that is either adequately resourced to cope with or not, depending on the interaction of b and c	Stage 2 Activators • Problems and challenges experienced with and within systems • Treatment of child • Treatment of parent • Organisational dysfunction

Table 9. The ABC-X model parent adaptability variables (Hill, 1958) and the essential super-advocacy theory (ESAT)

The double ABC-X model and the ESAT

Where the original ABC-X model is concerned with the precipitating variables of a crisis, the double ABC-X model considers post-crisis variables, to understand the factors that support family adaptation after the crisis. McCubbin and Patterson first developed this Model in 1982 as a response to the missing post-crisis factors of the original model (Weber, 2011).

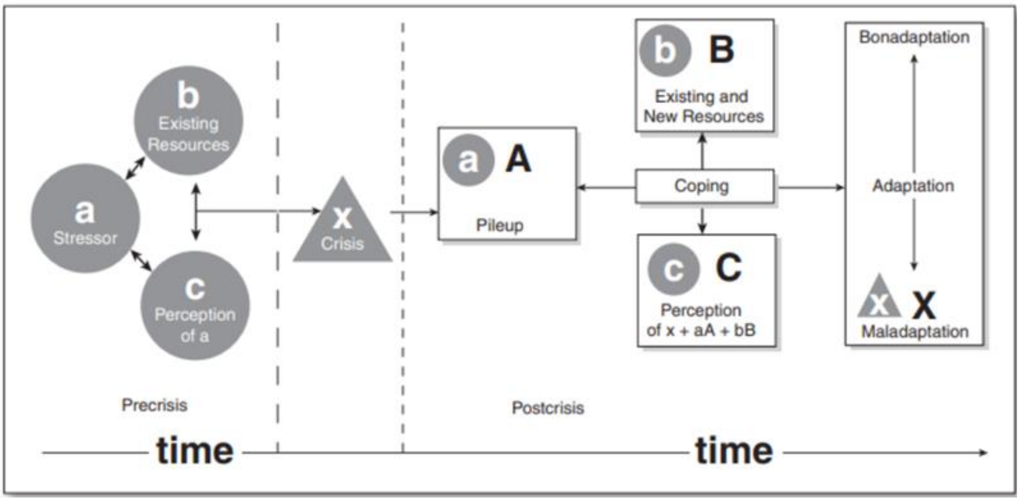


Figure 11. The double ABC-X model McCubbin & Patterson (1983) from (Weber, 2011, p., 86)

As seen in Figure 11, the ABC-X includes the original formula (variables represented in lowercase), with the added post-crisis variables including ‘Aa the ‘pileup of stressors', ‘bB’ ‘existing and new resources’, ‘Cc’ the ‘perception’ of ‘a’, ‘aA’, and ‘Bb’, and ‘xX’ ‘coping and adaptation’ to the post-crisis variables (McCubbin & Patterson, 1983).

This formula can be better applied to the theory of the current research. It recognises that crises create new stressors and that these new stressors call for new resources (see Table 8).

Post-Crisis	**Double ABC-X variables**	**Double ABC-X variables from the essential super-advocacy theory (ESAT)**
	aA- Pileup (of stressors)	Stage 2- Ongoing and/or escalating activators, including exclusions and Tribunals.
	bB- Existing and new resources	• Collaborative support/ • Specialist/expert advice?

		• Support groups? • Extensive knowledge and learning of autism and SEND Systems?
	cC- Perception of X, aA and bB	• Organisational dysfunction and lack of autism knowledge • Racial bias • Injustice
	Xx- Adaption The result of changes in the family system which evolves and is intended to have long-term consequences.	Outcomes and outlook- Stage 3

Table 10. The double ABC-X model parent adaptability variables (McCubbin & Patterson, 1983) and the essential super-advocacy theory (ESAT)

The EDG had a higher level of existing resources because of the earlier diagnosis of their child. This led to earlier intervention and systemic support and provided a head start to learning more about autism and the SEND system. Parents from the EDG were, therefore, able to process, accept and/or embrace their child's diagnosis at an earlier stage and overcome internal dissonance, as explained in the findings. As the formula would suggest, the EDG were more resourced entering stage 2. Nevertheless, they still needed to build connections, form supportive collaborations and commit to ongoing learning to become super-advocates, which relates to the bB variable- needing new resources.

Using this Formula, therefore, helps to illustrate and explain some of the reasons why the LDG appear to face a more intense level of hardship at Stage 1 and Stage 2 of the ESAT. They were less resourced. A significant 'pileup stressor' for the LDG was the intense difficulties their children experienced at mainstream school, including exclusion or the threat of exclusion. These stressors however acted as a catalyst to parents attaining the essential super-advocacy skills and resources that they needed which can be seen as accelerated adaptation.

Adaption in the double ABC-X model refers to "an outcome as a result of change in the family system, which evolves and is intended to have long-term consequences" (Weber, 2011, p. 88). 'bonadaptation' is the positive end of the adaptation scale, and 'maladaptation' is at the negative end, represented by 'xX' as seen in Figure 11.

Advocacy development was the greatest area of adaptation that emerged from the current research and would be seen as positive adaptation. There were smaller subthemes that might represent less positive adaptation, such as parent health and wellbeing and mother-father relationships that were impacted by the stressors and crises, nevertheless, advocacy development was the core concept of their experiences.

4.3.3.2 The double ABC-X and the Morgan study (2021)

Morgan (2021) used the double ABC-X model to explore the positive adaptation and advocacy development of Black American mothers who have children with autism. The 7 participants were trained parent advocates or ‘peer coaches’ to other parents of children with autism. Narrative enquiry and the phenomenological method of self-portraiture were used to gather data, and thematic analysis was used to analyse the findings.

Three main factors were found to be important for advocacy development and positive adaptation after diagnosis: 1) Trustworthy agents of support, 2) Advocacy value system development and 3) Positive adaptation.

‘Trustworthy agents of support’ included supportive people in the parents' lives. Family members, especially the maternal grandmother, were important members of this group by offering emotional and practical support. Service providers and professionals were also included, with reference made to those who listened, provided guidance to help navigate systems, and ‘shared cultural understanding’.

‘The advocacy value system development’ illustrates how stressors activate the development of advocacy, as also seen in the ESAT. Morgan’s advocacy value system considers pre-crisis stressors, personal stressors, intersectional barriers, and the stressors faced while advocating. The main stressor experienced by the mothers of this study while advocating was not being listened to by professionals. The interaction of these stressors led to parents seeking the help and resources that they needed, resulting in the development of advocacy and the important associated skills.

Finally, the positive adaptation phase shows the results of advocacy development over time. The mothers were found to show positive adaptation in three main ways: ‘acceptance’ of their child, pride in their new identity as advocates, and, lastly, the desire to become an agent of support for other parents in their community.

The Morgan study does not discuss maladaptation much, as it aims to explore positive adaptation and avoid a deficit approach. Nevertheless, it recognises the ‘excess mental and emotional energy that goes into this enervating process, which leaves very little space for other important factors like self-care' (Morgan, p. 81, 2021).

As the comparative review section will show, the development of advocacy skills is an important and recurring main theme across all the studies. The Morgan study, however, is especially relevant due to its process-based development structure, established using the double ABC-X Model, and the close corroboration and validation of the findings of the current research.

4.3.3.3 The double ABC-X model and Potential in Practice

The potential for the double ABC-X model to be used in assessment and intervention is promising. It can act as a tool for professionals to assess the type of support that each BCP might need based on the mediating factors found in the ESAT (e.g., age of the child, autism traits, gender, parent and family awareness of autism, perception of difference or neurodiversity etc.), and potentially some from the other studies e.g.., single parent status and faith and spirituality. The discussion chapter will explore this further.

A critique of this model is that it is linear and suggests that coping is a phase rather than an ongoing process. A very important aspect of the ESAT is the ongoing nature of the stressors seen in the super-advocacy cycle. There also comes a point when the scope for adapting falls outside the capabilities of the individual family because of weaknesses within systems. This points towards the importance of the development and adaptation by both the family and the systems, i.e., the school systems, local authority and legislative levels.

4.3.4 Disparity analysis frameworks

The disparity analysis frameworks examine factors behind the later autism diagnoses of Black American children in the U.S. and the challenges experienced in accessing services. Debabnah and colleagues (2018) emphasised that when controlling for socioeconomic status, racial disparities in diagnoses still exist, as confirmed by multiple studies (Feinberg et al., 2011; Jarquin et al., 2011; Mandell et al., 2007). Understanding the factors behind this is important to address the problem.

This section outlines the use of two disparity frameworks adopted by Debabnah and colleagues (2018) and Hong and Singh (2019) and how they were able to take into account individual, cultural, environmental, and systemic factors to understand later diagnosis and reduced access to services of Black American children with autism.

These studies and frameworks are relevant to the current research, as the ESAT is also concerned with the factors that contribute to the later diagnosis (particularly of the LDG), and to the difficulties accessing services, and aims for this information to inform how services and professionals support BCP families in future.

4.3.4.1 The public health critical race framework (PHCRF) (Ford & Airhihenbuwa, 2010) and the Debabnah and colleagues study (2018)

Ford and Airhihenbuwa (2010) developed the public health critical race framework (PHCRF), one of the first healthcare models to consider how structural racism and cultural factors might contribute to health disparities. Debabnah and colleagues adapted this model to examine barriers in the early stages of 22 Black American mothers' or caregivers' autism journey. They were especially interested in identifying how factors in the environment (external and healthcare environment) and within the population group can act as a barrier or facilitator to the child accessing an initial assessment and referral to relevant services. It focuses more on the primary healthcare system than schools (unlike the ESAT), however very similar patterns and themes occurred.

4.3.4.1.1 Barriers to diagnosis

Six main themes were found to contribute to delays in assessment and referral in the Debabnah study. Three of these related to the Healthcare environment, including early concerns about developmental delays, being ignored by healthcare practitioners (HCPs), (who often told mothers to ‘wait and see’ or ‘come back later’), inadequate HCP training on autism, and racial bias. Contributing factors by the caregiver were found to include distrust of clinical care due to negative experiences, custodial issues impacting the ability to follow up on appointments and referrals, and shame and stigma in the Black community.

Apart from custodial issues, all of these themes were identified as barriers and factors of diagnosis delay in the current research. Not being listened to by professionals when parents requested assessment was raised by all parents of the LDG. Parents of this group perceived that racial bias was related to this and the way they and their child were treated by schools.

Cultural stigma, including shame, fear of labels, and denial, was another theme that closely resonated with the findings of the ESAT. This is seen clearly in the Debabnah study (2018). One participant explained:

> *I think there are a lot in denial...I think mental illness is something you just don't talk about. Technically, autism isn't a mental illness; it's a developmental disorder, but you kind of just keep them on the side. … I have a cousin that's autistic, but they don't really talk about him'. p. 330*

Another significant finding that also matches the findings of the current research is that some family members, particularly fathers, were resistant to the autism label out of fear that the child might be treated differently. One mother explained:

> *[Child's] father actually just told me, a month or so ago, that he's not fully comfortable with [child's diagnosis]. He doesn't really know what it is. He doesn't want anyone to judge his son. (Debabnah et al, 2018 p. 330)*

Participants also shared that some members of the older generation in their family advised better discipline as a solution (another similarity to the current research) rather than seeking assessment. Prayer was also advised as an alternative, which was not a theme raised in the current research.

4.3.4.1.2 Socioeconomic status and factors of delay

This study adds valuable insight into how socioeconomic factors impact Black American parents' experiences when seeking help for their children with autism. An eye-opening finding was that socioeconomic status, including level of education and household income, did not appear to change reported experiences, i.e., parents from both higher and lower socioeconomic status reported racial bias influencing their interactions with HCPs, being dismissed or not listened to by professionals, and stigma within the Black community as barriers to diagnosis.

Interestingly, however, Debabnah and colleagues did find that caregivers from higher economic and educational backgrounds were a) more able to identify specific interactions and assumptions that were racially biased and b) more likely to persist in seeking assessment after being initially dismissed.

This is an important finding and stresses contextual factors that support the resiliency needed to persist in advocacy. It also highlights the likelihood that many Black American and BCPs are unable to advocate for their children in the way they would like to due to financial restraints and potentially experiencing greater difficulty in defending themselves and their children against racial bias.

Although specific details of income were not gathered from participants in the current research, all mothers had a university-level or equivalent qualification. This indicates that the ‘super-advocacy’ and persistence that formed the ESAT might have looked different had there been parents from more diverse educational backgrounds. The essential super-advocacy needed, however, might remain the same.

4.3.4.1.3 Factors that counteract delay

A beneficial aspect of using the public health critical race framework model is that as well as looking at factors that contribute towards disparities and delay, it also considers the factors that counter them.

Like the ESAT, Debabnah and colleagues found that some participants experienced attentive HCPs who listened and made the necessary referrals for screening and early intervention. Some participants also reported that there were friends and family from the Black community who encouraged them to seek an assessment for their child. This shows that while there are barriers in both the professional and community environments, there are also examples of support.

4.3.4.1.4 The importance of attentive professionals for early diagnosis

All children in the ESAT who were diagnosed before the age of 5 had the involvement of professionals who helped to identify traits and support referrals. These families were able to overcome stigma and internal conflict around diagnosis faster and were able to adapt to their child's needs with systemic support.

In the Debabnah study, all children diagnosed before the age of 4 also had the involvement of attentive professionals who supported parents in the referral and assessment process.

The primary autism traits of the children were not specified, so it is not clear if those diagnosed early had more visible traits, i.e., verbal communication delays. Nevertheless, it still shows that attentive and supportive HCPs and other professionals enable timely diagnosis and the right support to be put in place. The children of parents who reported being dismissed when they raised concerns with HCPs, however, were diagnosed at a later stage (between the ages of 4 and 8 years old).

The PHCRF has proven to be a valuable framework for identifying factors contributing to delay in diagnosis and access to services and also agents of support. This is helpful in the field to aid intervention and collaboration in both areas.

4.3.4.2 The cycle of environmental health disparities framework

Hong and Singh (2019) adapted the cycle of environmental health disparities framework to create ‘The cycle of autism disparities’ (see Figure 12). The cycle of environmental health disparities framework ‘outlines the complex environmental interactions in health disparities by identifying a range of interrelated adverse environmental risk factors at the individual residential and community levels (Rubin., et al. 2012). Hong and Singh use this to explore the social and structural factors that place low-income Black American families at risk of delayed autism diagnosis and limited access to therapeutic services. They interviewed 21 Black American female caregivers who use Medicaid in Atlanta. This study is, therefore, similar to the Debabnah study but also aims to assess the ability of Medicaid (the U.S. public health insurance), to meet the needs of these children and their families.

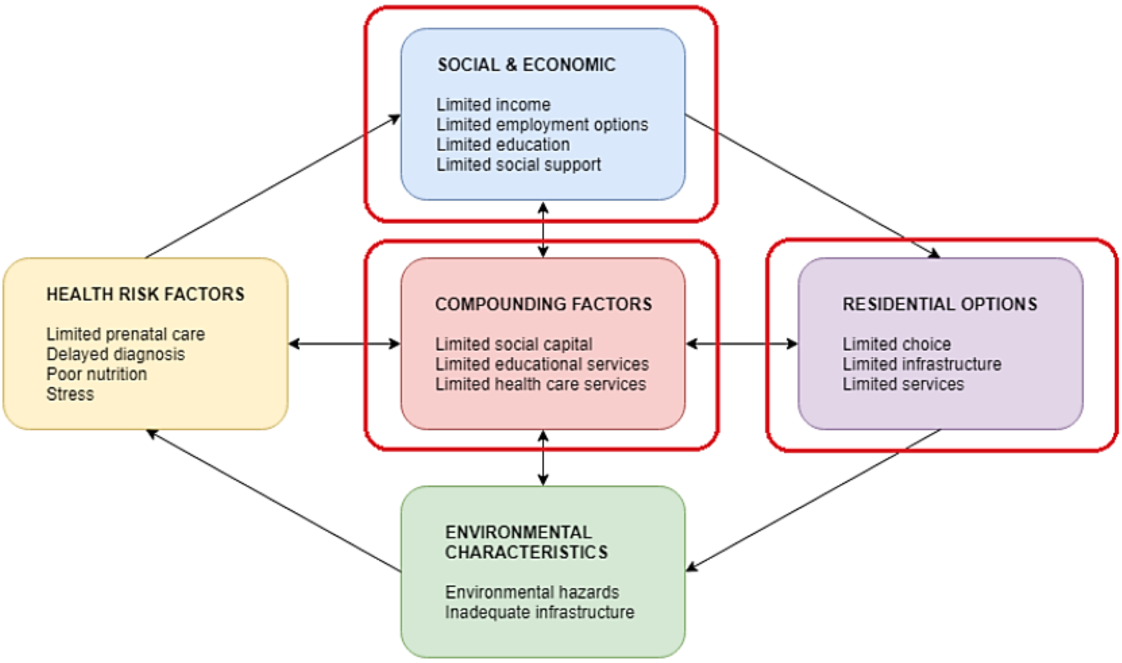


Figure 12. Cycle of autism disparities (Hong & Singh, 2019)

Low income and parental education, lack of autism awareness, complicated scheduling coordination and long waiting lists were found to be most associated with late diagnosis. Compounding factors included the intersection of race and gender, limited employment options, stressful day-to-day environments, and single parenthood, as explained in the CRT section.

This study further supports the Debabnah Study's finding that mothers with higher education and socioeconomic status are more likely to be successful in accessing services. However, they went further to find that extensive knowledge of the Medicaid system and additional support from the child's father were also necessary. Again, this reiterates the likelihood that the families and children with the least income and resources are the least likely to access the support that they need.

The findings concerning Medicaid found that the programme was not efficient in providing the support the children and families needed. Reasons included complex and confusing bureaucratic processes, year-long waiting lists, service locations being inaccessible, and out-of-pocket expenses for services that Medicaid does not cover. Some of these issues resonate with the difficulties parents from the current research faced with the EHCP process and ensuring the recommendations made in them were implemented at schools.

This disparity model mainly looks at barriers and socio-economic compounding factors, which are key to understanding delay and difficulty accessing services. Interestingly, there is no mention of cultural stigma, as mentioned in the previous study and the ESAT. This might be due to the aim of assessing the broader systemic issues that create barriers when mothers need and seek help, particularly those from low-income families.

4.3.5 Collaboration Theories

4.3.5.1 Communities of practice (Wenger, 1998)

The concept of communities of practice (CoP) was first developed by Ettienne Wenger (1998). Collaborations with other authors, i.e., McDermot & Snyder (2002) and Beverly Wenger-Treynor (2015), have seen the framework develop into what it is today. Communities of practice are groups of people who "share a concern or a passion for something they do, and learn how to do it better as they interact regularly" (Wenger-Trainer & Wenger-Trainer, 2015). With origins in social learning theory (Bandura, 1977), Wenger et al. suggests that CoP are not merely clubs or networks but defined by three important dimensions (see Figure. 13). The first is having a ‘domain’ or joint enterprise, which is the shared interest of the group and a commitment and competence in that domain. The second is ‘community’ or mutual engagement, which engages in joint activities to build relationships, learn together, share information, and help one another. The third dimension is the ‘practice’ or shared repertoire, where members are referred to as ‘practitioners’ who ‘develop a shared repertoire of resources including experiences, stories, tools and ways of addressing recurring problems’ (Wenger-Trayner & Wenger-Trayner, 2015).

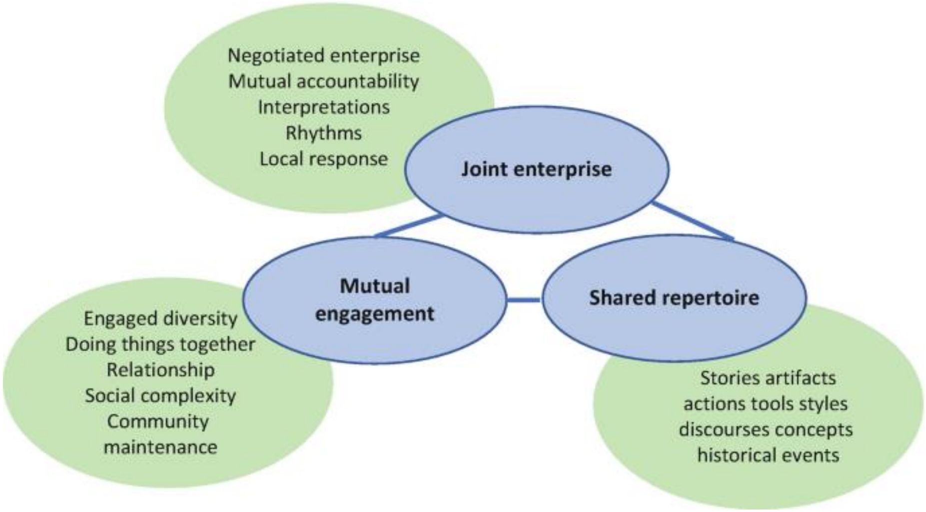


Figure 13. Dimensions of communities of practice adapted from Wenger, 1998, p. 73.

This section of relevant theories has been named ‘collaboration theories’ because, unlike those already discussed, these focus on the power of learning, growing, and solving problems through collaboration. The ESAT and many of the literature review studies all recognise the importance of parents sourcing support and knowledge from other parents of children with autism, and experts in the area. This theory, however, suggests that communities like these have the potential to create an ongoing positive change in parent-school partnerships through a CoP framework as it:

> “(a) provides an alternative to the traditional top-down approach, (b) allows space for uncertainty and trust, (c) closes the gap between espoused theory and theory in use about specialized expertise, and (d) dilutes the effect of power imbalances and competing priorities among parents and educators” (Mortier, 2018 pg1).

4.3.5.1.1 Brown and Mortier’s Study (2021)

Brown and Mortier took a unique approach in their aims to study the experiences of Black American parents who have children with autism. As well as interviewing 7 Mothers and 2 couples, they included a focus group of six ‘cultural brokers’ in their study. The authors explain that a cultural broker helps to bridge the gap between families and the education system, like advocacy partners, and they work with Black American families to support their children in the education system. Cultural brokers are often parents of children with additional needs themselves and have advanced knowledge and experience in education and special educational needs. The ethnicities of the 6 cultural brokers in the study were not specified. However, 3 were said to be parents of children with autism.

Although the cultural broker data was mainly used in the ‘Role of cultural brokers’ section of the study, it was an interesting addition. Their views corroborated the parents' voices of this study, as well as the parents of the ESAT, and the other literature review studies, almost providing a witness account of their experiences. It was not clear if the cultural brokers worked directly with the parent participants of the study, but it appeared that they shared a passion for better parent-school partnerships and greater cultural awareness and understanding by schools about the needs and experiences of Black American parents and their children with autism.

This paper was included in the literature review because findings were mainly based on parent interviews rather than cultural broker views. However, the inclusion of cultural broker experiences and views illustrates the potential for developing a system that supports Black parents and their children, and also supports building stronger partnerships through improved collaboration.

Parents and cultural brokers of this study felt that tailored support for Black American families, such as culturally specific support groups and clubs, would be important for both the parents and the children with autism, as well as raising representation and trust. Measures to improve autism awareness and acceptance in school communities, including administrators, students and teachers, was another area that parents and cultural brokers felt was paramount to improve parent-school partnerships and the wellbeing of Black American children with autism. Many of these suggestions resonate with those in the outcomes and outlook stage of the ESAT and also by the parents of the other literature review studies.

The other findings of this study also have very strong parallels with the current research and the literature. Brown and Mortier were interested in parent experiences in the family, community, and schools. Themes of Isolation, denial, and unfamiliarity with autism were key themes in the community context. Poor implementation and quality of services, tense communication, errors and mistakes with the school district, and lack of cultural awareness were disempowering experiences that parents faced with the education system. Brown and Mortier explain that there was significantly less data on positive experiences with schools, however parents did share experiences where effective communication and shared decision-making made them feel empowered as parents advocating for their children.

This paper is important when considering the significance of community and working together to build schools and communities of belonging. It found that where there is mutual respect, shared decision-making, learning together, and autism awareness, there is a greater chance for the best outcomes for their children. It did not specify how a community of practice can be set up and used in the domain, as this was not the aim of the study, however, it introduces the relevance of this concept and offers an example of how a community might look (perhaps in the early stages) with the inclusion of cultural brokers in the study. It also offers a collaborative approach for intervention and further research. As the authors state, many studies have shown that when teachers and parents engage as communities of practice, ‘new identities and relationships are formed’ (Brown & Mortier, 2021; Cooper et al., 2010; Mortier, 2018; Mortier et al., 2010).

4.3.6 Summary of Relevant Theories

This section has contextualised the literature review by discussing the relevant theories and frameworks used or developed by the selected studies, and their significance to the current research. These included CRT and intersectionality, strength-based theories, process theories, disparity analysis frameworks, and collaborative theories, which were summarised, discussed, and analysed in terms of their potential usefulness for improved practice and future research.

4.4 Comparative review of the ESAT and literature

The comparative review section aims to illustrate how the findings of the literature align with and validate the findings of the current research. To do this, the relevant findings of each study will be categorised with the corresponding stage of the ESAT using mind maps (see Appendix 9 for full-size versions). This section also presents a clear pattern in parents' experiences, with an emphasis on the parent voice. This is to deepen understanding of their experiences and demonstrate the links and similarities between the participant experiences in the studies and the current research. As the contexts of Stage 2 and 3 of the ESAT are widely covered in the relevant theories section of the literature review, stage 1 will be given more commentary in this comparative review section.

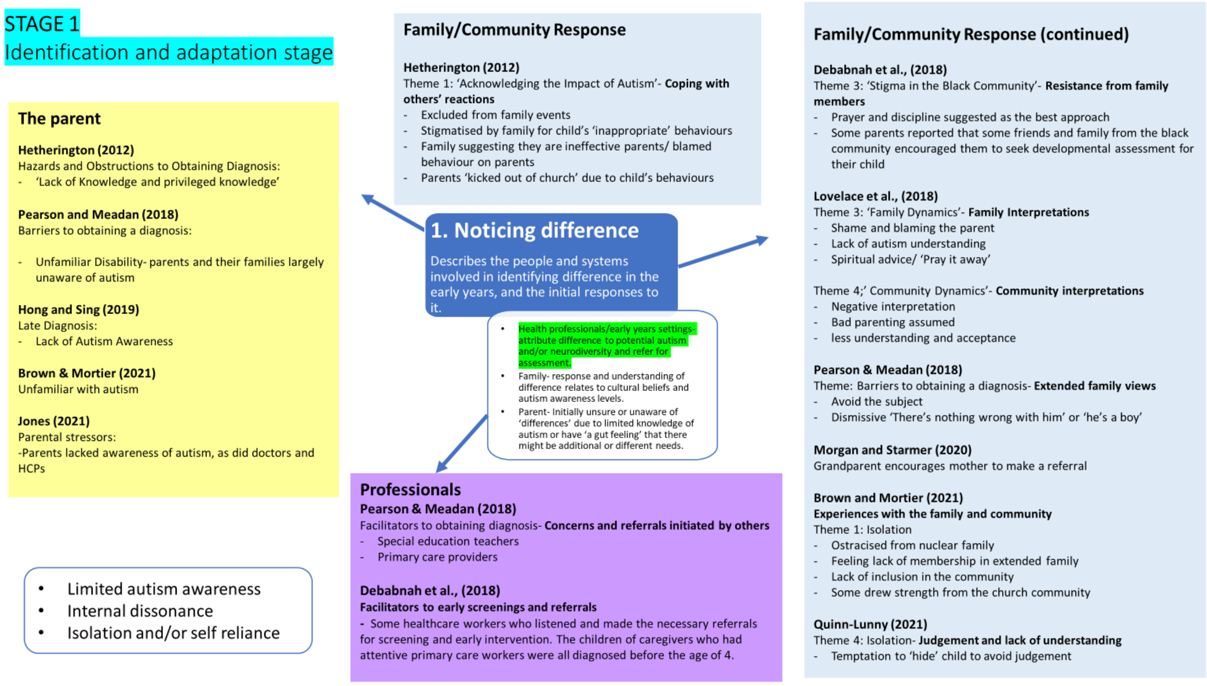
All citations in this section are either quotes from participants of the literature review studies or commentary from the referenced author/s. For a non-categorised breakdown of the main findings of each study, please see Appendix 10.

4.5 Comparative review of stage 1: The identification and adaptation stage

4.5.1 Noticing difference

Ten of the twelve studies had clear themes of noticing difference in their findings (Hetherington, 2012; Debabnah et al., 2018; Lovelace, 2018; Pearson & Meadan, 2018; Hong & Singh, 2019; Morgan & Stahmer, 2020; Brown & Mortier, 2021; Jones, 2021; Morgan, 2021 and Quinn-Lunny, 2021). This is the first category of stage 1 that relates to the reactions and responses by professionals, parents and the family/community to the child's undiagnosed autism traits. This category begins to contextualise the circumstances of parents at the beginning of their journeys. The essential super-advocacy factors are underdeveloped at this stage, resulting in limited autism awareness, internal conflict and self-reliance and/or isolation. These themes are prominent throughout stage 1 of the ESAT, and in the corresponding stages of parents' journeys in the studies.

> *"I did not know what it (autism) was about… like my son has 'what'?" (Hetherington, 2012, p. 140)*



STAGE 1
Identification and adaptation stage

The parent

Hetherington (2012)
Hazards and Obstructions to Obtaining Diagnosis:
- ‘Lack of Knowledge and privileged knowledge’

Pearson and Meadan (2018)
Barriers to obtaining a diagnosis:

- Unfamiliar Disability- parents and their families largely unaware of autism

Hong and Sing (2019)
Late Diagnosis:
- Lack of Autism Awareness

Brown & Mortier (2021)
Unfamiliar with autism

Jones (2021)
Parental stressors:
-Parents lacked awareness of autism, as did doctors and HCPs

- Limited autism awareness
- Internal dissonance
- Isolation and/or self reliance

Family/Community Response

Hetherington (2012)
Theme 1: ‘Acknowledging the Impact of Autism’- **Coping with others’ reactions**
- Excluded from family events
- Stigmatised by family for child’s ‘inappropriate’ behaviours
- Family suggesting they are ineffective parents/ blamed behaviour on parents
- Parents ‘kicked out of church’ due to child’s behaviours

1. Noticing difference

Describes the people and systems involved in identifying difference in the early years, and the initial responses to it.

- Health professionals/early years settings- attribute difference to potential autism and/or neurodiversity and refer for assessment.
- Family- response and understanding of difference relates to cultural beliefs and autism awareness levels.
- Parent- Initially unsure or unaware of ‘differences’ due to limited knowledge of autism or have ‘a gut feeling’ that there might be additional or different needs.

Professionals
Pearson & Meadan (2018)
Facilitators to obtaining diagnosis- **Concerns and referrals initiated by others**
- Special education teachers
- Primary care providers

Debabnah et al., (2018)
Facilitators to early screenings and referrals
- Some healthcare workers who listened and made the necessary referrals for screening and early intervention. The children of caregivers who had attentive primary care workers were all diagnosed before the age of 4.

Family/Community Response (continued)

Debabnah et al., (2018)
Theme 3: ‘Stigma in the Black Community’- **Resistance from family members**
- Prayer and discipline suggested as the best approach
- Some parents reported that some friends and family from the black community encouraged them to seek developmental assessment for their child

Lovelace et al., (2018)
Theme 3: ‘Family Dynamics’- **Family Interpretations**
- Shame and blaming the parent
- Lack of autism understanding
- Spiritual advice/ ‘Pray it away’

Theme 4;’ Community Dynamics’- **Community interpretations**
- Negative interpretation
- Bad parenting assumed
- less understanding and acceptance

Pearson & Meadan (2018)
Theme: Barriers to obtaining a diagnosis- **Extended family views**
- Avoid the subject
- Dismissive ‘There’s nothing wrong with him’ or ‘he’s a boy’

Morgan and Starmer (2020)
Grandparent encourages mother to make a referral

Brown and Mortier (2021)
Experiences with the family and community
Theme 1: Isolation
- Ostracised from nuclear family
- Feeling lack of membership in extended family
- Lack of inclusion in the community
- Some drew strength from the church community

Quinn-Lunny (2021)
Theme 4: Isolation- **Judgement and lack of understanding**
- Temptation to ‘hide’ child to avoid judgement

Figure 14. Noticing difference comparative review map

As seen in Figure 14 above, ‘family/community response’ was the biggest category in ‘noticing difference’ identified in the papers. This mainly refers to stigma manifesting as denial, blame, and ostracisation.

> *“My family just assumed that it was something that I did wrong because [he] came out with autism; it was my fault. ‘You must have been drinking, or you must have been using drugs.’ No, I didn’t do anything. They didn’t want to accept it.” … Additionally, Latisha described her family turning to their faith, sometimes at the expense of therapy: “I have a religious family, and they just ‘pray it away, pray it away.’ Look, ok, you can pray all you want, I’m going to pray and go ahead and get treatment and therapy.” (Lovelace, 2018, p. 11)*

It is important to note that some parents in the studies (and current research) also identified family or Black community members as facilitators of early diagnosis, although there were less of them. The family also feature as part of the parent’s collaborative support system during the activation advocacy stage, as will be seen later. Parents explained that as they grew in knowledge about autism and began to accept and/or embrace their child’s diagnosis, they were able to educate their family members better, which is likely why there is more family support at the later stage. This highlights the importance of raising awareness of autism in whole communities to increase the chances of greater support and understanding for parents and their children during this most vulnerable stage.

As seen in the ESAT, some families however had attentive professionals intervene at this early stage and support them in making a referral.

> *All of the children whose caregivers reported their primary healthcare providers listened to their concerns were diagnosed with ASD by four years old or younger, and many before three years old. One participant (P5), a mother with a high school education, discussed how, despite hearing concerns from daycare teachers, she was reluctant to follow up until her child's paediatric office referred her to early intervention services, saying, "I was uncomfortable still, but it made me feel better that it was his nurse practitioner that said it's time to do something about this. (Debabnah, 2018, p. 378)*

4.5.2 Internal dissonance

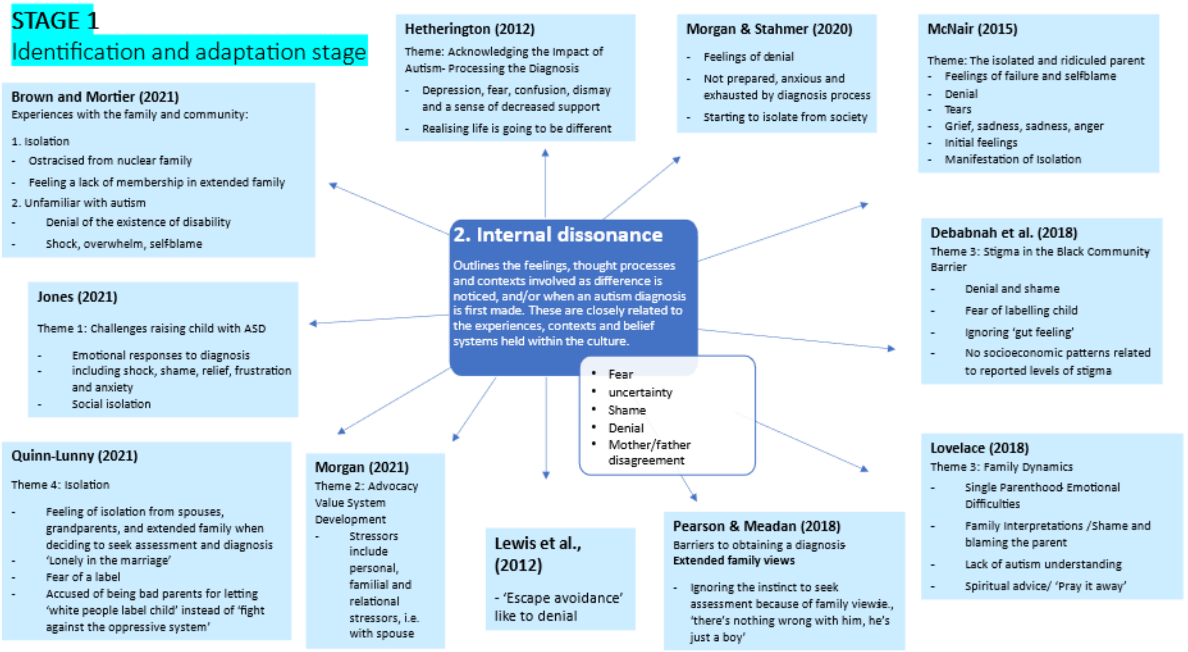


Figure 15. Internal dissonance comparative review map

> *"I didn't know what autism was, so I was very shocked, guilty, and at the same time overwhelmed. I wondered if I did something strange during my pregnancy. Am I overlooking something? Then I started thinking about how to take care of this child." (Jones, 2021, p. 67)*

> *“I was in my bed—I remember distinctly that it was two days of just crying. I just didn’t know what to do. I felt abandoned by my faith. I felt abandoned by family. And I also felt guilty. Like what in the world could I have done to deserve this?” (Hetherington, 2012, p. 140)*

Internal dissonance was an overwhelmingly prominent theme, featuring strongly in 11 of the 12 studies (Hetherington, 2012; McNair, 2015; Debabnah et al., 2018; Lovelace, 2018; Pearson & Meadan, 2018; Morgan & Stahmer, 2020; Brown & Mortier, 2021; Jones, 2021; Morgan, 2021; Quinn-Lunny, 2021 and Lewis et al., 2022), as seen in Figure 15. Parents (all female caregivers) shared that they experienced feelings of denial, grief, self-blame, fear, frustration, isolation and even depression either when realising that their child might have an additional need or when they were officially diagnosed. The apparent universality of these feelings among the mothers of these studies is a significant finding and one that will need further consideration regarding implications for practice, especially as it may contribute towards a delay in early diagnosis (Debabnah et al., 2018; Lovelace, 2018; Pearson & Meadan, 2018; Jones, 2021). Family and community response and autism awareness levels seem to relate to these feelings; however, the complex intersection of race and autism is also likely to be a factor, particularly around fear and distrust of the healthcare and educational systems, as discussed in the relevant theories section.

> *“My mother and sister accused me of being a bad mother for allowing “White people” to put a label on my child, and scorned us as parents to protect our children and help them fight the system of oppression, instead of helping them to label them.” (Quinn-Lunny, 2021, p.43)*

Advocacy soon becomes the priority after diagnosis, which appears to ‘hijack’ Internal dissonance as seen in the ESAT and the literature. This seems to be due to the immediate need to turn attention to the child's defence and protection. This is followed by self-education, greater autism awareness, and the building of collaborative support, which is seen to act as an antidote to the isolating and stagnating power of internal conflict. The activation of stage 2 is, therefore, seen to drive the move away from internal dissonance and toward super-advocacy.

> *“It required me to remove myself out of that grief state and realize I have to figure out what was gonna benefit my son.” (Morgan & Stahmer, 2020, p.12)*

On the other hand, it is important to consider that some participants felt relief when their child received their diagnosis, even if they experienced internal dissonance beforehand. This demonstrates that for some parents, the diagnosis supported the overcoming of internal conflict and led them to grow in the essential super-advocacy factors.

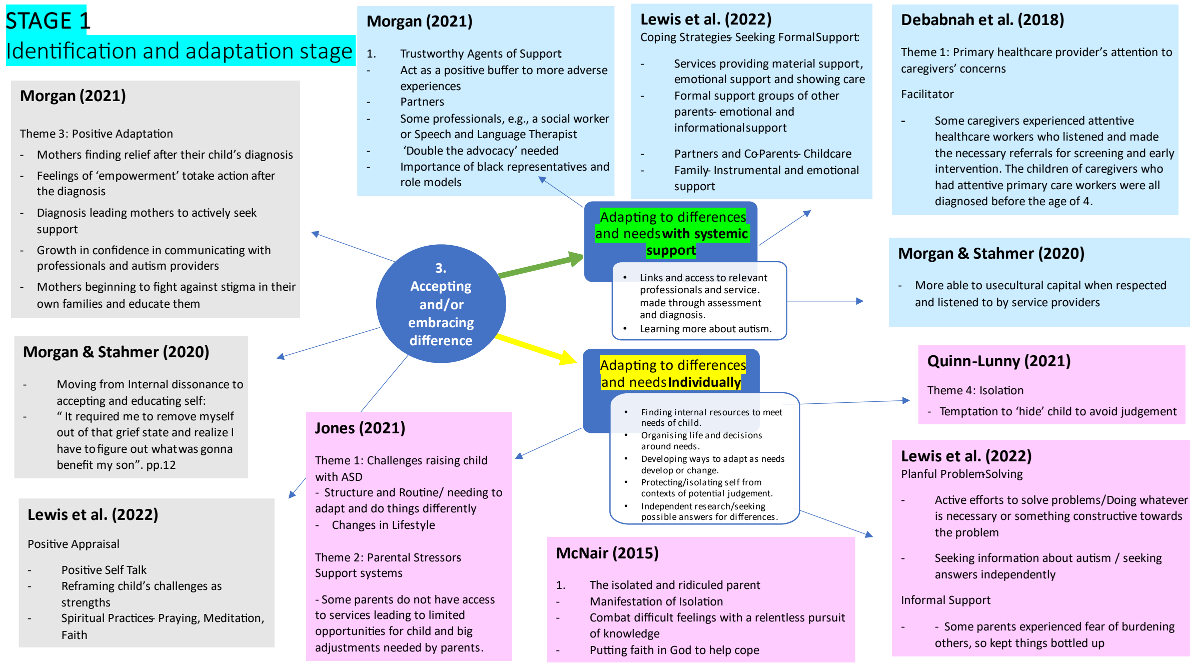
> *“I went through stages of grieving, sadness, anger . . . but relieved because now I could research to figure out how to help him.” (McNair, 2015, pp.75)*

In the ESAT, this was mainly seen with mothers from the early-diagnosed group, who had more access to systemic support after diagnosis. However, it was difficult to identify an EDG and an LDG parent in the literature due to the age of diagnosis not being specified in most of the studies.

The Hong and Singh paper (2018) was the only study that did not have themes of internal dissonance in their findings. This might have fit in their ‘barriers to diagnosis’ or ‘compounding factors’ categories but did not appear. An explanation for this might be that they were mostly concerned with broader systemic themes, such as socioeconomic status affecting the 21 single Black caregivers and the structural constraints around accessing Medicaid rather than the emotional response to autism. Nevertheless, considering the prominence of internal dissonance in the other studies, its absence here is noticeable.

4.5.3 Accepting, embracing and adapting (with and without systemic support)

Seven of the 12 studies featured clear themes of accepting and/or embracing difference, and adapting to difference in their findings (McNair, 2015; Debabnah et al., 2018; Morgan & Stahmer, 2020; Jones, 2021; Morgan, 2021; Quinn-Lunny, 2021; Lewis et al., 2022), as seen in Figure 16. The studies that are shown in blue below present the findings related to systemic support that parents received following their child’s diagnosis. This includes services and support from professionals, family members, and partners. This differs slightly from the ESAT, as family and partners were not a main theme at this stage. One participant mentioned the support of her partner, especially during the advocacy stage, and another stated her mother had been a crucial support on her journey, however, at this adapting stage there were only two main themes, which were support from services resulting from the diagnostic process (EDG) or adapting individually (LDG). The inclusion of family and partners in the studies, however, is significant as it might indicate two things. Firstly, that despite stigma in the community, some members do not let this impact their involvement and support of the parent/s. Secondly, that some family members and partners learn to embrace, accept and adapt alongside the parent, i.e., by the parent gaining confidence in communicating the child's needs and educating others as they learn.



STAGE 1
Identification and adaptation stage

Morgan (2021)

Theme 3: Positive Adaptation

- Mothers finding relief after their child's diagnosis
- Feelings of 'empowerment' totake action after the diagnosis
- Diagnosis leading mothers to actively seek support
- Growth in confidence in communicating with professionals and autism providers
- Mothers beginning to fight against stigma in their own families and educate them

Morgan & Stahmer (2020)

- Moving from Internal dissonance to accepting and educating self:
- " It required me to remove myself out of that grief state and realize I have to figure out what was gonna benefit my son". pp.12

Lewis et al. (2022)

Positive Appraisal

- Positive Self Talk
- Reframing child's challenges as strengths
- Spiritual Practices- Praying, Meditation, Faith

3. Accepting and/or embracing difference

Jones (2021)

Theme 1: Challenges raising child with ASD
- Structure and Routine/ needing to adapt and do things differently
- Changes in Lifestyle

Theme 2: Parental Stressors
Support systems

- Some parents do not have access to services leading to limited opportunities for child and big adjustments needed by parents.

Morgan (2021)

1. Trustworthy Agents of Support
- Act as a positive buffer to more adverse experiences
- Partners
- Some professionals, e.g., a social worker or Speech and Language Therapist
- 'Double the advocacy' needed
- Importance of black representatives and role models

Lewis et al. (2022)
Coping Strategies- Seeking Formal Support:

- Services providing material support, emotional support and showing care
- Formal support groups of other parents- emotional and informational support
- Partners and Co-Parents- Childcare
- Family- Instrumental and emotional support

Debabnah et al. (2018)

Theme 1: Primary healthcare provider's attention to caregivers' concerns

Facilitator

- Some caregivers experienced attentive healthcare workers who listened and made the necessary referrals for screening and early intervention. The children of caregivers who had attentive primary care workers were all diagnosed before the age of 4.

Adapting to differences and needs **with systemic support**

- Links and access to relevant professionals and service. made through assessment and diagnosis.
- Learning more about autism.

Morgan & Stahmer (2020)

- More able to usecultural capital when respected and listened to by service providers

Adapting to differences and needs **Individually**

- Finding internal resources to meet needs of child.
- Organising life and decisions around needs.
- Developing ways to adapt as needs develop or change.
- Protecting/isolating self from contexts of potential judgement.
- Independent research/seeking possible answers for differences.

Quinn-Lunny (2021)

Theme 4: Isolation

- Temptation to 'hide' child to avoid judgement

Lewis et al. (2022)
Planful Problem-Solving

- Active efforts to solve problems/Doing whatever is necessary or something constructive towards the problem
- Seeking information about autism / seeking answers independently

Informal Support

- - Some parents experienced fear of burdening others, so kept things bottled up

McNair (2015)

1. The isolated and ridiculed parent
- Manifestation of Isolation
- Combat difficult feelings with a relentless pursuit of knowledge
- Putting faith in God to help cope

Figure 16. Accepting, embracing, and adapting comparative review map

The studies shown in pink above present the themes in the studies that resonated with parents of the LDG at this stage who tried to adapt more individually. As mentioned earlier, it could not be determined in most of the studies which parents had children diagnosed at a later age. However, these more challenging aspects of their journeys at this stage were experienced by the LDG in the current study for a longer period of time. Isolation was a main theme and being apprehensive about asking for support.

> *"Being out in public is very difficult, as you never know what will trigger her angry outburst. Looks, comments, and eye rolls from all over have become a norm.*

> *Everyone (almost) just assumes you're a bad parent." and P4 said, "I avoid certain activities or outings because it is just too hard." (Jones, 2021, p. 90)*

> *"There was a level of shame associated with needing to access services. Tasha states, "We're so used to doing our own so much that we just don't reach out for help." Pp.11 (Lovelace, 2018, p. 11)*

Nevertheless, some early signs of essential super-advocacy factors are also shown i.e., active efforts to solve problems and seeking information that will help to best support their child. Also, like in the current study, this was sometimes spurred by a 'catalyst' or crisis point by some parents e.g., Josephine from the Morgan and Stahmer study who decided to seek help after a traumatic experience:

> *Her daughter would engage in self-injurious and dangerous behaviours such as running away from her in public (i.e., eloping) or having uncontrollable tantrums in stores, which caused Josephine to withdraw from most activities out of the home. It was a traumatic event during a trip to the grocery store in which her daughter was almost hurt that became a pivotal moment for Josephine: "At that point, nothing else was important, and that's when everything just changed for me because I'm like "I'm gonna lose my child if I don't get it together." (Morgan & Stahmer, 2020, p.11)*

The studies presented in grey in Figure 16 highlight the experiences of parents who felt a great sense of relief and empowerment when their child received their autism diagnosis. They shared that they felt more confident to take action, educate others, and seek support as a result of the confirmation which also allowed them to better understand and embrace their child's differences.

> *"I was actually relieved. And I know a lot of parents don't feel that way. But it was like when you know what it is, that you can form a course of action. And that made me feel empowered." (Morgan, 2021, p. 72)*

A source of support seen to help parents adapt to their child's needs, differences and/or diagnosis at this stage in the literature but not present in the current research, is faith. Faith and spirituality was a prominent theme in 5 of the studies (McNair, 2015; Debabnah et al., 2018; Lovelace, 2018; Pearson & Meadan, 2018; Morgan, 2021; Quinn-Lunny, 2021; Lewis et al., 2022) as a source of support to adapt and embrace, as seen in Figure 16, and also to advocate and defend as will be seen at Stage 2- the activation advocacy stage.

> *“I say the Creator didn’t give me more than I can handle. Sometimes it can be a bit much, but the Creator gave me just what He knew I could handle.” (Lewis et al., 2022, p. 2021)*

It is possible that more room was needed to explore faith in the current research, as it was not featured as a theme in parent stories. Future research should consider this to better understand the full breadth of coping strategies that might be supportive of BCPs on their journey.

4.6 Comparative review of stage 2: The activation advocacy stage

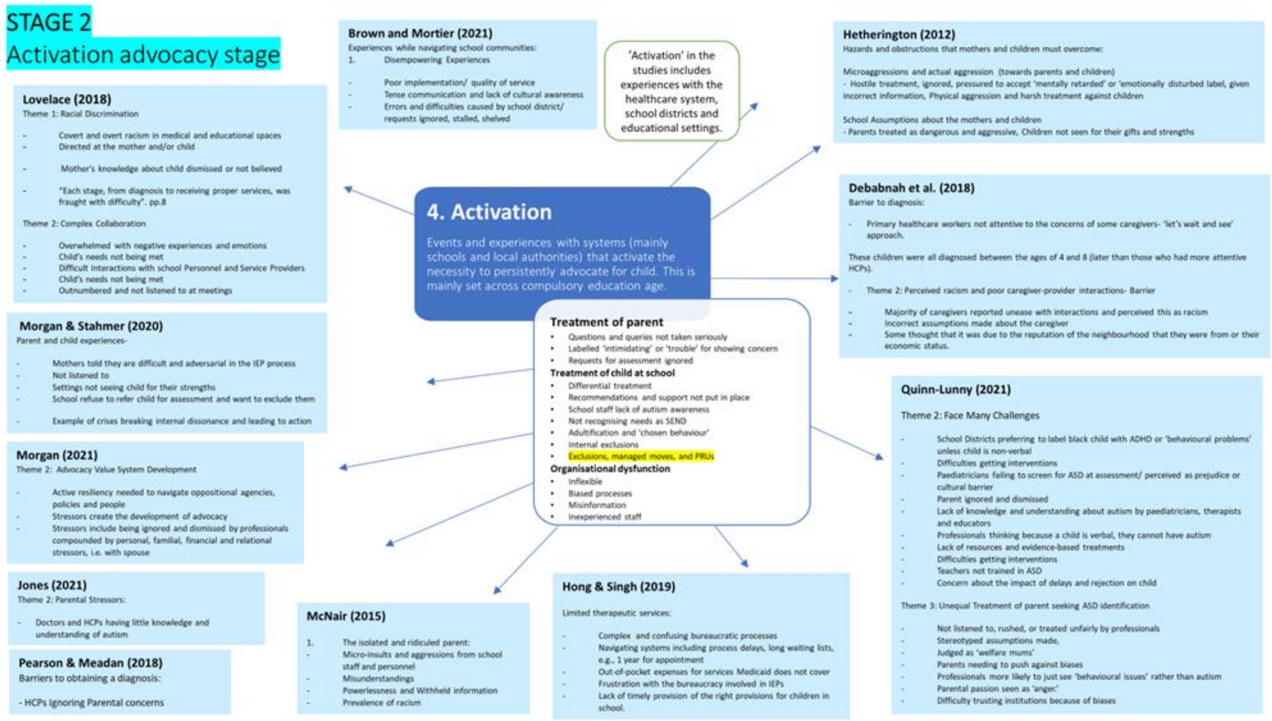
Stage 2 of the ESAT was uniformly the most represented stage in the literature, particularly the ‘activators’ and the super-advocacy cycle (as seen in Figures 17 and 18). As outlined in the relevant theories section, it was found that the intersecting factors of race and autism present hazards and obstructions to the child accessing the support they need and to their parents effectively advocating for them. This stage, therefore, presents how parents were able to cope with and overcome the barriers in systems to fight for their child. It also demonstrates an important process of advocacy development and how parents attained the skills and resources needed to become the super-advocates they needed to be. All of the 12 studies feature this stage in their findings, with some having persistent advocacy as a central finding, e.g., McNair with ‘The parent warrior’ (2015), Lovelace with ‘Resilient advocacy’ (2018), Morgan with ‘Advocacy value system development’ (2021), and Quinn-Lunny with ‘The relentless fighter’ as the global phenomenon (2021).

Stage 2 is divided into three categories: *activation, preparation, and advocate*. These three parts make up the essential super-advocacy cycle, which is not linear but repeats. This is where advocacy development happens the most. Another small category of this stage is supportive practice, which provides examples of where parents found some services and professionals helpful during this process.

4.6.1 Activation

Eleven of the twelve studies had explicit activators in their main findings, i.e..., events and circumstances calling for urgent advocacy (see Figure 17). The only study not including activators in their main findings was the Lewis et al. study (2022). Their findings focused on the different coping strategies of parents rather than the factors and events that required them. Nevertheless, the stressors that parents were up against are acknowledged in the paper and are consistent with the other studies.

The eleven studies show evidence of the three areas in the activation category: treatment towards the parent, treatment towards the child, and organisational dysfunction.



STAGE 2
Activation advocacy stage

Lovelace (2018)
Theme 1: Racial Discrimination

- Covert and overt racism in medical and educational spaces
- Directed at the mother and/or child
- Mother's knowledge about child dismissed or not believed
- "Each stage, from diagnosis to receiving proper services, was fraught with difficulty". pp.8

Theme 2: Complex Collaboration

- Overwhelmed with negative experiences and emotions
- Child's needs not being met
- Difficult Interactions with school Personnel and Service Providers
- Child's needs not being met
- Outnumbered and not listened to at meetings

Morgan & Stahmer (2020)
Parent and child experiences-

- Mothers told they are difficult and adversarial in the IEP process
- Not listened to
- Settings not seeing child for their strengths
- School refuse to refer child for assessment and want to exclude them
- Example of crises breaking internal dissonance and leading to action

Morgan (2021)
Theme 2: Advocacy Value System Development

- Active resiliency needed to navigate oppositional agencies, policies and people
- Stressors create the development of advocacy
- Stressors include being ignored and dismissed by professionals compounded by personal, familial, financial and relational stressors, i.e. with spouse

Jones (2021)
Theme 2: Parental Stressors:

- Doctors and HCPs having little knowledge and understanding of autism

Pearson & Meadan (2018)
Barriers to obtaining a diagnosis:

- HCPs Ignoring Parental concerns

Brown and Mortier (2021)
Experiences while navigating school communities:
1. Disempowering Experiences

- Poor implementation/ quality of service
- Tense communication and lack of cultural awareness
- Errors and difficulties caused by school district/ requests ignored, stalled, shelved

'Activation' in the studies includes experiences with the healthcare system, school districts and educational settings.

4. Activation

Events and experiences with systems (mainly schools and local authorities) that activate the necessity to persistently advocate for child. This is mainly set across compulsory education age.

Treatment of parent
- Questions and queries not taken seriously
- Labelled 'intimidating' or 'trouble' for showing concern
- Requests for assessment ignored

Treatment of child at school
- Differential treatment
- Recommendations and support not put in place
- School staff lack of autism awareness
- Not recognising needs as SEND
- Adultification and 'chosen behaviour'
- Internal exclusions
- Exclusions, managed moves, and PRUs

Organisational dysfunction
- Inflexible
- Biased processes
- Misinformation
- Inexperienced staff

McNair (2015)

1. The isolated and ridiculed parent:
- Micro-insults and aggressions from school staff and personnel
- Misunderstandings
- Powerlessness and Withheld information
- Prevalence of racism

Hong & Singh (2019)

Limited therapeutic services:

- Complex and confusing bureaucratic processes
- Navigating systems including process delays, long waiting lists, e.g., 1 year for appointment
- Out-of-pocket expenses for services Medicaid does not cover
- Frustration with the bureaucracy involved in IEPs
- Lack of timely provision of the right provisions for children in school.

Hetherington (2012)
Hazards and obstructions that mothers and children must overcome:

Microaggressions and actual aggression (towards parents and children)
- Hostile treatment, ignored, pressured to accept 'mentally retarded' or 'emotionally disturbed label, given incorrect information, Physical aggression and harsh treatment against children

School Assumptions about the mothers and children
- Parents treated as dangerous and aggressive, Children not seen for their gifts and strengths

Debabnah et al. (2018)
Barrier to diagnosis:

- Primary healthcare workers not attentive to the concerns of some caregivers- 'let's wait and see' approach.

These children were all diagnosed between the ages of 4 and 8 (later than those who had more attentive HCPs).

- Theme 2: Perceived racism and poor caregiver-provider interactions- Barrier

- Majority of caregivers reported unease with interactions and perceived this as racism
- Incorrect assumptions made about the caregiver
- Some thought that it was due to the reputation of the neighbourhood that they were from or their economic status.

Quinn-Lunny (2021)

Theme 2: Face Many Challenges

- School Districts preferring to label black child with ADHD or 'behavioural problems' unless child is non-verbal
- Difficulties getting interventions
- Paediatricians failing to screen for ASD at assessment/ perceived as prejudice or cultural barrier
- Parent ignored and dismissed
- Lack of knowledge and understanding about autism by paediatricians, therapists and educators
- Professionals thinking because a child is verbal, they cannot have autism
- Lack of resources and evidence-based treatments
- Difficulties getting interventions
- Teachers not trained in ASD
- Concern about the impact of delays and rejection on child

Theme 3: Unequal Treatment of parent seeking ASD identification

- Not listened to, rushed, or treated unfairly by professionals
- Stereotyped assumptions made,
- Judged as 'welfare mums'
- Parents needing to push against biases
- Professionals more likely to just see 'behavioural issues' rather than autism
- Parental passion seen as 'anger.'
- Difficulty trusting institutions because of biases

Figure 17. Activation comparative review map

Treatment towards the parent

Not being listened to or believed, being judged as aggressive or difficult, having important information withheld, microaggressions and actual aggression, and perceived racism were the most common themes in the findings of the studies regarding treatment towards parents, and reflect the treatment described by parents in the ESAT also. Healthcare professionals, including doctors, teachers and school personnel, were the main people associated with this treatment, with some examples from staff from the school district.

As discussed in the relevant theories section, this treatment was a barrier to accessing timely assessment and services and was also found to cause parents' significant stress.

> *"Probably the biggest assumption as an African American was that I was violent, and I would do or say something that was uncontrollable. For example, whenever we set a [IEP] meeting where they felt like they were going to tell me something that didn't jive or go with what I was requesting—that was within my rights—they would make sure that the police were there, or some sort of security." (Brown & Mortier, 2021, p.35)*

> *"[I] don't understand why teachers act like the parent is the enemy when the[y] act like they want to hide the information." (McNair, 2015, p. 78)*

> *"I felt with a lot of the psychiatrists and stuff, like, 'do you think I'm lying?' . . . I was ignored or what I was saying was trivial to them, and it was very demeaning." (Lovelace, 2018, p. 8)*

Treatment towards the child

The findings of the studies highlight the fear and concern that parents had regarding the treatment of their child within the education system. The main areas of concern included the child's needs not being met, refusing to refer the child for assessment, preferring 'educational classification' or labels such as 'mentally retarded' and 'emotionally disturbed' rather than autism or developmental disability, disproportionally harsh and aggressive treatment towards the child, and not recognising the child's skills and strengths (Hetherington, 2012; McNair, 2015; Lovelace, 2018; Morgan & Stahmer, 2020; Brown & Mortier, 2021; Morgan, 2021 and Quinn-Lunny, 2021). Many parents chose to remove their child from schools because of such treatment and were compelled to seek help and equip themselves with what was needed to get their children the support they needed.

> *"It is difficult to prove that the unwillingness to classify him as autistic was race-based; however, it is also difficult to understand why, in the face of medical and psychological "evidence," the school district refused to give him the services that would help to support a child with a diagnosis of an autism spectrum disorder." (Hetherington, 2012, p. 147)*

> *“Our son didn’t have a cubby, he was always being talked to for certain actions like playing with his pencil or looking at the endless posters and signs on the classroom walls and getting sad faces on most of the papers that he brought home.” (McNair, 2015, p. 79)*

> *Rita transitioned from a private pre-school to public school for kindergarten. As a terrified, screaming five-year-old, Rita was forcibly pulled off the bus by 3 school staff. No effort had been made to help her make the change to a new school. This was a significant misstep because difficulty making transitions is one of the primary characteristics of autism spectrum disorders. (Hetherington, 2012, p. 121)*

The treatment of the child in the studies also strongly resembles the accounts that parents gave in the current research. One difference noticed is that there appear to be more examples of harsh treatment towards younger children, e.g., those below 6 years with a diagnosis, than in the current research. It is unclear how significant this is due to the smaller sample sizes of the studies;

Some of the examples here relate to organisational dysfunction and a lack of knowledge by professionals and school staff. This is a very important point to consider, as racial bias can also be compounded by a lack of knowledge and awareness about autism, as raised in the relevant theories section.

Organisational dysfunction

Organisational dysfunction was also a prominent theme in the studies. This was mainly in relation to doctors, teachers and other healthcare and educational professionals not having adequate knowledge about autism, overly complex bureaucratic processes, long waiting times, and lack of timely provision. These were all considered as contributory factors towards delays in accessing assessment and services and causing distress and frustration to both parent and child. Parents were particularly concerned that dysfunction and lack of knowledge by services and providers often exacerbated their child's difficulties, as seen in the example of Rita from the Hetherington paper above.

Teachers/ schools

“So many people are uncertified, untrained to deal with children and do not know about autism”; “I see for my little one no differentiation of curriculum and that concerns me, because he is always getting it wrong. I worry because when children experience too much failure, it’s not that they failed, but that they are a failure. I do not want my son internalizing something that is not true” (Quinn-Lunny, 2021, p. 38)

‘ “How can you expect him to be consistent if you’re not?” The data indicate that parents felt schools failed to read or follow recommendations in signed IEPs; a parent indicated, “If you do not read the child’s file, then you are going to automatically assume there is always a problem with the student, and that is a problem.” (Brown & Mortier, 2021, p. 34)

Doctors/ health care professionals

“The first paediatrician we had was just a general practitioner. She is like, ‘I really don’t know anything about it [autism]’. (Pearson & Meadan, 2018, p. 25)

“There is a lack of understanding and training around autism for providers, period, even more so during this trying time. They need to understand that all these kids are not the same, and if they can’t even get an understanding then how are they going to educate me as a parent?” (Jones, 2021, p. 76)

“My paediatrician said he didn’t know about autism to say yay or nay”; “I don’t believe all paediatricians understand what autism is. They go by the look. The look is nothing,” and “Paediatricians think that if they are verbal, they can’t have autism. (Quinn-Lunny, 2021, p. 37)

Waitlists

‘Waiting is another stressor for me…It take a while to get a call back or when you get a call back is to tell you they have to put you on a waiting list. When I finally got my child the ABA services it was like 6 to 7-month’ (Jones, 2021, p. 7)

Bureaucratic processes

> *Although Wilma was college educated, possessed a teaching credential, and had strong communication skills she expressed feeling disempowered and lost in terms of how to navigate the complexities of service interventions for her son. She states, 'I kinda felt like I was powerless but yet I had a voice and I had some validity in what I was saying.' (Morgan & Stahmer, 2020, p. 11)*

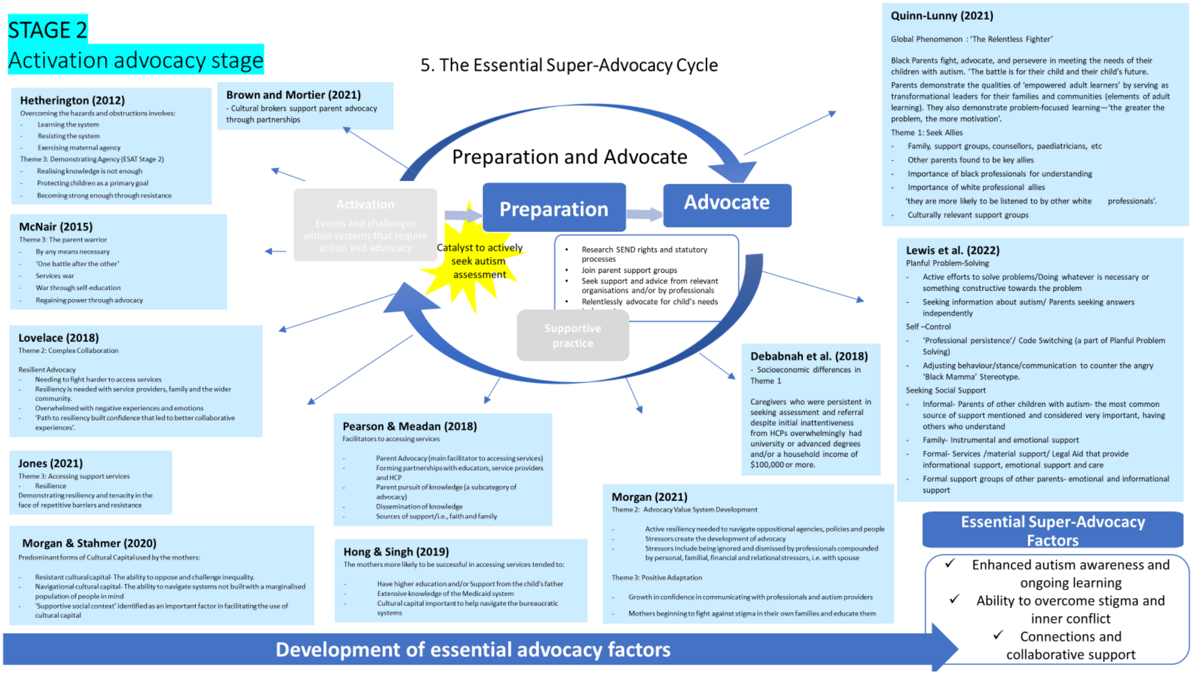
> *"I felt, I guess, like we were in a trial without a lawyer. We just didn't know what to expect, what questions to ask or not ask. It was frustrating." With mounting frustrations mixed with microassaults and microinvalidations from school professionals, James knew there was more available to his son; he just was unsure how to access it. He felt powerless. (McNair, 2015, p. 71)*

4.6.2 Preparation and advocate

The preparation and advocate category was highly represented in all of the papers themes of resiliency, learning, resistance, building connections, and empowerment were seen throughout the studies, as seen in Figure 18. This demonstrates how central the role of the super-advocate is to the Black parent who has a child with autism.

There was one difference between the ESAT and some of the literature concerning collaborative support. Lewis et al. (2022), Morgan & Stahmer (2020) and Pearson & Meadan (2018) found that family played an important role in supporting parents both emotionally and practically during this stage of fierce advocacy. Although this is only three out of twelve studies, it suggests that some family members can learn, adapt, and support parents despite initial reactions or community stigma. This is likely supported by the empowered parent sharing knowledge and educating family about autism.

Another important finding found in the literature was that the parents most likely to be persistent during this stage of intense advocacy overwhelmingly had university or advanced degrees and/or had a household income of $100,000 (£78,000) or more (Debabnah et al. 2018). Hong and Singh (2019) added to this and said that higher education and support from the child's father enabled persistence. This is important, as it will require professionals, services, and schools to go above and beyond, especially for parents who do not have these additional factors. Although household income was not recorded in the current research, all parents had higher education qualifications, supporting this finding.



- Research SEND rights and statutory processes
- Join parent support groups
- Seek support and advice from relevant organisations and/or by professionals
- Relentlessly advocate for child's needs

✓ Enhanced autism awareness and ongoing learning
✓ Ability to overcome stigma and inner conflict
✓ Connections and collaborative support

Hetherington (2012)
Overcoming the hazards and obstructions involves:
- Learning the system
- Resisting the system
- Exercising maternal agency

Theme 3: Demonstrating Agency (ESAT Stage 2)
- Realising knowledge is not enough
- Protecting children as a primary goal
- Becoming strong enough through resistance

Brown and Mortier (2021)
- Cultural brokers support parent advocacy through partnerships

McNair (2015)
Theme 3: The parent warrior
- By any means necessary
- 'One battle after the other'
- Services war
- War through self-education
- Regaining power through advocacy

Lovelace (2018)
Theme 2: Complex Collaboration

Resilient Advocacy
- Needing to fight harder to access services
- Resiliency is needed with service providers, family and the wider community.
- Overwhelmed with negative experiences and emotions
- 'Path to resiliency built confidence that led to better collaborative experiences'.

Jones (2021)
Theme 3: Accessing support services
- Resilience

Demonstrating resiliency and tenacity in the face of repetitive barriers and resistance

Morgan & Stahmer (2020)
Predominant forms of Cultural Capital used by the mothers:

- Resistant cultural capital- The ability to oppose and challenge inequality.
- Navigational cultural capital- The ability to navigate systems not built with a marginalised population of people in mind
- 'Supportive social context' identified as an important factor in facilitating the use of cultural capital

Pearson & Meadan (2018)
Facilitators to accessing services

- Parent Advocacy (main facilitator to accessing services)
- Forming partnerships with educators, service providers and HCP
- Parent pursuit of knowledge (a subcategory of advocacy)
- Dissemination of knowledge
- Sources of support/i.e., faith and family

Hong & Singh (2019)
The mothers more likely to be successful in accessing services tended to:

- Have higher education and/or Support from the child's father
- Extensive knowledge of the Medicaid system
- Cultural capital important to help navigate the bureaucratic systems

Debabnah et al. (2018)
- Socioeconomic differences in Theme 1

Caregivers who were persistent in seeking assessment and referral despite initial inattentiveness from HCPs overwhelmingly had university or advanced degrees and/or a household income of $100,000 or more.

Morgan (2021)
Theme 2: Advocacy Value System Development

- Active resiliency needed to navigate oppositional agencies, policies and people
- Stressors create the development of advocacy
- Stressors include being ignored and dismissed by professionals compounded by personal, familial, financial and relational stressors, i.e. with spouse

Theme 3: Positive Adaptation

- Growth in confidence in communicating with professionals and autism providers
- Mothers beginning to fight against stigma in their own families and educate them

Quinn-Lunny (2021)

Global Phenomenon : 'The Relentless Fighter'

Black Parents fight, advocate, and persevere in meeting the needs of their children with autism. 'The battle is for their child and their child's future.

Parents demonstrate the qualities of 'empowered adult learners' by serving as transformational leaders for their families and communities (elements of adult learning). They also demonstrate problem-focused learning—'the greater the problem, the more motivation'.

Theme 1: Seek Allies
- Family, support groups, counsellors, paediatricians, etc
- Other parents found to be key allies
- Importance of black professionals for understanding
- Importance of white professional allies
  'they are more likely to be listened to by other white professionals'.
- Culturally relevant support groups

Lewis et al. (2022)
Planful Problem-Solving
- Active efforts to solve problems/Doing whatever is necessary or something constructive towards the problem
- Seeking information about autism/ Parents seeking answers independently

Self –Control
- 'Professional persistence'/ Code Switching (a part of Planful Problem Solving)
- Adjusting behaviour/stance/communication to counter the angry 'Black Mamma' Stereotype.

Seeking Social Support
- Informal- Parents of other children with autism- the most common source of support mentioned and considered very important, having others who understand
- Family- Instrumental and emotional support
- Formal- Services /material support/ Legal Aid that provide informational support, emotional support and care
- Formal support groups of other parents- emotional and informational support

Figure 18. Preparation and advocate comparative review map

Enhanced knowledge and ongoing learning

> *"I need a lot of info in regards to things to better him, and better understand the system. I'm like a sponge–I need to soak up any and everything. … Once I started attending workshops on my own, that empowered parents to stand up for their children . . . made us feel proud to be a parent instead of guilty like we made our kid special" (McNair, 2015, p. 83)*

> *"It's just me taking advantage and going to the classes and trying to learn stuff." Similarly, Lynette shared, "I had to go for parental classes. So, they could teach us how to work with the children in therapy. I think it was like four or five sessions of that for myself." (Pearson & Meadan, 2018, p. 26)*

Building connections and collaborative support

> *"We talked to an advocate who lived in the area who empowered us and offered to help if we needed by coming to the IEP meetings and offering other resources as well." This was his empowerment to become an advocate himself. After seeking out someone who knew what was needed, James then felt empowered to do it himself." (McNair, 2015, p. 77)*

> *Often times mothers found allies and strong partners in service delivery agencies and organizations (i.e., case workers, teachers, other parents are support groups) who equipped them to handle the next stressors that came their way. … They served more as resources that the mother commonly pulled upon to advocate for her children in response to a stressor. (Morgan, 2021, p.59)*

Non-stop fight

> *"I have been waitlisted, yelled at, encountered sleepless nights, arguments in Individual Education Plan meetings, and frustrated with doctors and providers, but I tell you what. I kept going, nothing was going to stop me from getting the services that my child needed. Giving up was never an option for me and my family." (Jones, 2021, p. 82)*

> *"It was one battle after another . . ." (McNair, 2015, p. 82)*

> *"The type of resiliency needed by these mothers on behalf of their children was seen by others as excessive. In response to the difficulty needed to access wrap around services, Latisha shares, "My mother was sick. She couldn't believe it. No one could believe it. My sister was like file a lawsuit [for] discrimination. I thought maybe it's just this location so I'll go to the [other] location. I go to the [other] location, the same lady. I don't really know what it was. I don't know if it was me. I don't know if it was my child." (Lovelace, 2018, p. 9)*

> *Wilma was one of two mothers interviewed that went through the courts to exercise their parental right to be full partners in their child's special education process. Wilma won her case against the school district and when asked, she felt that her voice was finally heard and validated when she utilized the legal system and exercise her parental rights. (Morgan & Stahmer, 2020, p. 11)*

Advocacy development and empowerment

> *"However, the path to resiliency for each of the mothers created a confidence that led to improved collaborative experiences. Mothers became very direct. … Tasha: "I'm going to make you do this right because I'm holding up my end of the bargain, but I'm*

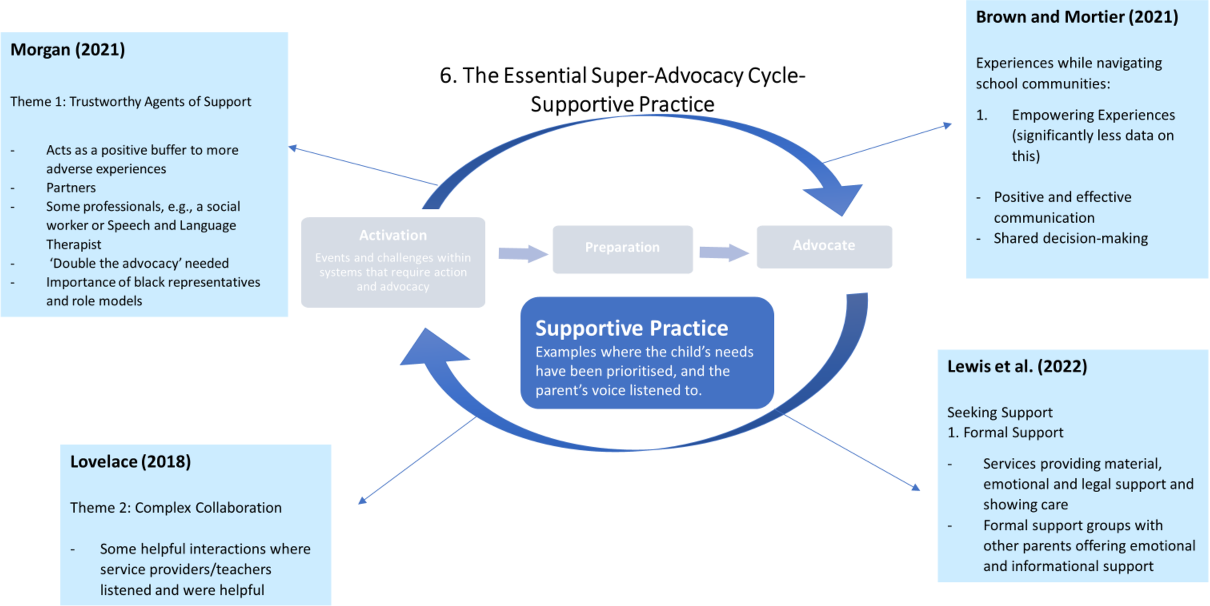
> *going to make you hold up yours." They also began to know their rights as caregivers and Latisha shared, "there shouldn't be anything that anyone can say to you to knock you off your square because you know what you're doing." (Lovelace, 2018, p. 9)*

> *"And I will tell you this. That's what came through the years in the journey of standing up to people in a room that don't look like you. It requires you to use the knowledge you have. It requires you to use the understanding you have. It requires you to realize that you got this. You know what's best for your child." (Morgan & Stahmer, 2020, p. 9)*

4.6.3 Supportive practice

There were some examples of supportive practice by schools and services, but as seen in Figure 19, there were far fewer. Where parents felt that schools and services supported them, it was found to help negate some of the negative experiences they had and help them to empower other parents, as seen in the ESAT. This stresses the importance of professionals who have the interpersonal skills to listen and be sensitive to the needs of parents of children with autism, especially those who face many intersectional-related obstacles within the system.

STAGE 2
Activation advocacy stage



Supportive Practice
Examples where the child's needs have been prioritised, and the parent's voice listened to.

Morgan (2021)

Theme 1: Trustworthy Agents of Support

- Acts as a positive buffer to more adverse experiences
- Partners
- Some professionals, e.g., a social worker or Speech and Language Therapist
- 'Double the advocacy' needed
- Importance of black representatives and role models

Brown and Mortier (2021)

Experiences while navigating school communities:

1. Empowering Experiences (significantly less data on this)

- Positive and effective communication
- Shared decision-making

Lovelace (2018)

Theme 2: Complex Collaboration

- Some helpful interactions where service providers/teachers listened and were helpful

Lewis et al. (2022)

Seeking Support
1. Formal Support

- Services providing material, emotional and legal support and showing care
- Formal support groups with other parents offering emotional and informational support

Figure 19. Supportive practice comparative review map

"They were not trying to rush me out his office; they listened, they observed. It seemed like they had a genuine interest in my child, not like he was just a patient. They cared. …That's what you want to see." (Lovelace, 2018, p. 9).

There was also evidence that service delivery providers who had cultural connections made a difference for mothers during and after their children were diagnosed. For example, Trust stated that she had a social worker assigned to her …. in addition to being a licensed social worker, was a Black mother of a child on the autism spectrum. (Morgan, 2021, p. 60)

"She … found great allies in people that she did not think she would be able to partner with. One such person included a White female speech-language pathologist (SLP) … she had a straightforward "tell it like it is" approach to communicating with families. Nandi enjoyed this type of communication and ended up creating a strong relationship with the therapist, so much so that the SLP advocated for her and her sons in venues that her family was being discriminated against such as in this instance during an IEP." (Morgan, 2021, p. 69)

4.7 Comparative review of stage 3: The outcomes and outlook Stage

4.7.1 Outcomes

Outcomes in the literature were mainly based on parent outcomes, as the studies focused on parent experiences. These included how parents felt their journeys as advocates and supporting their children with autism had impacted them and their lives (McNair, 2015; Lovelace, 2018; Jones, 2021; Morgan, 2021; Quinn-Lunny, 2021 and Lewis et al., 2022) as seen in Figure 20. In the ESAT, there were both positive and negative outcomes with some distinct differences. As mentioned previously, 'spiritual practices' and 'faith' featured as significant coping strategies for some parents in the literature. Other than this, we see very similar themes in the literature and the ESAT including realising strengths, areas of growth, passing on knowledge, supporting other parents and also the emotional, physical and financial stress that the journey so far had on them.

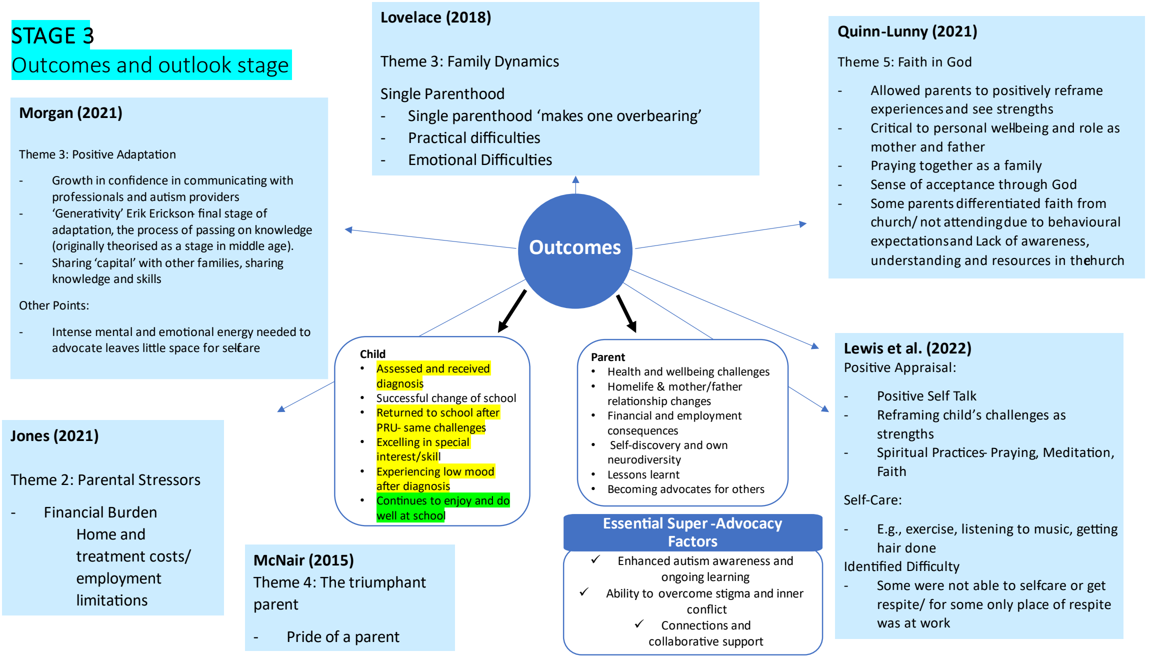


Figure 20. Outcomes comparative review map

Learning and passing on knowledge

> *“Well, if I've never heard of it and I'm Black, then how many other people that are Black have never heard of autism? And that really began my journey. So I found out that there are not a lot of people that are in our community that even have resources that identify what autism is. None of the school districts here had information on autism. None of the teachers in our school system really were identifying kids that may have autism. And so, oh, my God, I made a pledge right then and there. We're going to have to do something about this. We're going to have to spread this information.” (Morgan, 2021, p. 73)*

Celebrating success

> *“When she [the teacher] explained to me how he was doing, it made me feel accomplished because, for a while, I felt in a way that I was failing because he was autistic. So hearing that reassured me that I was doing everything I could do.” pp.93 (McNair, 2015, p. 93)*

> *“This journey has and will be my legacy and I hope my legacy is to show that anything is possible. I believe I was put on this earth for my daughter, because the skills I have and the needs she has, I am able to give that to her. And I believe no one else would be able to do that.” (Quinn-Lunny, 2021, p. 32)*

Developed coping/self-care strategies

> *“I would not have made it without faith and believing that things happen for a reason.” (Quinn-Lunny, 2021, p. 44)*

> *“I go to the hairdresser, just sitting under that dryer, or getting my hair washed. That’s my time, that’s my time.” (Lewis et al., 2022, p. 2021)*

Continued challenges

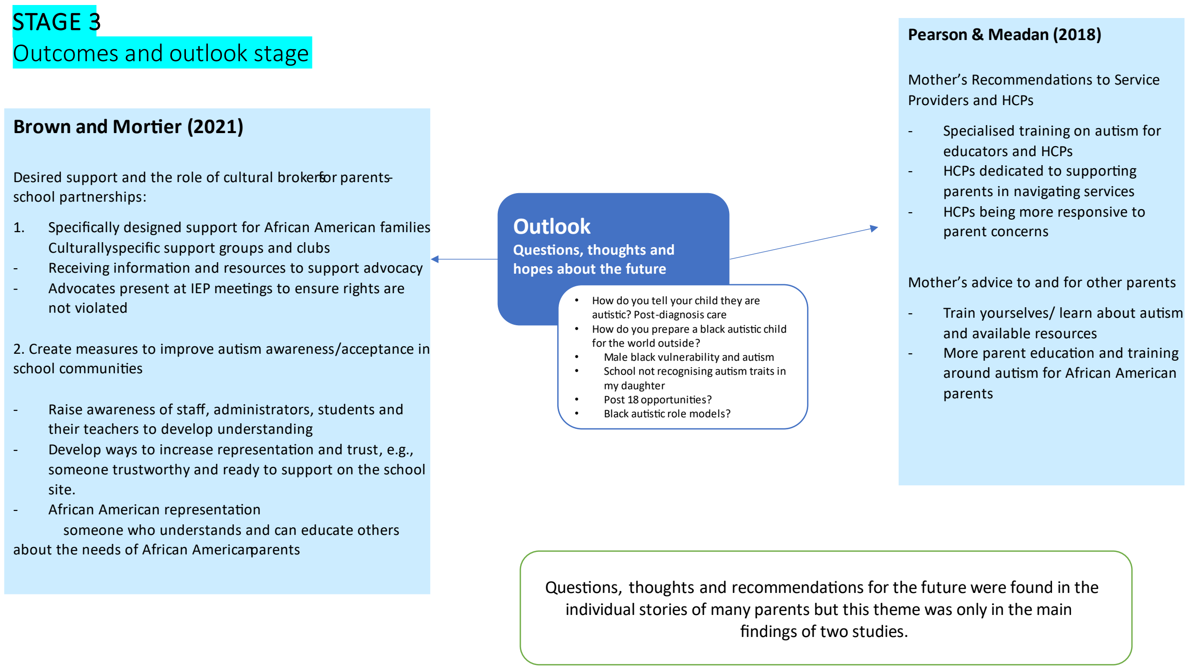
> *“To tell you the truth I have no more savings. I used to be able to have some on the side in case of emergencies, but my household only have one income now.” (Jones, 2021, p. 72)*

> *For some parents, they could only receive respite from caregiving while at work. For one parent, not socializing with colleagues at work caused problems with them, yet she insisted lunchtime at work "is my only time." (Lewis et al, 2022, p. 2021)*

> *For the women in this study, the knowledge, time, and energy necessary to navigate ASD services were compounded by the various challenges related to being a single parent. For example, single parents carry the burden of both unwaged and waged labor. In this case, the unwaged labor consists of navigating the bureaucratic processes needed to obtain ASD services in addition to all the other caregiving work required to raise a child with special needs. (Hong & Singh, 2019, p. 375)*

4.7.2 Outlook

Parent's 'outlook', i.e., their hopes, dreams and concerns for the future of their children and systems, was mainly weaved throughout individual stories in the literature rather than a part of their main findings. Nevertheless, the main findings of Brown & Mortier's (2021) and Pearson & Meadan's (2018) papers include parent recommendations which encapsulate the desires of the parents throughout the studies regarding how schools and services can best support them (see Figure 21). Culturally specific care and representation was a big theme including staff, materials and support groups. Professionals and services having an awareness and understanding of the cultural and intersectional factors affecting Black families of children with autism was also a strong desire of the parents. Parents expressed that more Black professionals would be important for this. Some parents also shared that white professionals having this knowledge and professional care would also be important due to the influence more likely held within systems (Quinn-Lunny, 2021). Generally, however, parents spoke of the desire for professionals, services and organisations to have a greater awareness of autism and be attentive to their needs.



STAGE 3
Outcomes and outlook stage

Brown and Mortier (2021)

Desired support and the role of cultural brokers for parents-school partnerships:

1. Specifically designed support for African American families
   Culturally specific support groups and clubs
- Receiving information and resources to support advocacy
- Advocates present at IEP meetings to ensure rights are not violated

2. Create measures to improve autism awareness/acceptance in school communities

- Raise awareness of staff, administrators, students and their teachers to develop understanding
- Develop ways to increase representation and trust, e.g., someone trustworthy and ready to support on the school site.
- African American representation
  someone who understands and can educate others about the needs of African American parents

Outlook
Questions, thoughts and hopes about the future

- How do you tell your child they are autistic? Post-diagnosis care
- How do you prepare a black autistic child for the world outside?
- Male black vulnerability and autism
- School not recognising autism traits in my daughter
- Post 18 opportunities?
- Black autistic role models?

Pearson & Meadan (2018)

Mother's Recommendations to Service Providers and HCPs

- Specialised training on autism for educators and HCPs
- HCPs dedicated to supporting parents in navigating services
- HCPs being more responsive to parent concerns

Mother's advice to and for other parents

- Train yourselves/ learn about autism and available resources
- More parent education and training around autism for African American parents

Questions, thoughts and recommendations for the future were found in the individual stories of many parents but this theme was only in the main findings of two studies.

Figure 21. Outlook comparative review map

Recommendations for schools, services and organisations

> *"I think that putting more knowledge out there specifically geared towards Black Americans. Examples of Black Americans that have children on the spectrum that are getting services, that are actually benefiting in some way, and encouraging them to be more involved in their child's services, and their child's education as well, it would really, really, really, really, really, help." (Lovelace, 2018, p. 12)*

> *"Her teacher has a special education certification, not a certification in autism, and there is a difference. She has had teachers that are specialized in autism and I could see the difference immediately." (Pearson & Meadan, 2018, p. 28)*

> *"I feel like a part of what is going to be most critical is to make the needs of parents like us and communities like ours . . . known . . . educating people about what we need and try[ing] to remedy some of the issues that we're dealing with in special education." (Brown & Mortier, 2021, p.35)*

Advice for other parents

> *“As a parent of an ASD child you have good days and bad days. On your good days take it, enjoy it and love it. On the bad days, step outside, take a deep breath, cry if you have to. Pull yourself back together, because your child needs you.” (Quinn-Lunny, 2021, p. 31)*

> *“If you know your kid, then you know what he can do. And you can't put limitations on him just because he's got a certain label. … Don't focus on the label. Focus on what you want your child to do, where you want your child to go.” (Morgan, 2021, p. 82)*

> *“Advocate and continue to advocate. Change doctors as frequently as you need to”; and “Don’t underestimate your child. They are capable. Keep pushing.” (Quinn-Lunny, 2021, p. 32)*

4.7.3 Comparative overview summary

The comparative overview section demonstrates how the literature supports and compares with the ESAT. While the literature review studies and current research have relatively small sample sizes, ranging from 5 to 22 participants (see Table 7), the participant experiences show many similarities. This supports the validity of the findings and strengthens the areas identified that need improvement and intervention.

5 DISCUSSION

5.1 Chapter overview

This chapter uses the findings, relevant theories, and literature to provide implications for practice, and recommendations. As the literature review chapter compared the findings to the literature in detail, this chapter will focus on how the findings can be applied to improve BCP experiences and enhance professional practice.

5.2 Implications and recommendations

This research found that BCPs must become fervent and persistent 'super advocates' to provide their children with autism the support, protection and advocacy that they need. The process of becoming a super-advocate requires parents to acquire a crucial set of skills (the essential super-advocacy skills), where they must educate themselves about autism and SEND systems, overcome internal conflict about labels and difference, and make vital connections to cultivate collaborative support.

BCPs experienced many barriers while trying to advocate for their children. Some of these barriers were related to personal, familial and community factors. The main barriers were related to difficulties with schools and Local Authorities. These were either interactional barriers or those regarding treatment towards and/or decisions made about their child. Intersectional factors, including the age of diagnosis and/or the child's gender, were found to compound some of these difficulties. Socio-economic status and Black female single parenthood were other significant intersections from the supporting studies, which adds to the interactional and practical aspects of the 'non-stop fight'.

These findings draw attention to the areas that professionals and services need to address. It is envisioned that educational psychologists will play a central part of this and support schools and services to implement the recommendations made in this research. This aligns with the EP role of championing social justice, which has been understood by EPs as focusing on 'fairness, equity, and equality, awareness, advocacy, and cultural competence' (Embieta & Birch, 2024). The British Psychological Society (BPS) code of ethics stresses the importance of recognising and developing awareness of different cultural groups to provide effective person-centred intervention and to help ensure fair and unbiased representation (British Psychological Society, 2021).

The concepts of ‘cultural competence’ and, more recently, ' cultural responsiveness’ have become increasingly more prominent in EP research. Cultural competence has been defined as a tripartite model that includes three essential components for working effectively with culturally diverse groups: cultural awareness, knowledge, and skills (Sue et al., 1982, 1992). Cultural responsiveness, on the other hand, takes this a step further by emphasising the action of challenging and dismantling social injustice and acknowledging the ongoing learning, reflection, and humility required by practitioners (Sakata, 2024). It highlights advocating with minority cultural groups rather than for them (Williams et al., 2021), the importance of recognising personal and cultural strengths and accomplishments (Gay, 2002) and the impact of culture and social experiences on wellbeing, worldview, and sense of belonging (Lopez et al., 2013). This will be crucial for all aspects of the EP role i.e., consultation, assessment, intervention, research and training to develop a truly culturally responsive practice.

These culturally competent and responsive principles raised in key educational and school psychology research closely align with the aims, implications and recommendations of this research (see Table 9). There are four implications that are closely related. They highlight the necessity for increased collaboration, awareness, and representation of Black Caribbean families who have children with autism within the schools, settings and services they engage with. This improved involvement aims to enhance relationships, understanding, and support, fostering a sense of belonging and ultimately leading to better outcomes and wellbeing for both the children and their families.

These outcomes will include better identification and earlier autism diagnosis for Black Caribbean children, which will support more timely and appropriate intervention. It will also likely change one of the current functions of obtaining a diagnosis by BCPs according to the ESAT. Instead of diagnoses serving as an urgent form of protection against stigma, racial bias, incorrect assumptions and harsh treatment, the function will more likely be to confirm the needs of the child that have already been recognised and appropriately addressed, by the supportive and culturally responsive systems around the child, and with the resources accessible to them.

Supportive approaches by schools, settings, and services will, therefore, include:

1	**The intentional building of trusting and non-judgemental relationships, and fostering a sense of belonging, understanding and respect.** In response to the finding that: Participants have many disempowering experiences with schools, services and settings where they are dismissed, ignored, and harshly judged, delaying access to assessment, diagnosis and/or support for the child, causing significant distress to both parent and child. Additionally, parents found it made a significant and positive difference when professionals and services came alongside them, listened and involved them in processes that will support their child. This will involve: - Open and non-judgemental communication with parents, valuing their knowledge of their child, involving them in decisions, and showing a mutual desire to support their child. - A commitment to listen to parents' concerns, following the correct procedures (according to the SEND Code of Practice), and taking the necessary steps to address them. - Recognising and celebrating the child’s strengths and achievements and communicating these to parents and the child regularly. - Exploring all possibilities, including neurodiversity, when addressing issues impacting the child at school (pre and/or post-diagnosis), with the parent and consultation from a specialist, e.g., an educational psychologist, if needed. - Ensuring that any diagnoses do not inappropriately restrict curriculum and opportunities for the child and that their academic and social strengths and abilities are recognised and nurtured. - Utilising parents' knowledge, e.g., when planning interventions, relevant training and/or materials.

2	**Representation and culturally specific support** In response to the finding that: There is limited representation and cultural understanding of Black and Black Caribbean children and families, e.g., in schools, services, support groups and resources about autism. This compounds isolation, not getting access to the support needed, and parental internal dissonance. Representation and culturally specific support will involve: - Ensuring that leaflets, websites, videos, apps, displays and other resources regarding autism have Black families and young people represented in them. - Co-creating or consulting with BCPs about these resources. - Developing (or helping develop) support groups for BCPs who have children with autism. These might be led or co-led by BCPs or by someone knowledgeable and sensitive to the needs of this group. - Having a list of relevant and culturally specific organisations and services that can be offered to parents for additional support (alongside the universal services). - Bearing representation in mind when recruiting staff and volunteers. - Seeking to understand potential compounding factors that might impact BCPs, e.g., attending meetings and childcare/work responsibilities, and seeking to be flexible and supportive. - An advocacy champion (like the role of a ‘cultural broker’ in the Brown & Mortier Paper (2021) who is passionate and knowledgeable about the needs of children and families with SEND and has a good understanding of issues facing Black Caribbean and diverse families, that can support the development of the above recommendations over time.

3.	**A whole-organisation autism awareness strategy** In response to the finding that: There are staff at schools and other educational settings (including teachers and leadership) and professionals from healthcare, e.g., GPs, that have limited knowledge and understanding about autism and how to identify traits and support young people. This can exacerbate difficulties experienced by the child, compound bias and disproportionately harsh treatment, and contribute towards delays in assessment, diagnosis and support. A whole-organisation autism awareness strategy will involve: - A commitment to implementing a whole-organisation agenda that raises awareness and acceptance of autism among staff, including admin and the organisation community, i.e., pupils, their families, service users, etc.). - Completing a needs assessment, which includes the voices of the staff, pupils, parents and service users to understand gaps in knowledge and understanding and areas for development. - Regular staff training delivered by autism specialist organisations and/or professionals that meets the organisation's development needs. Cultural diversity and autism should also be a part of this training. - Training, including raising awareness of autism traits that can be attributed to misbehaviour (e.g., repetitive behaviours, literal interpretation, different or less use of facial expressions, sensory over/under-stimulation), and understanding ways to support the child and address the situation. - Discussion and identification of children and young people presenting with potential autism traits with the involvement of parents to conduct individualised planning and investigate further.

	- Training that ensures all children with autism get appropriate and adequate provision that nurtures strengths, gifts and talents and maintains high expectations. - Regular assessment of the strategy to ensure effectiveness, which will also include the voice parents, children and young people.
4.	**Raising awareness of autism in Black Caribbean communities** In response to the finding that: There is limited awareness about autism in Black Caribbean communities, leading to delays in identifying traits, seeking support, and understanding. This was found to contribute towards feelings of shame, emotional isolation, and social isolation. Raising awareness of autism in Black Caribbean communities will involve: - All of the implications and recommendations above. A foundation of trust, representation and sound knowledge to build awareness in Black Caribbean communities. - Utilising and valuing the experience of BCPs who have children with autism to support and engage other BCPs and parents. - Partnering with key institutions and figures within Black Caribbean communities to make information accessible and representative. - Ensuring that awareness strategies involve plans to engage Black Caribbean fathers and men in the wider Black Caribbean community. - Being mindful of the use of language and focusing on needs and strengths rather than deficits. - Signposting to further information on the SEND system, and step-by-step instructions and support about what to do, if traits are identified.

Table 9. Implications and recommendations

Raising cultural awareness and addressing cultural and racial bias will be important for the implementation of the above. Cultural competency, responsiveness , and unconscious bias training, (for example), can support this; but should not be used as a standalone solution. A UK meta-analysis by the Equality and Human Rights Commission (2018), found that unconscious bias training can be effective for raising awareness, (especially when implicit association testing is used and discussed and interactive workshops are included), however they also found that there needs to be better regulation and a more rigorous evidence-base to ensure efficacy (Atewologun et al., 2018). Similar conclusions were made for research on cultural competency training (George et al. (2015), so while these are important, there needs to be a commitment to long-term and embedded development.

It is therefore proposed that frameworks such as communities of practice (CoP) (Wegner, 1998), as discussed in the literature review, are used to establish long-term collaborative cultures of self-reflection, initiative and passion around improving provision for Black Caribbean children and young people with autism and their families. As discussed, research on CoP in inclusive education has found that it can provide:

> “An alternative to the traditional top-down approach, (b) allow space for uncertainty and trust, (c) close the gap between espoused theory and theory in use about specialized expertise, and (d) dilute the effect of power imbalances and competing priorities among parents and educators” (Mortier, 2018, p. 1).

Furthermore, research on CoP with Black American and culturally diverse family-school partnerships also found that this approach of joint enterprise, learning, and shared practice can redefine and restore relationships and trust (Cooper et al., 2010). This could open the possibility for collaborations with other institutions, e.g., the police, and the opportunity to raise awareness of autism and the concerns of BCPs. This is a broader systemic issue, however, that needs further research.

Although the discussed implications and recommendations can be addressed without a CoP, a collaborative approach such as CoP can help to establish the needed partnership from the onset and start work on the proposed changes with purpose and momentum.

5.3 Tools to support parent advocacy and effective parent-school partnerships- An area for future research

A crucial finding of the ESAT is that early diagnosis supports early parent empowerment, adaptability, and the development of *the essential super-advocacy skills*. These are key for the role of super-advocate, particularly during the years of mainstream education. Early diagnosis also leads to better outcomes for the child which is supported by the current research as discussed. It will therefore be important for educational psychologists and professionals who work with BCPs to work together to prevent delay in diagnosis and enable a good understanding of the child to support progress and wellbeing. The implications and recommendations outlined above will be essential for this.

An important area for future research, however, will be to develop assessment approaches that will a) make clear the support and essential advocacy skills a parent might need at the earliest stage to enable targeted intervention and b) provide a structured and culturally sensitive way to start meaningful conversations, and build relationships. Below are two approaches proposed for development and future research. One utilises the double ABC-X model and the other an intervention concept from Narrative Therapy.

5.3.1 An advocacy resource assessment

An advocacy resource assessment would help professionals to understand the skills, strengths and resources that a BCP and their family have, and the ones that they need. This will enable early targeted support to equip parents and help reduce the intensity of the possible future challenges (i.e., during stage 2 of the ESAT). The current research identified the essential skills and factors that empower and support parent advocacy, and so, with an appropriate tool, they could be assessed for this early intervention purpose. As discussed in the literature review, the ABC-X model can be used to illustrate this preventative approach (see Figure 22 and Table 10). The ‘Existing Resources’ variable (b), will be the important area to assess. Perception of the stressor is also important but can be mediated with improved resources (McCubbin & Patterson, 1983), as seen in the ESAT. To make an assessment like this preventative, it would need to be completed at the earliest stage possible, i.e., soon after ‘noticing difference’ (variable (a) the stressor) and when a parent raises concerns or a professional recommends that an assessment be considered.

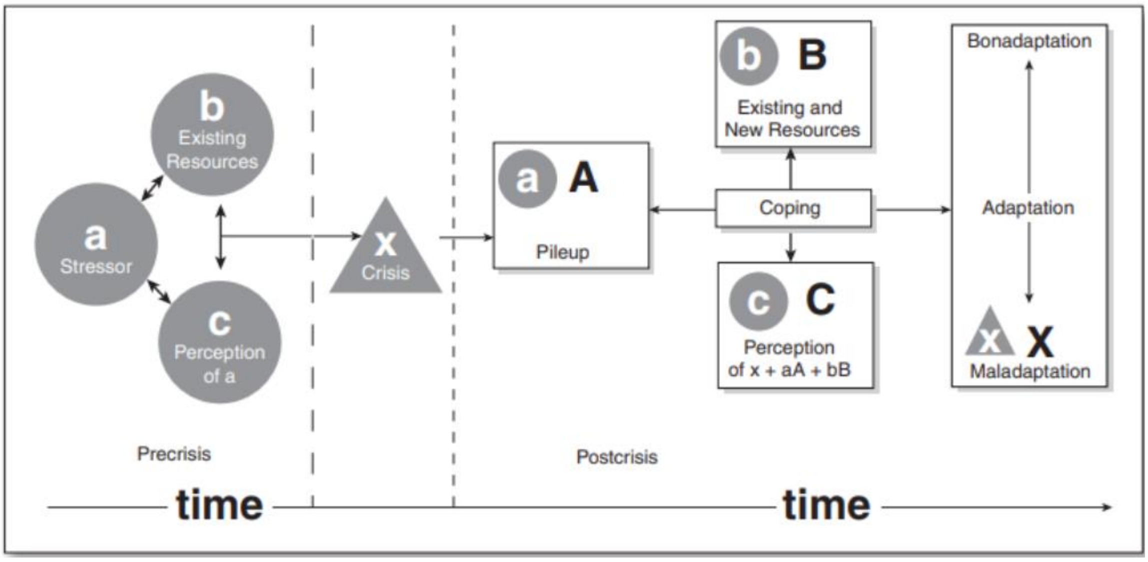


Figure 22. ABC-X model (Hill, 1958)

	ABC-X variables	**ABC-X variables from the essential super-advocacy theory (ESAT)**
Pre-crisis	**a- The stressor** A situation for which the family has had little or no prior preparation.	Noticing difference • Child's behaviours not understood, misunderstood or dismissed • Behaviours interpreted by some as a result of bad parenting • Socially excluded from some events • Withdrawing from some social events and settings • Emotional and social isolation
	b- Existing resources? **Protective factors within and around the family that can help prevent crises and/or improve coping.**	• **Autism knowledge and understanding?** • **Family support (extended and immediate, e.g., spouse/partner)?** • **Family autism knowledge and understanding?** • **Supportive and informative professionals, services and educational settings?** • **Knowledge of SEND systems and processes?**

		• Access to systemic support, i.e., relevant services and Therapies? **• Access to collaborative support with experienced parents of children with autism and support groups?**
	c- Perception of (a)? The definition that the family makes of the event. The more negatively the family define the stressor, the less able they are to adapt and cope with crisis, and vice versa.	Internal dissonance? • Fear • Uncertainty • Denial • Shame Accepting and/or embracing difference?
	X- The crisis The event that is either adequately resourced to cope with or not, depending on the interaction of b and c	Stage 2 Activators • Problems and challenges experienced with and within systems • Treatment of child • Treatment of parent • Organisational dysfunction
Post-Crisis	**aA- Pileup (of stressors)**	Stage 2- Ongoing and/or escalating challenges, including exclusions and Tribunals.
	bB- Existing and new resources	• Collaborative support • Specialist/expert advice? • Support groups? • Extensive knowledge and learning of SEND Systems?
	cC- Perception of X, aA and bB	• Organisational dysfunction and lack of autism knowledge

		• Racial bias • Injustice
	Xx- Adaption The result of changes in the family system which evolves and is intended to have long-term consequences.	Outcomes and outlook

Table 10. The double ABC-X model parent adaptability variables (McCubbin & Patterson, 1983) and the essential super-advocacy theory (ESAT)

In addition to the essential super-advocacy factors and resources outlined above (in blue), some other characteristics and aspects were identified that facilitate parent advocacy and early diagnosis. In contrast, others were found to compound challenges. It will be important for an assessment tool to consider these, as families with more compounding factors will likely need a higher level of support, even with the presence of some protective factors (see Table 11).

Compounding factors	**Additional factors that facilitate early diagnosis, advocacy development, and persistence**
• Later diagnosis/ undiagnosed in mainstream education • Without speech and language difficulties • Male child with autism • More than one child with autism or SEND • Single parent • Lower household income	• Early engagement by a supportive professional who supports assessment referral • Child has speech and language difficulties and delay at the time of identification • Parent has university-level or equivalent qualification • Higher household income

Table 11. ESAT factors that compound challenges and factors that also facilitate early diagnosis and advocacy development

It is important to use an appropriate method to gather this information, and involving BCPs in the development of the assessment tool will help ensure its effectiveness. It's also important to note that schools and settings, as outlined in the implications and recommendations, will also need to conduct an assessment on their own autism strategy and ability to support BCP families well. The systems surrounding the child and family must work towards establishing trusting partnerships with BCP families. This leads to the second proposed intervention approach.

5.3.2 A narrative therapy approach- Tree of life (ToL)

The tree of life (ToL) is a therapeutic and strength-based tool and intervention strategy that aims to develop engagement, connectedness and the ‘re-authoring’ of narratives (Lock, 2016; Ncube, 2006; Parham, et al., 2019).

Participants draw or are given an outline of a tree symbolising different aspects of their lives, including origins, skills, hopes, important people, and gifts received (see Illustration 5). Through a series of guiding questions, they reflect on and detail these aspects, recording them on the corresponding feature of the tree. This exercise can be done with groups, culminating in the presentations of individual narratives. Each tree created is displayed together to form a ‘forest’ of life symbolising the uniqueness and shared experience of the group. The ToL is also used with individuals, and if working with a parent, they can be completed about the child, e.g., discussing their child’s skills, interests, challenges, hopes and dreams.

The ToL has routes in narrative therapy and positive psychology. Due to its person-centred approach, it has been considered an inclusive and culturally sensitive tool that can be used with diverse groups and cultures and support a sense of belonging and connection.

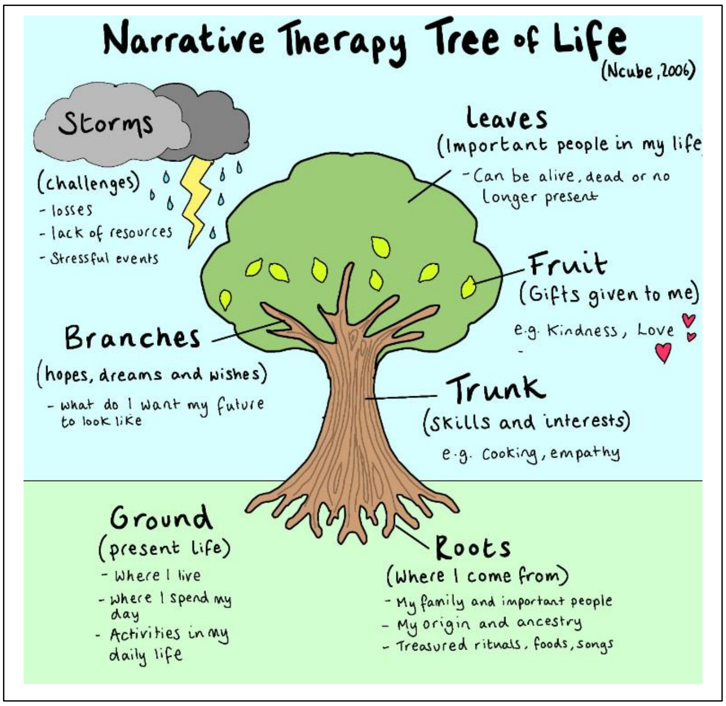


Illustration 5. Tree of life (Ncube, 2006) Illustration by Juliet Young

The ToL was first developed by Ncube (2006) in South Africa to support vulnerable children and communities to overcome difficult life experiences. It has since been adapted for use in clinical and educational settings internationally and the UK, i.e. to address self-esteem, identity and cultural differences in schools (German, 2013) and refugee engagement with health services (Hughes, 2014). It has also been used successfully with Black and Black Caribbean communities, e.g., to improve African, Caribbean and mixed heritage children and young people's emotional health and wellbeing with CAMHS in the London Borough of Hackney (Fiveways et al., 2022) and Black Caribbean male engagement in talking therapies with the NHS (Byrne et al., 2011).

There is growing use of ToL in educational psychology. This is due to its therapeutic qualities and ability to gather rich information in a strength-based and culturally sensitive way.

ToL has also been found to help parents feel more engaged and equipped to support their children's needs, resulting in better outcomes for their children and supporting the improvement of teacher-student relationships, encouraging shared learning through the reauthoring and presenting of personal stories (Hughes, 2014; Rowley et al., 2020).

The researcher has used ToL in their own practice and has found this to be the case. It has been particularly helpful when dominant 'problem narratives' surround a young person and/or their family, as it helps to restore a sense of self beyond the ‘problem’ and offer new depth and understanding about the child and their family.

For these reasons, adopting a narrative approach such as the ToL, with BCPs and their children, can provide helpful structure and guidance to professionals to start relationship building and information gathering that will help improve partnership and understanding. It also acts as an intervention for the family, as mentioned, that is not centred around a problem but seeks to understand the whole child and their contexts. This is something that participants of the current research valued in their interactions with supportive professionals and settings.

Further research could explore how this approach might be used in conjunction with an advocacy resources assessment tool. As mentioned earlier, participatory research would be a helpful way to do this. The aim would be to ensure that the information gathered and the experience of completing these assessments/interventions will lead to greater trust, understanding, and targeted support.

5.4 Areas for future research

In addition to researching the assessment and intervention tools asdiscussed above, this study identified that the following areas are important for further research:

- How can Black autistic children be prepared for interactions with the police? How can autism awareness be raised among law enforcement?
- Identifying autism traits in high-functioning Black males with autism: What are the main factors that lead to diagnosis? How can early identification and support be improved?
- The experiences of the diagnostic process, e.g., with CAMHS
- The experiences of BCPs from broader socioeconomic backgrounds
- The experiences of Black Caribbean fathers who have children with autism
- The experiences of BCPs who have daughters with autism
- Prevalence rates and age of diagnosis among Black Caribbean children in the UK
- The experiences of parents from other Black and diverse cultures in the UK

5.4.1 Theoretical transferability and further research

The ESAT is a theoretical model that presents the experiences of BCPs who have children with autism. While it is specific to their experiences, the model's foundations have the potential to apply to the experiences of parents of children with autism and SEND more broadly, e.g., key aspects of stage 2- the activation stage that focuses on experiences of parents within systems have been highlighted in many UK studies. The Lamb Report (2009), a government study investigating the effectiveness of SEND systems in the UK, found that parents frequently had negative and stressful experiences with local authorities and schools. Many felt unheard and dismissed, often leading to feelings of blame.

More recent studies have similarly reported that parents found professionals within SEND systems, including local authority officers, as lacking the necessary knowledge and training to handle situations with professionalism and respect (Cullen & Lindsey, 2019; Adams et al., 2018).

Additionally, other aspects of the ESAT, particularly stage 1- the identification and adaptation stage- have been identified in other studies that focus on the emotional wellbeing of parents who have children with autism and how they have adapted to their child's diagnosis. Research, such as Gray's study on the 'felt and enacted stigma of parents of children with high-functioning autism' (2002) and Makino and colleagues' study on parent experiences of autism diagnosis (2021), have also identified a range of emotions that parents experience following an autism diagnosis, as well as their responses to the perceived or 'enacted' judgments of others as also seen in the ESAT. These similarly included feelings of guilt, shame, self-blame, and grief.

The structure of the ESAT also has scope for theoretical transferability due to the universality of its key stages. It can be argued that all parents experience an identification and adaptation stage, a stage where they interact more with systems, and work to access resources, and a stage of reflection and planning for the future. The ESAT is centred around the development of super-advocacy, a crucial skill for BCPs to attain. However, there may be nuances or different factors that are more prominent in the journeys of parents from other cultural groups.

An example of this can be seen in Theara and Abbot's study (2015), which found that a group of South Asian parents in the UK primarily viewed autism through a medical lens rather than adopting the more social model of disability and difference. The authors discuss that this perspective aligns with the high level of respect and trust that exists for the medical field and profession in South Asian communities. Understanding autism in this way provided a familiar and culturally relevant framework, enabling parents to address their child’s needs with greater openness and confidence. This is closely linked to stage 1 of the ESAT, especially ‘adapting, accepting, and embracing child’s differences’ and ‘reconciling and overcoming stigma’, as it provided the empowerment needed to take action and seek support and understanding for their child. This begins to demonstrate the potential transferability of the ESAT’S foundations to the journeys of parents from different cultural groups, while still emphasising the key concepts relevant for each of them. The Theara and Abbot finding is important for non-medical professionals who work with families, such as educational psychologists, as it highlights the need to be aware and sensitive to the reasons behind a medical understanding of autism. It can also aid in building trust and understanding around the social model of disability and difference WITH THE South Asian community and outline its significance within the context of current UK SEND systems.

Overall, this example illustrates the potential for the ESAT to be used to explore the experiences and journeys of parents from different demographics, especially less-represented groups, to improve cultural responsiveness and the outcomes of children and their families from diverse backgrounds

5.5 Dissemination

A central aim of this research was to understand the journeys of BCPs who have children with autism to improve experiences and develop culturally responsive practice. To do this, their stories and the derived theory and recommendations must be shared. The plan for dissemination of this research includes:

- Presenting findings at researcher's Educational Psychology Service (EPS)
- Presenting research at educational psychology conferences (e.g., The BPS and Association of Educational Psychologists (AEP) annual conferences)
- Producing a leaflet summarising the main findings and recommendations of the research for Educational Psychology Services, local authority Children services, and CAMHS autism assessment centres
- Offering to present findings at educational psychology services focusing on locations with high Black Caribbean populations
- Sharing the research with national autism organisations and charities, including the National Autistic Society and offering to present findings

- Contacting organisations, charities and parent groups that support Black Caribbean families
- Sharing research findings with professionals and researchers in the educational psychology and related fields with an interest in autism, ethnicity and culture
- Share research findings and recommendations with the participants
- Publish the findings in relevant journals, including the British Journal of Educational Psychology

It is also important to consider how the disseminated information will be implemented to bring about the required change. It is suggested that equipping schools and services with the tools to develop parent-school and service partnerships be a priority. With improved relationship, trust and shared vision, recommendations can more effectively be applied. Due to the evidence-base around narrative approaches and CoP as discussed, it is proposed that educational psychologists take the lead in gaining enhanced competency in these areas. This will enable them to model and provide training, consultation and systemic support in the implementation and embedding of these practices. The researcher aims to start by developing this locally and continuing professional development on narrative therapy and seeking more insight into CoP. Piloting projects and building practice-based evidence will support the sharing and facilitating of other EPs doing the same. Disseminating new evidence and knowledge more widely will be a part of this. It is also intended that the dissemination of this research as outlined above will also spark similar initiatives in EPS’ and other services for the same reasons.

5.6 Limitations of research

This research was a small-scale qualitative study involving six participants, all of whom were mothers. They were passionate about raising awareness of autism and had similar levels of education. To further develop this research, it will be beneficial to explore the experiences of fathers and BCPs from broader socioeconomic backgrounds. Additionally, since most of the participants' children were boys, there is more to learn about parents with daughters. Hearing from professionals and organisations who support BCP families, including charities and support groups, will provide useful information to learn what things have worked in practice and those that have not. A broad spectrum of perspectives will develop the richness and depth of this research area, which can further be used to improve practice and experiences. Additionally, there were no UK studies on this topic at the time of writing, so a culturally and statistically similar population group was used to conduct the literature review. This group was found to be appropriate, with a number of parallels found with the current research. Nevertheless, as more research is conducted with BCPs in the UK, researchers will be able to conduct literature reviews on the same population group.

6 CONCLUSION

This research contributed to a small but growing area of research on autism, culture, and ethnicity and is the first UK study to exclusively explore the experiences of Black Caribbean Parents who have children with autism. The grounded 'essential super-advocacy' theory provides a snapshot into the strength, persistence and resilience BCPs need to advocate for their children with autism. The participants, motivated by love and the desire to see their children thrive, became learners, gathered support and overcame complex and difficult feelings to ensure their children's needs were recognised and supported. Also to ensure that professionals and adults working with their children can see their strengths and share positive aspirations for them. These participants were self-aware and had a good understanding of the things that support them and their children. They were also outward thinking and used their developed advocacy skills to equip and support other parents. They have enabled the opportunity to develop specific support to improve outcomes and the wellbeing of Black Caribbean children who have autism and their families. This research also stresses that greater partnership, understanding and cultural awareness by systems will be crucial. It also provides recommendations and potential targeted interventions to achieve this.

6.1 Researcher reflections

I aimed to derive a theory that conveyed the shared journeys of BCPs without compromising the complexities and dimensions within them. This was not an easy task, but once the core concept of 'essential super-advocacy' was named, and it was recognised that this was not a static concept but one of process and development, it became easier. One of the most rewarding aspects of this research was meeting and interviewing the participants. I was struck by their willingness to be open and vulnerable, which I believe allowed the ESAT to have the depth that it does. It was an honour to be entrusted with their stories, which can now provide the research world and relevant systems with unique insight to bring about positive and much-needed change.

REFERENCES

American Psychological Association. (n.d.). Ethnicity. In APA dictionary of psychology. Retrieved March 25, 2025, from [https://dictionary.apa.org/ethnicity]

A. Missouri Sherman-Peter. (2022, March 24). *The Legacy of Slavery in the Caribbean and the Journey Towards Justice*. United Nations. https://www.un.org/en/un-chronicle/legacy-slavery-caribbean-and-journey-towards-justice

American Psychiatric Association. (2022). Diagnostic and statistical manual of mental disorders. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR)*, *5*(5). https://doi.org/10.1176/appi.books.9780890425787

Anello, A., Reichenberg, A., Luo, X., Schmeidler, J., Hollander, E., Smith, C. J., Puleo, C. M., Kryzak, L. A., & Silverman, J. M. (2009). Brief Report: Parental Age and the Sex Ratio in Autism. *Journal of Autism and Developmental Disorders*, *39*(10), 1487–1492. https://doi.org/10.1007/s10803-009-0755-y

Atewologun, D., Cornish, T., & Tresh, F. (2018). *Unconscious bias training: An assessment of the evidence for effectiveness*.

Bandura, A. (1977). *Social Learning Theory*. Englewood Cliffs, N.J. : Prentice Hall ; Toronto : Prentice-Hall of Canada.

Berry, J. W. (2013). *Cross-cultural psychology : research and applications*. Cambridge Univ. Press.

Berry, J. W., Poortinga, Y. H., Breugelmans, S. M., Chasiotis, A., & Sam, D. L. (2009). *Cross-Cultural Psychology*. https://doi.org/10.1017/cbo9780511974274

Bhaskar, R. (2008). *A Realist Theory of Science*. Verso Books. (Original work published 1975)

Bhopal, K., & Chapman, T. K. (2018). International minority ethnic academics at predominantly white institutions. *British Journal of Sociology of Education*, *40*(1), 98–113. https://doi.org/10.1080/01425692.2018.1486698

Blumer, H. (1969). *Symbolic Interactionism: Perspective and Method*. University of California Press.

Bourdieu, P., (1973). *Cultural Reproduction and Social Reproduction*. London: Tavistock 178

Braun, V., & Clarke, V. (2006). Using Thematic Analysis in Psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Sage.

British Psychological Society. (2021). Code of ethics and conduct. *British Psychological Society*. https://doi.org/10.53841/bpsrep.2021.inf94

Brown, I., Mortier, K. (2021). Watch Your Tone": The Experiences of African American Parents of Students on the Autism Spectrum in Parent-School Partnerships. *Multicultural Education,* 28, (1) 31-38.

Bureau, U. C. (2020, June 10). *Black High School Attainment Nearly on Par With National Average*. The United States Census Bureau. https://www.census.gov/library/stories/2020/06/black-high-school-attainment-nearly-on-par-with-national-average.html

Byrne, A., Warren, A., Joof, B., Johnson, D., Casimir, L., Hinds, C., & …Griffiths, S. (2011). 'A powerful piece of work': African and Caribbean men talking about the 'tree of life'. *Context,* 117, 40–45.

Charmaz, K. (2014). Grounded Theory in Global Perspective. *Qualitative Inquiry*, *20*(9), 1074–1084. https://doi.org/10.1177/1077800414545235

Charmaz, K., & Thornberg, R. (2020). The Pursuit of Quality in Grounded Theory. *Qualitative Research in Psychology*, *18*(3), 1–23. https://doi.org/10.1080/14780887.2020.1780357

Children's Commissioner. (2022). *Family and Its Protective Effect Part 1 of the independent family review 2*. https://assets.childrenscommissioner.gov.uk/wpuploads/2022/12/cc-family-and-its-protective-effect-part-1-of-the-independent-family-review-.pdf

Coard, B. (2021). *How the West Indian child is made educationally sub-normal in the British school system* (5th ed.). Mcdermott Publishing. (Original work published 1971)

Cooper, C. W., Riehl, C. J., & Hasan, A. L. (2010). Leading and Learning with Diverse Families in Schools: Critical Epistemology amid Communities of Practice. *Journal of School Leadership*, *20*(6), 758–788. https://doi.org/10.1177/105268461002000604

Cooper, J., & Shriberg, D. (2021). *Social justice, anti-racism and school psychology: Reconciling with our past to build an equitable future*.

Corbin, J., & Strauss, A. (2015). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (4th ed.). Sage.

Crenshaw, K. (1989). *Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics*. Chicago Unbound. http://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8?utm_source=chicagounbound.uchicago.edu%2Fuclf%2Fvol1989%2Fiss1%2F8&utm_medium=PDF&utm_campaign=PDFCoverPages

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. London: Sage Publications.

Dababnah, S., Shaia, W. E., Campion, K., & Nichols, H. M. (2018). “We Had to Keep Pushing”: Caregivers’ Perspectives on Autism Screening and Referral Practices of Black Children in Primary Care. *Intellectual and Developmental Disabilities*, *56*(5), 321–336. https://doi.org/10.1352/1934-9556-56.5.321

Denzin, N. K., & Lincoln, Y. S. (2011). *The SAGE Handbook of Qualitative Research* (4th ed.). Sage.

Department for Education. (2015). *Special educational needs and disability code of practice: 0 to 25 years Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities*. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf

Department for Education. (2022). *Outcomes by ethnicity in schools in England Topic Note 2022 Central Analysis Division, Department for Education*. https://assets.publishing.service.gov.uk/media/628f39518fa8f5039a1bd625/Ethnicity_Schools_Note.pdf

Department for Education . (2023, February 7). *Permanent exclusions*. Www.ethnicity-Facts-Figures.service.gov.uk. https://www.ethnicity-facts-figures.service.gov.uk/education-skills-and-training/absence-and-exclusions/permanent-exclusions/latest/

Desai, M. U., Divan, G., Wertz, F. J., & Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder. *Transcultural Psychiatry*, *49*(3-4), 613–637. https://doi.org/10.1177/1363461512447139

Duberley, J., Johnson, P., & Cassell, C. (2012). Philosophies Underpinning Qualitative Research. *Qualitative Organizational Research: Core Methods and Current Challenges*, 15–34. https://doi.org/10.4135/9781526435620.n2

Edwardraj, S., Mumtaj, K., Prasad, J. H., Kuruvilla, A., & Jacob, K. S. (2010). Perceptions about intellectual disability: a qualitative study from Vellore, South India. *Journal of Intellectual Disability Research*, *54*(8), 736–748. https://doi.org/10.1111/j.1365-2788.2010.01301.x

Embeita, C., & Birch, S. (2024). Social justice in educational psychology: Understanding and practice. *Educational and Child Psychology*, *41*(2), 77–107. https://doi.org/10.53841/bpsecp.2024.41.2.77

Equal Justice Initiative. (2022). *The Transatlantic Slave Trade | Equal Justice Initiative*. Equal Justice Initiative Reports. https://eji.org/report/transatlantic-slave-trade/

Farragher, R., & Coogan, D. (2018). Constructivist Grounded Theory: Recognising and Raising the Voice of Young People with Experience of Care Systems. *Child Care in Practice*, 1–12. https://doi.org/10.1080/13575279.2018.1521377

Feinberg, E., Silverstein, M., Donahue, S., & Bliss, R. (2011). The Impact of Race on Participation in Part C Early Intervention Services. *Journal of Developmental & Behavioral Pediatrics*, *32*(4), 284–291. https://doi.org/10.1097/dbp.0b013e3182142fbd

Fergus, S., & Zimmerman, M. A. (2005). ADOLESCENT RESILIENCE: A Framework for Understanding Healthy Development in the Face of Risk. *Annual Review of Public Health*, *26*(1), 399–419. https://doi.org/10.1146/annurev.publhealth.26.021304.144357

Fernell, E., Eriksson, M. A., & Gillberg, C. (2013). Early diagnosis of autism and impact on prognosis: a narrative review. *Clinical Epidemiology*, *5*, 33–43. https://doi.org/10.2147/clep.s41714

Fiveways, & Discovery Research. (2022). *Evaluating the Growing Minds service in Hackney Final report*. https://cityandhackneycamhs.org.uk/wp-content/uploads/2023/03/Growing-Minds-Evaluation-Report-2022.pdf

Ford, C. L., & Airhihenbuwa, C. O. (2010). Critical Race Theory, Race Equity, and Public Health: Toward Antiracism Praxis. *American Journal of Public Health*, *100*(1), 30–35. https://doi.org/10.2105/ajph.2009.171058

Freeman, B. J. (1997). Guidelines for evaluating intervention programs for children with autism. *Journal of Autism and Developmental Disorders*, *27*(6), 641–651. https://doi.org/10.1023/a:1025850715183

George, R. E., Thornicroft, G., & Dogra, N. (2015). Exploration of cultural competency training in UK healthcare settings: A critical interpretive review of the literature. *Diversity & Equality in Health and Care*, *12*(3). https://doi.org/10.21767/2049-5471.100037

German, M. (2013). Developing our cultural strengths: Using the “Tree of Life” strength-based, narrative therapy intervention in schools, to enhance self-esteem, cultural understanding and to challenge racism. *Educational and Child Psychology*, *30*(4), 75–99. https://doi.org/10.53841/bpsecp.2013.30.4.75

Giddens, A. (1993). *New rules of sociological method : a positive critique of interpretative sociologies*. Stanford University Press.

Glaser, B. (2017). *Discovery of Grounded Theory*. Routledge. (Original work published 1967)

GOV.UK. (2014). *Children and Families Act 2014*. Legislation.gov.uk. https://www.legislation.gov.uk/ukpga/2014/6/contents

GOV.UK. (2023, August 10). *Stop and search*. Www.ethnicity-Facts-Figures.service.gov.uk. https://www.ethnicity-facts-figures.service.gov.uk/crime-justice-and-the-law/policing/stop-and-search/latest/#:~:text=stop%20and%20searches-

Gray, D. E. (2002). “Everybody just freezes. Everybody is just embarrassed”: felt and enacted stigma among parents of children with high functioning autism. *Sociology of Health & Illness*, *24*(6), 734–749. https://doi.org/10.1111/1467-9566.00316

HCPC. (2008). *Standards of conduct, performance and ethics for practitioner psychologists.* London: Health Professions Council (HCPC)

Hetherington, S.A. Year (2012). "They think we don't have the knowledge:" The Intersection of Autism and Race. [Doctor of Philosophy, University of Rochester Rochester].

Hill, R. (1949). *Families Under Stress*. Praeger.

Hill, R. (1958). Sociology of Marriage and Family Behaviour, I945-56. *Current Sociology*, *7*(1), 1–33. https://doi.org/10.1177/001139215800700102

Hong, A., & Singh, J. (2019). Contextualizing the social and structural constraints of accessing autism services among single Black female caregivers in Atlanta, Georgia. *Int J Child Health Hum Dev*, *12*(4), 365–378.

Hughes, G. (2013). Finding a voice through “The Tree of Life”: A strength-based approach to mental health for refugee children and families in schools. *Clinical Child Psychology and Psychiatry*, *19*(1), 139–153. https://doi.org/10.1177/1359104513476719

Janice Gauthier Weber. (2011). *Individual and family stress and crises*. Los Angeles Sage.

Jarquin, V. G., Wiggins, L. D., Schieve, L. A., & Van Naarden-Braun, K. (2011). Racial Disparities in Community Identification of Autism Spectrum Disorders Over Time; Metropolitan Atlanta, Georgia, 2000–2006. *Journal of Developmental & Behavioral Pediatrics*, *32*(3), 179–187. https://doi.org/10.1097/dbp.0b013e31820b4260

John-Baptiste, A. (2021, May 20). The black children wrongly sent to “special” schools in the 1970s. *BBC News*. https://www.bbc.co.uk/news/uk-57099654

Jones., A. (2012). *African American Parents’ Experience Accessing Support Services for Their Autistic Child.* [Doctor of Philisophy, Walden University*].*

Kao, G., & Thompson, J. S. (2003). Racial and Ethnic Stratification in Educational Achievement and Attainment. *Annual Review of Sociology*, *29*(1), 417–442. https://doi.org/10.1146/annurev.soc.29.010202.100019

Kieran O'Hagan. (2001). *Cultural competence in the caring professions*. Jessica Kingsley Publishers.

Legislation.gov.uk. (2010). *Equality Act 2010*. Legislation.gov.uk; Gov.uk. https://www.legislation.gov.uk/ukpga/2010/15/contents

Lewis, E. M., Dababnah, S., Hollie, K. R., Kim, I., Wang, Y., & Shaia, W. E. (2022). The creator did not give me more than I can handle: Exploring coping in parents of Black autistic children. *Autism*, 136236132110708. https://doi.org/10.1177/13623613211070865

Liptak, G. S., Benzoni, L. B., Mruzek, D. W., Nolan, K. W., Thingvoll, M. A., Wade, C. M., & Fryer, G. E. (2008). Disparities in Diagnosis and Access to Health Services for Children with Autism: Data from the National Survey of Children??s Health. *Journal of Developmental & Behavioral Pediatrics*, *29*(3), 152–160. https://doi.org/10.1097/dbp.0b013e318165c7a0

Lock, S. (2016). The Tree of Life: A review of the collective narrative approach. *EDUCATIONAL PSYCHOLOGY RESEARCH and PRACTICE*, *2*(1), 2–20. https://repository.uel.ac.uk/download/9a01f61aefbe271759157e9c379b73f6bab51c371893ea193952123c55b4db57/402604/Educational%20Psychology%20Research%20and%20Practice%202016%2003%20Lock.pdf

Lopez, E. C., & Bursztyn, A. M. (2013). FUTURE CHALLENGES AND OPPORTUNITIES: TOWARD CULTURALLY RESPONSIVE TRAINING IN SCHOOL PSYCHOLOGY. *Psychology in the Schools*, *50*(3), 212–228. https://doi.org/10.1002/pits.21674

Lovelace, T., Robertson, R., & Tamayo, S. (2018). *Experiences of African American Mothers of Sons with Autism Spectrum Disorder: Lessons for Improving Service Delivery*.

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., Giarelli, E., Morrier, M. J., Nicholas, J. S., Pinto-Martin, J. A., Shattuck, P. T., Thomas, K. C., Yeargin-Allsopp, M., & Kirby, R. S. (2009). Racial/Ethnic Disparities in the Identification of Children With Autism Spectrum Disorders. *American Journal of Public Health*, *99*(3), 493–498. https://doi.org/10.2105/ajph.2007.131243

Marshall, C., & Rossman, G. B. (2006). *Designing qualitative research*. Sage.

Matsumoto, D. R. (2001). *The handbook of culture & psychology*. Oxford University Press.

Mbire-Chigumba, E., Hartwell, B., Faupel, A. and Dhillon, J. (2024). Rethinking and reviewing the use of culturally responsive practices for promoting young people's sense of school belonging. A systematic review. *Educational Psychology Research and Practice.* 10 (1), pp. 1-34. https://doi.org/10.15123/uel.8yv9v

Mc Cubbin, H. I., & Sussman, M. B. (2014). *Social Stress and the Family*. https://doi.org/10.4324/9781315804439

McConkey, R. (2020). The rise in the numbers of pupils identified by schools with autism spectrum disorder (ASD): a comparison of the four countries in the United Kingdom. *Support for Learning*, *35*(2), 132–143. https://doi.org/10.1111/1467-9604.12296

McCubbin, H. I., & Patterson, J. M. (1983). The Family Stress Process. *Marriage & Family Review*, *6*(1-2), 7–37. https://doi.org/10.1300/j002v06n01_02

McCubbin, H. I., Patterson, J. M., & Sussman, M. B. (2014). *Social stress and the family : advances and developments in family stress theory and research*. Routledge.

McNair., C. (2015). *My Life, My Son, Our Journey: Case Studies Examining Roles of African-American Parents of Autistic Males.* [Doctor of Educational, University of Redlands].

Mead, G. (1932). *The Philosophy of the Present*. La Salle, IL: Open Court Press.

Mead, G. (1934). *Mind, Self, and Society*. University of Chicago Press.

Mead, G. (1938). *The philosophy of the act*. The University Of Chicago Press.

Morgan., E. (2021). *The Developmental Process of Parent Advocacy for Black Mothers of Children on the Autism Spectrum.* [Doctor of Philosophy, University of California].

Morgan, E. H., & Stahmer, A. C. (2020). Narratives of single, black mothers using cultural capital to access autism interventions in schools. *British Journal of Sociology of Education*, *42*(1), 48–65. https://doi.org/10.1080/01425692.2020.1861927

Morse, J. M. (2000). Determining Sample Size. *Qualitative Health Research*, *10*(1), 3–5. https://doi.org/10.1177/104973200129118183

Mortier, K. (2018). Communities of Practice: a Conceptual Framework for Inclusion of Students with Significant Disabilities. *International Journal of Inclusive Education*, *24*(3), 1–12. https://doi.org/10.1080/13603116.2018.1461261

Mortier, K., Hunt, P., Leroy, M., Van de Putte, I., & Van Hove, G. (2010). Communities of practice in inclusive education. *Educational Studies*, *36*(3), 345–355. https://doi.org/10.1080/03055690903424816

Murry, V. M., Butler-Barnes, S. T., Mayo-Gamble, T. L., & Inniss-Thompson, M. N. (2018). Excavating new constructs for family stress theories in the context of everyday life experiences of Black American families. *Journal of Family Theory & Review, 10*(2), 384–405. https://doi.org/10.1111/jftr.12256

Ncube, N. (2006). The Tree of Life Project: Using narrative ideas in work with vulnerable children in Southern Africa. *The International Journal of Narrative Therapy and Community Work*, 1, 3-16.

O’Nions, E., Petersen, I., Joshua E.J. Buckman, Charlton, R. A., Cooper, C., Corbett, A., Happé, F., Manthorpe, J., Richards, M., Saunders, R., Zanker, C., Mandy, W., & Stott, J. (2023). Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. *The Lancet Regional Health*, *29*(1), 100626–100626. https://doi.org/10.1016/j.lanepe.2023.100626

Oliver, D. G., Serovich, J. M., & Mason, T. L. (2005). Constraints and Opportunities with Interview Transcription: Towards Reflection in Qualitative Research. *Social Forces*, *84*(2), 1273–1289. https://doi.org/10.1353/sof.2006.0023

Oxley, L. (2016). An examination of Interpretative Phenomenological Analysis (IPA). *Educational and Child Psychology*, *33*(3), 55–62. https://doi.org/10.53841/bpsecp.2016.33.3.55

Parham, S., Ibrahim, J., & Foxwell, K. (2021). Could the Tree of Life Model Be a Useful Approach for UK Mental Health Contexts? *Narrative Works*, *9*(2), 44–70. https://doi.org/10.7202/1076525ar

Pearson, J., & Meadan, H. (2018). *African American Parents’ Perceptions of Diagnosis and Services for Children with Autism* (pp. 17–32). Education and Training in Autism and Developmental Disabilities.

Perepa, P. (2014). Cultural basis of social “deficits” in autism spectrum disorders. *European Journal of Special Needs Education*, *29*(3), 313–326. https://doi.org/10.1080/08856257.2014.908024

Peters, M. and Massey, G. C. (1983). *Mundane extreme environmental stress in family stress theories.* Marriage &Amp; Family Review, 6(1-2), 193-218. https://doi.org/10.1300/j002v06n01_10

Peters, M. and Massey, G. C. (1983). Mundane extreme environmental stress in family stress theories. Marriage &Amp; Family Review, 6(1-2), 193-218. https://doi.org/10.1300/j002v06n01_10

Prithvi Perepa, & Jordan, R. (2019). *Autism, ethnicity and culture : working with children and families from minority communities*. Jessica Kingsley Publishers.

Quinn-Lunny., M. (2021). *A Phenomenological Study: Lived Experiences of Black Parents Through the Autism Spectrum Disorder Identification Process* [Doctor of Philosophy, Florida Atlantic University].

Ravindran, N., & Myers, B. J. (2012). Cultural Influences on Perceptions of Health, Illness, and Disability: A Review and Focus on Autism. *Journal of Child and Family Studies*, *21*(2), 311–319. https://doi.org/10.1007/s10826-011-9477-9

Roberts, N., & Bolton, P. (2023). Educational outcomes of Black pupils and students. *Commonslibrary.parliament.uk*. https://commonslibrary.parliament.uk/research-briefings/cbp-9023/

Roman-Urrestarazu, A., van Kessel, R., Allison, C., Matthews, F. E., Brayne, C., & Baron-Cohen, S. (2021). Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England. *JAMA Pediatrics*, *175*(6), e210054. https://doi.org/10.1001/jamapediatrics.2021.0054

Rosino, M. (2016). ABC-X Model of Family Stress and Coping. *Encyclopedia of Family Studies*, 1–6. https://doi.org/10.1002/9781119085621.wbefs313

Rowley, J., Rajbans, T., & Markland, B. (2020). Supporting parents through a narrative therapeutic group approach: a participatory research project. *Educational Psychology in Practice*, *36*(2), 115–132. https://doi.org/10.1080/02667363.2019.1700349

Rubin, L., Geller, R. J., Nodvin, J., Marcus, M., Howett, M., & Merrick, J. (2012). Break the Cycle of environmental health disparities in vulnerable children. *International Journal on Disability and Human Development*, *11*(4). https://doi.org/10.1515/ijdhd-2012-0054

Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical Child Psychology and Psychiatry*, *17*(2), 229–245. https://doi.org/10.1177/1359104510365203

Sakata, E. (2024). A self-reflective framework for culturally responsive educational psychology practice. *Educational Psychology in Practice*, *40*(3), 1–38. https://doi.org/10.1080/02667363.2024.2325925

Sebastian, K. (2019). Distinguishing Between the Strains Grounded Theory: Classical, Interpretive and Constructivist. *Journal for Social Thought*, *3*(1).

Service, R. W. (2008). Book Review: Corbin, J., & Strauss, A. (2008). Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory (3rd ed.). Thousand Oaks, CA: Sage. *Organizational Research Methods*, *12*(3), 614–617. https://doi.org/10.1177/1094428108324514

Slade, G. (2014). *Diverse perspectives: The challenges for families affected by autism from Black, Asian and Minority Ethnic communities*. The national autistic society.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis*. SAGE.

Social Mobility Commission. (2023). *State of the Nation 2023: People and Places*. GOV.UK. https://www.gov.uk/government/publications/state-of-the-nation-2023-people-and-places

Solorzano, D. G., & Bernal, D. D. (2001). Examining Transformational Resistance Through a Critical Race and Latcrit Theory Framework. *Urban Education*, *36*(3), 308–342. https://doi.org/10.1177/0042085901363002

Strand, S. (2011). The limits of social class in explaining ethnic gaps in educational attainment. British Educational Research Journal, 37 (2), 197–229. http://doi.org/10.1080/014

Strand, S. (2015). Ethnicity, deprivation and educational achievement at age 16 in England: Trends over time (DFE Research Report 439B). London: Department for Education.

Strand, S., & Lindorff, A. (2018). *Ethnic disproportionality in the identification of Special Educational Needs (SEN) in England: Extent, causes and consequences*.

Strand, S., & Lindorff, A. (2021). Ethnic Disproportionality in the Identification of High-Incidence Special Educational Needs: A National Longitudinal Study Ages 5 to 11. *Exceptional Children*, *87*(3), 344–368. https://doi.org/10.1177/0014402921990895

Strauss, A. L., & Corbin, J. M. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). SAGE Publications.

Theara, G., & Abbott, D. (2015). Understanding the experiences of South Asian parents who have a child with autism. *Educational and Child Psychology*, *32*(2), 47–56. https://doi.org/10.53841/bpsecp.2015.32.2.47

Tie, Y. C., Birks, M., & Francis, K. (2019). Grounded Theory research: a Design Framework for Novice Researchers. *SAGE Open Medicine*, *7*(1), 1–8. NCBI. https://doi.org/10.1177/2050312118822927

Urcia, I. A. (2021). Comparisons of Adaptations in Grounded Theory and Phenomenology: Selecting the Specific Qualitative Research Methodology. *International Journal of Qualitative Methods*, *20*(1), 1–14. https://doi.org/10.1177/16094069211045474

Vierck, E., & Silverman, J. M. (2014). Brief Report: Phenotypic Differences and their Relationship to Paternal Age and Gender in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *45*(6), 1915–1924. https://doi.org/10.1007/s10803-014-2346-9

Wallace, D., & Joseph-Salisbury, R. (2021). How, still, is the Black Caribbean child made educationally subnormal in the English school system? *Ethnic and Racial Studies*, *45*(8), 1426–1452. https://doi.org/10.1080/01419870.2021.1981969

Walsh, F. (2002). Bouncing Forward: Resilience in the Aftermath of September 11. *Family Process*, *41*(1), 34–36. https://doi.org/10.1111/j.1545-5300.2002.40102000034.x

Walsh, F. (2003). Family Resilience: A Framework for Clinical Practice. *Family Process*, *1*. https://doi.org/10.1111/famp.2003.42.issue-1

Wenger, E. (1998). Communities of Practice and Social Learning Systems. *Organization*, *7*(2), 225–246. https://doi.org/10.1177/135050840072002

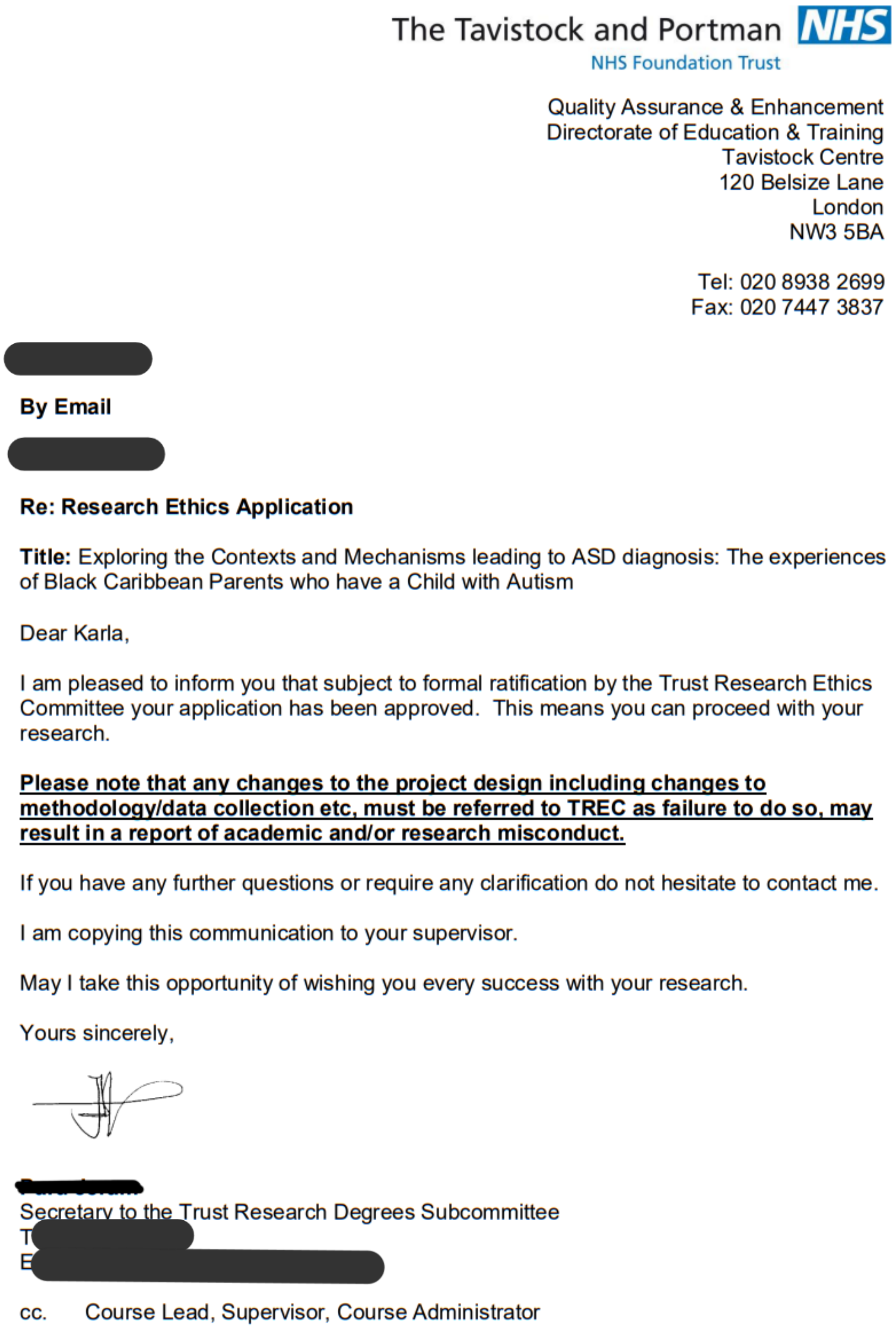
Wenger-Trayner, E., & Wenger-Trayner, B. (2015). *Introduction to communities of practice*. Wenger-Trayner.com. https://wenger-trayner.com/introduction-to-communities-of-practice/

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology & Health*, *15*(2), 215–228. https://doi.org/10.1080/08870440008400302

Yosso, T. J. (2005). Whose culture has capital? A critical race theory discussion of community cultural wealth. *Race Ethnicity and Education*, *8*(1), 69–91. https://doi.org/10.1080/1361332052000341006

APPENDICES

Appendix 1: Ethics application approval



The Tavistock and Portman NHS
NHS Foundation Trust

Quality Assurance & Enhancement
Directorate of Education & Training
Tavistock Centre
120 Belsize Lane
London
NW3 5BA

Tel: 020 8938 2699
Fax: 020 7447 3837

[redacted]

By Email

[redacted]

Re: Research Ethics Application

Title: Exploring the Contexts and Mechanisms leading to ASD diagnosis: The experiences of Black Caribbean Parents who have a Child with Autism

Dear Karla,

I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved. This means you can proceed with your research.

Please note that any changes to the project design including changes to methodology/data collection etc, must be referred to TREC as failure to do so, may result in a report of academic and/or research misconduct.

If you have any further questions or require any clarification do not hesitate to contact me.

I am copying this communication to your supervisor.

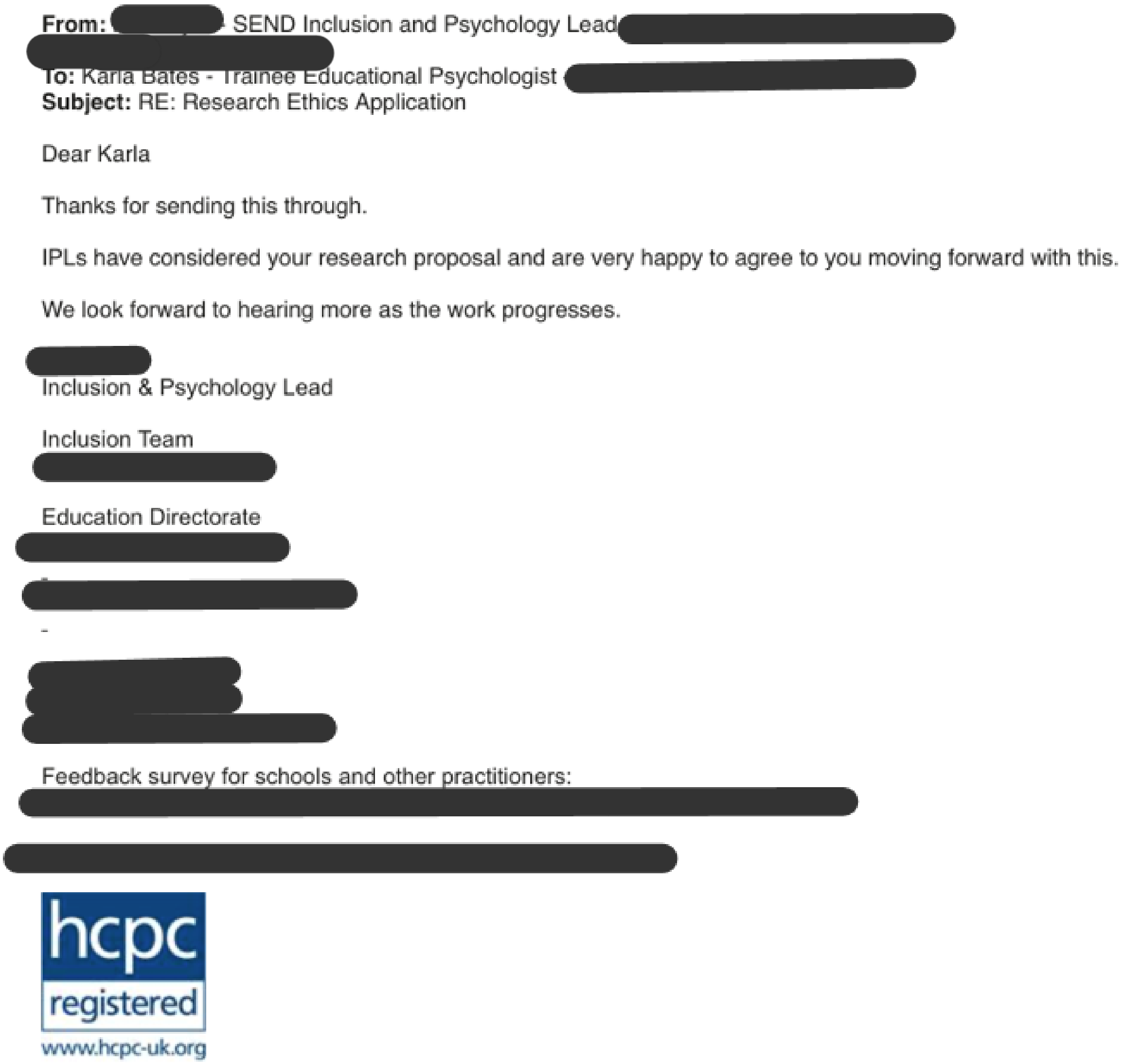
May I take this opportunity of wishing you every success with your research.

Yours sincerely,

[redacted]
Secretary to the Trust Research Degrees Subcommittee
T[redacted]
E[redacted]

cc. Course Lead, Supervisor, Course Administrator

Appendix 2: LA approval of research



From: [redacted] - SEND Inclusion and Psychology Lead [redacted]
[redacted]
To: Karla Bates - Trainee Educational Psychologist [redacted]
Subject: RE: Research Ethics Application

Dear Karla

Thanks for sending this through.

IPLs have considered your research proposal and are very happy to agree to you moving forward with this.

We look forward to hearing more as the work progresses.

[redacted]
Inclusion & Psychology Lead

Inclusion Team
[redacted]

Education Directorate
[redacted]
[redacted]
-

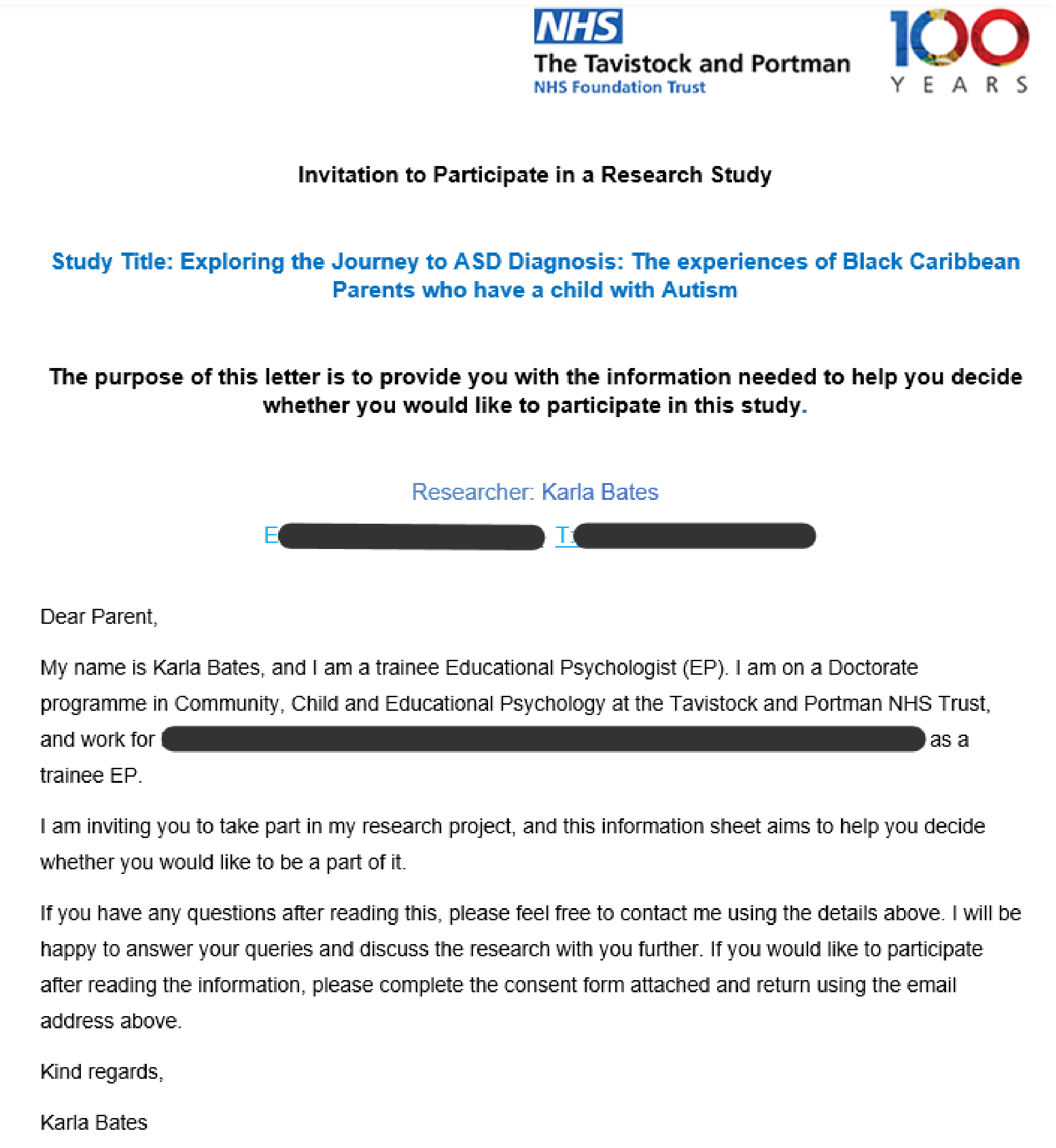
[redacted]

Feedback survey for schools and other practitioners:
[redacted]

[redacted]

hcpc
registered
www.hcpc-uk.org

Appendix 3: Research information letter



NHS
The Tavistock and Portman
NHS Foundation Trust
100 YEARS

Invitation to Participate in a Research Study

Study Title: Exploring the Journey to ASD Diagnosis: The experiences of Black Caribbean Parents who have a child with Autism

The purpose of this letter is to provide you with the information needed to help you decide whether you would like to participate in this study.

Researcher: Karla Bates

E[redacted] T[redacted]

Dear Parent,

My name is Karla Bates, and I am a trainee Educational Psychologist (EP). I am on a Doctorate programme in Community, Child and Educational Psychology at the Tavistock and Portman NHS Trust, and work for [redacted] as a trainee EP.

I am inviting you to take part in my research project, and this information sheet aims to help you decide whether you would like to be a part of it.

If you have any questions after reading this, please feel free to contact me using the details above. I will be happy to answer your queries and discuss the research with you further. If you would like to participate after reading the information, please complete the consent form attached and return using the email address above.

Kind regards,

Karla Bates

Who am I?

I am a second year Trainee Educational Psychologist who has an interest in autism and issues of diversity and culturally aware practice in psychology. I have a background in teaching and mental health therapies for children and young people.

What is this research about?

This research project aims to explore the experiences of Black Caribbean parents who have a child with autism, particularly focusing on the processes involved in identification and diagnosis and the parent's views and ideas around autism.

My research has been approved by Tavistock and Portman Trust Research Ethics Committee (TREC). It follows the standard of research ethics set by the British Psychological Society.

Why is this research being done?

This research aims to develop knowledge and understanding about the experiences of Black Caribbean parents on the journey towards their child's diagnosis. There is currently a lack of research on autism in Minority Ethnic Groups, so this project aims to specifically identify aspects of the experiences of black Caribbean children and families to inform and support culturally aware practice in autism identification processes.

Current research also says different things about the prevalence of autism in black Caribbean Children, with some research suggesting there is an under identification, and others suggesting an over identification. This research aims to explore these findings through the views and experiences of parents.

Why have you been invited to take part?

I am hoping to interview parents of black Caribbean heritage who have a child diagnosed with Autism and who:

- ✓ Were born in the Caribbean or the UK
- ✓ Are the primary carer of the child diagnosed with autism (ASD) since birth
- ✓ Are willing to talk about experiences related to having a child with autism
- ✓ Has English as their primary language
- ✓ Autism is the primary diagnosis their child has received
- ✓ Child with autism can access the mainstream curriculum

If all of the above apply to you, I would like to invite you to participate in this research project.

What will Participation Involve?

Participation involves an informal interview with me. Before the interview, I will go through this information sheet with you again and you can ask any questions related to the study. I will also check if you are still happy to take part. The maximum time the interview will take is 60mins. If, at any point during the interview, you would like to stop, you can do so at any time.

I will take notes during the interview, and the interview will also be audio recorded. Recordings will be stored on a digital recorder and transferred to a password secure computer. It will then be transcribed (typed up word for word) and deleted after this is complete. When transcribed all real names will be replaced with made-up names.

What is the time frame?

Interviews will be arranged at a time convenient for you and will take place between March and June 2021. If you wish, a summary of the findings will be shared with you by July 2022. If you have any questions beforehand you may ask them at any point.

What are the benefits of taking part?

By taking part in this study, you will have the opportunity to share your experiences, views and opinions on Autism and the processes of assessment and diagnosis. This will help contribute towards the gap in research and allow professionals to hear the voices of black Caribbean parents to inform best practice when working with children and families from black Caribbean backgrounds.

Will the information I provide be confidential?

Yes, your privacy and safety will be respected at all times. Under the Data Protection Act (2018), all data (including interview recordings and transcripts) will be kept in a safe and secure place.

As the participant group is small however, there is a chance that people who have good knowledge of you might recognise some features even when anonymised. Additionally, In the case information being shared about anyone being in harm to self and/or others, I will have to share this with the relevant agencies to safeguard those involved.

This research is independent of any treatment and or services you might be accesses through the Tavistock and Portman or Essex County Council and will have no impact on them.

What are the possible risks of taking part?

There are no anticipated risks. There is a chance that recalling experiences about the journey to your child's diagnosis might be upsetting. If you feel distressed at any stage of the interview, you will be able to have a break or stop the interview. I will also check to see if you are feeling comfortable and If any difficult thoughts or feeling have arisen. I will offer advice about services that can provide support.

Do I have to take part?

Participating in this research is entirely voluntary, and you do not have to take part unless you would like to.

What will happen if I don't want to carry on with the study?

You are free to withdraw from the study at any time and to have your data removed from the study up until the point your data is being analysed. You can do this without any explanation, disadvantage, or consequence. At this point in time, your data will have influenced the findings and will be difficult to extract.

What if there is a problem?

If there are any problems you can contact me, or if there are any queries about the conduct of this research please contact:

[redacted] Trust Quality Assurance Officer

[redacted]

Contact Details

If you would like further information or have any questions about this research, please do not hesitate to contact me using these details:

[redacted]

E:[redacted]

T:[redacted]

If you would like to take part, please read, and sign the attached consent form and return to my email address above.

Thank you for taking the time to read this information.

The Tavistock and Portman NHS
NHS Foundation Trust

Consent to Participate in a Research Study

Title: Exploring the Journey to ASD Diagnosis: The experiences of Black Caribbean Parents who have a child with Autism

I have read the information letter relating to the above research that I have been asked to participate in and have been given a copy to keep. The purpose of the research has been explained to me and I have had the opportunity to discuss the details and ask questions about this information.

I understand that:

- I have been asked to participate in a 1hr interview that will be audio recorded
- My involvement and the data from this research will remain strictly confidential and all names will be changed
- Only the researchers involved in the study will have access to the data
- In the case of information being shared about someone being in danger to themselves or others, confidentiality might be breached to safeguard those involved
- That findings will be included in a research paper and shared with professionals and other parents.
- That I have the right to withdraw from the study at any point before analysis of data without disadvantage to myself and without having to give a reason.

I agree with the above statements and consent to participate in this study:

Participant's Name (BLOCK CAPITALS) …………………………………………………………

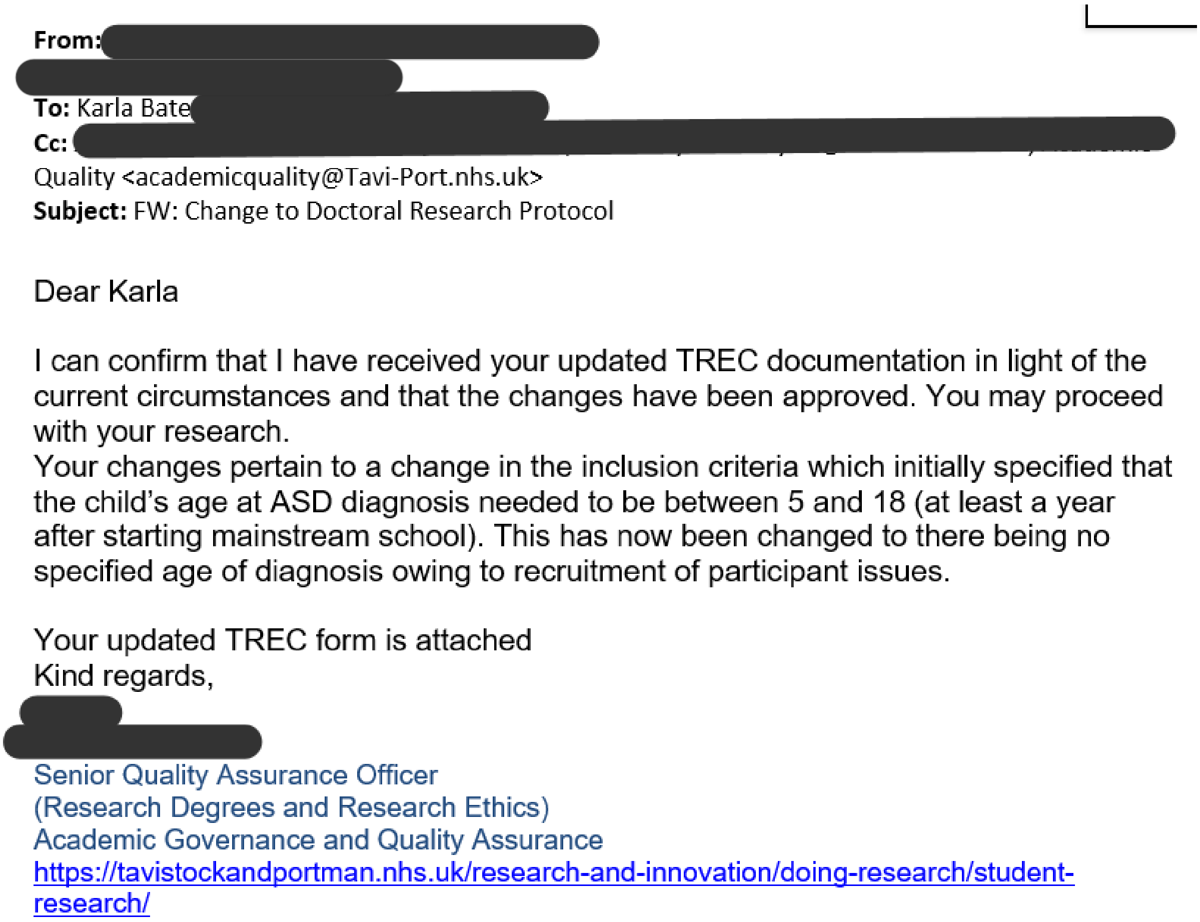
Participant's Signature ………………………………………………………………………………

Researcher's Name (BLOCK CAPITALS) …………………………………………………………

Researcher's Signature ……………………………………………………………………………

Date: ………………………

Appendix 4: TREC amendment approval



From: [redacted]

To: Karla Bate[redacted]
Cc: [redacted] Quality <academicquality@Tavi-Port.nhs.uk>
Subject: FW: Change to Doctoral Research Protocol

Dear Karla

I can confirm that I have received your updated TREC documentation in light of the current circumstances and that the changes have been approved. You may proceed with your research.
Your changes pertain to a change in the inclusion criteria which initially specified that the child's age at ASD diagnosis needed to be between 5 and 18 (at least a year after starting mainstream school). This has now been changed to there being no specified age of diagnosis owing to recruitment of participant issues.

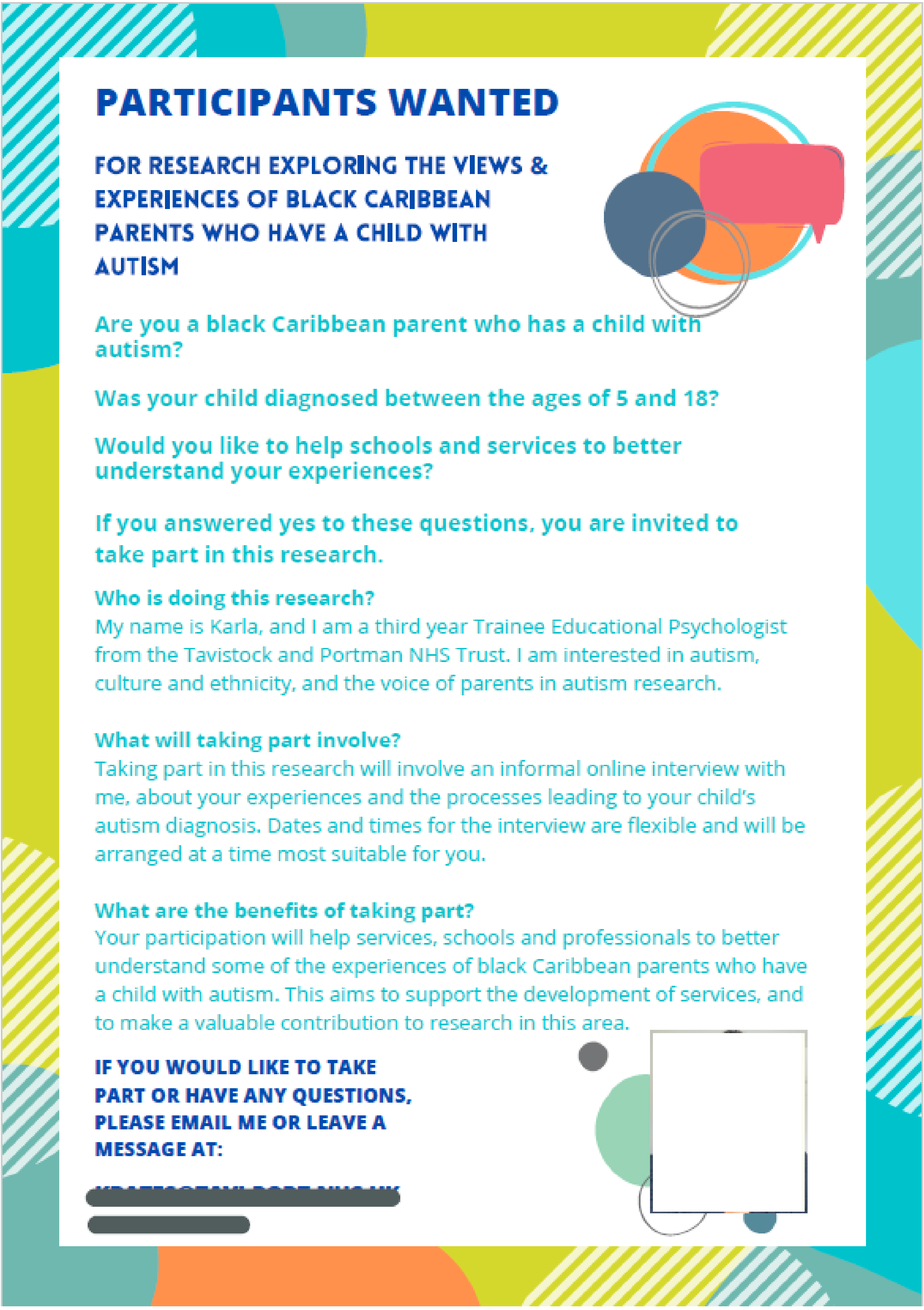
Your updated TREC form is attached
Kind regards,
[redacted]
Senior Quality Assurance Officer
(Research Degrees and Research Ethics)
Academic Governance and Quality Assurance
https://tavistockandportman.nhs.uk/research-and-innovation/doing-research/student-research/

Appendix 5: Participant inclusion criteria

Parents of black Caribbean heritage who have a child diagnosed with Autism and who:

- ✓ Were born in the Caribbean or the UK
- ✓ Are the primary carer of the child diagnosed with autism (ASD) since birth
- ✓ Are willing to talk about experiences related to having a child with autism
- ✓ Has English as their primary language
- ✓ Autism is the primary diagnosis their child has received

Appendix 6: Research information poster



PARTICIPANTS WANTED

FOR RESEARCH EXPLORING THE VIEWS & EXPERIENCES OF BLACK CARIBBEAN PARENTS WHO HAVE A CHILD WITH AUTISM

Are you a black Caribbean parent who has a child with autism?

Was your child diagnosed between the ages of 5 and 18?

Would you like to help schools and services to better understand your experiences?

If you answered yes to these questions, you are invited to take part in this research.

Who is doing this research?
My name is Karla, and I am a third year Trainee Educational Psychologist from the Tavistock and Portman NHS Trust. I am interested in autism, culture and ethnicity, and the voice of parents in autism research.

What will taking part involve?
Taking part in this research will involve an informal online interview with me, about your experiences and the processes leading to your child's autism diagnosis. Dates and times for the interview are flexible and will be arranged at a time most suitable for you.

What are the benefits of taking part?
Your participation will help services, schools and professionals to better understand some of the experiences of black Caribbean parents who have a child with autism. This aims to support the development of services, and to make a valuable contribution to research in this area.

IF YOU WOULD LIKE TO TAKE PART OR HAVE ANY QUESTIONS, PLEASE EMAIL ME OR LEAVE A MESSAGE AT:

[redacted]

Appendix 7: Semi-structured interview questions

Main Questions

- Tell me a bit about yourself and your family
- When was it first identified that your child might have an additional need?
- How did you first become aware of these additional needs?
- Were you the first to notice, or did another person bring them to your attention?
- What did you (or) they notice?
- What was your (or) their understanding of these things?
- What happened after these things were identified? How did you feel about this?
- What were your experiences with the processes of identification, assessment and diagnosis e.g. who was involved, timeframes, and engagement with professionals?
- How were the reasons for diagnosis explained to you? How did you feel about this?
- What support, advice, and information were you given during diagnosis?
- Did you tell others about the diagnosis at the time?
- How do you think that autism is understood and perceived in the black Caribbean community?
- Did you find anything helpful about the process of diagnosis? If so what?
- Is there anything that you think would have made it better?
- How have things been since receiving the diagnosis? Has anything changed?
- What would you say you have learnt on this journey so far? E.g., about yourself, your child, or anything else.

Appendix 8: MAXqda code system

Appendix 8: MAXqda coding system

Code System	Frequency
	1005
Identification and Adaptation	0
Noticing Difference	4
Not knowing what autism is	9
Early signs of 'difference'	22
Parenting criticism	6
Not trying to speak for all black Caribbean people	1
Lack of awareness	1
Seeing difference as character	1
Professionals identifying difference	8
Not all about milestones	1
Nursery identifying autism and referring	1
Setting putting support in place	1
Gut Instinct	2
Signs of difference	1
Family identifying difference	1
Summer baby	1

Internal Processes	0
Cultural views and attitudes	19
Parenting criticism (1)	6
How race impacts parenting/parenting to protect	2
Family/cultural stigma	2
Shame	7
Fear of label	6
Conflict around seeking a diagnosis	5
Stigma and Family reaction to Autism news	9
Male family reaction	1
Fear of Autism and society	1
Internalised discrimination	3
denial	1
Denial due to lack of knowledge	2
Managing grief and disappointment	3
Grief	2
Language to use with black Caribbean families	1
shame/defence/confusion on how to respond	5
Invisible disability	1
Label/diagnosis as help	1
Gut Instinct (1)	2
Socially isolating (1)	1

Where does autism come from	2
Parent reaction to diagnosis	1
Accepting Embracing Difference	0
Parent doing own research	4
Embracing your child	1
Diagnosis as clarity	1
Adapting with Systemic Support	4
Help from services (some relevant here)	19
Diagnosis not an excuse	3
Setting putting support in place (1)	1
Adapting Individually (without systemic support)	2
Drawing from own skills	0
Adapting and learning	1
Helping children while want to develop their independence	1
parent self preservation	1
Parent teaching child important skills	10
Helping the child understand Autism	5
Family not much help	0
Not being able to leave kids with family	2
Help educating family- especially the father	5

Mother father Views	1
Organising life around needs	0
Capacity to adapt	1
Parent making changes to help symptoms	1
Parent controlling environments	4
Parent adapting to early differences	9
Understanding child	1
Not knowing but still adapting	7
Normalising early differences	1
Difficulties increasing at home	1
Trying to establish boundaries at home	1
Regretting ways of managing behaviour	2
No boundaries at dad's	1
Lack of support, isolation	1
Socially isolating	1
Activation Advocacy	0
Problems and Challenges	0
Additional Parent views	0
importance of the right school that meets the child’s needs	1
preparation and transition (1)	2

Early intervention key	1
Private assessment (1)	2
Transition to adulthood (1)	1
Challenge and adapting to later differences	2
Organisational dysfunction	0
'incestuous relationship between schools/governors/organisation'	2
Unstable school system	4
Very long waiting times	3
Local Authority mistakes/failings and impact	5
Local Authority mistakes re confidentiality	2
Diminished trust of the Local Authority	2
Misinformation and lies from professionals	1
Assessment takes 2 plus years	1
Treatment of parent and parent-school relationship	0
Parent seeing it from the teacher’s point of view	1
Taking child out of the school (1)	5
Parent information sharing with school	1
Mismatched priorities for son (School/parent)	2
Lack of information sharing between parent and school	3
Difficult relationship with Teachers/Headteachers	6
Raising autism assessment with school/setting	3

Schools not taking parent's desires/concerns seriously	10
Parent voice as governor not heard	1
Parent expertise not valued by services or schools	1
Seeing parents as equals	1
Treatment of child at school	0
Staff lack of knowledge and inexperience	0
Teachers attitudes about autism	1
Schools not supporting autism well	1
Professionals not knowing the process as well as the parent	1
School not managing low level disruption	1
Disabilities not being understood	4
Teacher not knowing how to manage daughter's differences	1
Exclusions managed moves and PRU/Catalyst	0
diagnosis as access to resources	3
PRU	9
More Tribunals (1)	2
Permanent exclusion pain for the parent	2
fighting nonstop	9
Partner	1
Incident leading to permanent exclusion	1
I actually think he might be autistic- last minute urgency	5

Fixed term, managed moves and permanent exclusions	8
last minute urgency	8
School stages	0
Things went 'downhill' from secondary school	2
Causes of behaviour deterioration	0
Broken dreams as cause of behaviour deterioration	2
Understanding of why things went down hill at secondary school	0
Teacher's mistreatment/ not knowing how to work with son (1)	3
'his behaviour gradually rising to the top'	1
Lack of information sharing with parents	11
Lack of Information sharing between schools	2
Given too much leeway due to difficulties at home	2
Leeway cause of behavior deterioration	1
Primary school	1
Positive reputation	2
Thrived at primary school/skills attributes	3
When changes and difficulties started	1
Event that highlighted differences	1
rules applied more harshly	1

Incidents at primary school	1
Schools' interpretation vs Parent interpretation	4
Not seeing child's needs as SEND	0
reason for behaviour escalation	3
Disagreement about best school for child	1
Bullying was the cause of behaviour getting her into trouble	1
Trying to discover root of difficulties- not dyslexic	1
Not putting support or recommendations in place	0
Recommendations not put in place/ being made (+)	7
Not disruptive equals no help	6
Excuses made for not using EHCP properly	2
Difficulty getting a statement	1
Similar issues sports club not understanding disabilities	5
EP involvement and EHCP- advice not taken	1
Reasonable adjustments not made or prioritised	2
Outrageous objections by school	2
School refusing or reluctant to do referral	7
Parent found out the need of the child	1
Strategy to prevent permanent exclusion	1
Reason given for refusing to do assessment	1

	Differential treatment and attitudes due to race	14
	Low expectations from professionals	1
	inequity of the system	1
	Child forgotten	3
	low expectations at school	2
	Teachers treatment of black children with additional needs	6
	Culture of exclusion	2
	School describing problems but not asking questions	11
	You're black, you're trouble you're gone	1
	Internally excluded or 'othered'	3
	Teacher's mistreatment/ not knowing how to work with son	5
	Underhanded punishment from school that child senses	1
	Can't raise race AND disability	1
	Couldn’t fight racism as well	1
	Adultification	4
	'Chosen behaviour'	4
	Primary school's handling of early incident	1
	Understanding of changing behaviours	2
	Mother's poor health impacting children	1
	Temporary new home/new environment	1

School holding on to behaviour that let the school down	1
response to differential treatment	0
Black child vulnerability	8
Teachers not wanting to help but just exclude	3
Not knowing the language to use with a young black kid with ASD	3
Psychiatrist not knowing how to deal with ASD child	1
Translating reports and explain diagnosis	1
Black vulnerability when excluded	1
Black male vulnerability	7
Preparation to Defend and Advocate	5
System is a minefield	2
Parent raising EHCP leading to ASD assessment	1
Diagnosis &/or EHCP as a protected status	6
Diagnosis as an 'excuse'	3
Parent seeking formal learning about autism	3
Other parents	4
Parent helping other parents	5
researching autism	1
Helpful projects and services	2
couldn’t keep fighting (2)	1

Advocate	1
Fighting the permanent exclusion decision	1
Tribunal experiences	8
fighting for the impossible- from PRU back to same school	1
You have to go the extra mile to be listened to	1
Respected by tribunal	4
More Tribunals	2
School armed themselves with lots of legal representation	1
Willing to go through tribunal to defend daughter	1
Calling daughter rude	1
Parent tried the 'non-confrontational' route unsuccessfully	1
fighting back to eliminate ableism	1
Parent teaching organisation how to treat child by fighting	3
Parent aspirations and cheerleading	7
Parent making decisions about schooling	3
Parent as SEND advocate	3
Educating Tribunal Panels	2
Take him out of school	1
Parent learning as you go along	1
Importance of relationship/ parent with teachers	1

parents trying to work with school	1
Private assessment	2
Appeal process	1
couldn’t keep fighting (1)	1
Humanising son	1
Supportive Practice	2
Pro's and cons of the PRU	6
Additional agency intervention	1
EHCP fast process at PRU	2
The educational psychologists, was very good	1
Personalised school pathway	1
Good relationship with SENCO helps	2
SENCO Supportive	3
Schools good practice	2
Support on apprenticeship	1
Helpful projects and services (1)	4
The signs of a good school	5
Outcomes and Outlook	0
Outcomes Child	4
Limited options for child	4

School reintroduction unsuccessful- Experience angered child	2
Not in school/ further education	1
Temporary support/short lived	2
Services ending at 18	1
Struggle impact on child self-esteem	2
Self esteem	2
The ownership of the label	1
Partner struggling with diagnosis	1
Children depressed with the diagnosis	2
We had the appointment with the psychiatrist, it was just awful	2
Convincing the child	1
Diagnosis and Services	1
Intellectual but not socially developed yet	1
Diagnosed autism and adhd	1
Lack of after care	2
New school	1
Parent removing child from school	1
Taking child out of the school	5
Child success	3
Parent supporting child’s interests and ambitions	2
excelling in talent area	9

Against all odds	5
Tried strategies to get him to school	1
Outcomes Parent	1
Parent own diagnosis	4
Support system	5
Self discovery	6
Dangers of internalised discrimination	2
CAHMS should suggest its genetic	1
'It was horrendous' Health Wellbeing	9
Impact on siblings	1
parent unable to train child due to own disabilities	1
couldn’t keep fighting	1
Financial impact	8
Outlook- questions, thoughts, hopes, concerns about the future	0
Parent skills/knowledge	1
Child safety not being flagged up	2
Lack of representation on LA panel	1
Black professional representation	6
Help educating family- especially the father (1)	5
More warning about the difficulties families might face	1
Creating a positive autistic black identity	12

Showing black people are thought about in terms of role models	3
Parent worry about the future of children	1
Parent aspirations and cheerleading (1)	7
Co production- using parent expertise	1
The black community un utilised as a resource	1
lack of representation in the professional sphere	2
What would be important to families	3
help one group helps many	1
Bringing things out into the open	1
Black vulnerability when excluded (1)	1
Being beacons and pioneers	3
Personalising care and professional help e.g. Inner city	1
Difficulty with girl diagnosis	3
Schools not recognising Autism in girls	1
Schools recognising autism in girls	1
Advice to other parents	3
How to take up advice	1
Find a tribe	1
black representation of parents with children with autism	1
limited options for the future	1
Temporary support/short lived (1)	2
lack of support after 18	2

Transition to adulthood	1
How to tell child about diagnosis	3
aspiration	1
Preparing Black children for life outside school	1
Provisions specifically for parents of Black backgrounds	1
preparation and transition	2
having voice heard	1
About the Family	0
Parenting styles	0
Mum's parenting style/character traits	6
Dad not engaging	6
Dad's parenting	6
Few boundaries, very few rules and very few expectations	1
Autism terminology	3
Preferred terminology	1
Problematic terminology	1
Family Background	6
Parent	5
Parent family structure	2
Interest in research	3
Parent education/learning	6

Parent Cultural background	6
Helpful background/experiences	3
Parent skills/style	3
Parent occupation	3
Parent age	2
Children	2
Additional Needs	6
Identifying child struggles but not knowing what to do	2
Parent struggling with grief and loss	1
Girls/ Daughter different signs	8
Possible reasons for academic difficulties	1
unknown reasons for academic difficulties	1
Still struggling with undiagnosed ASD	1
Didn't tell anybody she was hearing voices	1
Hearing voices went away	1
Selective Mutism	1
Gender Identity	3
Gender identity finding resolve	1
School were very supported when daughter was bullied	2
Helpful response from GP re gender identity	1
Parent reaching out to for support for daughter re gender	1

Difficulties with puberty, gender and undiagnosed ASD	1
School adapting to daughters gender identity needs	1
Age of diagnosis	3
Introducing the children	10
Comparing son and daughter	4
Learning from first sibling	1
Characteristics/personality/presentations	6
Complications due to undiagnosed autism	3
Opportunities	2
Differing opportunities	2
Child hobbies/Interests	4
Son	2
Older child less attention	1
Not in college or education	2
Anxiety looks like aggression	2
School experience having negative impact on future	2
Miscellaneous	0
Doubles &already categorised	0
miscellaneous	0
Trying to get him taken away from dad due to safety	1
Surprise there were so many minority Ethic Groups	2

	Visual stress needs not being met/misunderstood at school	1
	Parent not picking up early signs of visual stress	1
	Traumatic prior experiences with professionals	4
	Support system	1
	Helpful projects and services (2)	4
	Okay, so I am one of four children four girls, black Caribbean.	0
	introducing	1
	Birth experiences	2
	Homeschool (1)	2
	parent's experiences of school	1
	Black Caribbean People aware of Autism	1

Appendix 9: Comparative review mind maps

STAGE 1
Identification and adaptation stage

The parent

Hetherington (2012)
Hazards and Obstructions to Obtaining Diagnosis:
- 'Lack of Knowledge and privileged knowledge'

Pearson and Meadan (2018)
Barriers to obtaining a diagnosis:

- Unfamiliar Disability- parents and their families largely unaware of autism

Hong and Sing (2019)
Late Diagnosis:
- Lack of Autism Awareness

Brown & Mortier (2021)
Unfamiliar with autism

Jones (2021)
Parental stressors:
-Parents lacked awareness of autism, as did doctors and HCPs

- Limited autism awareness
- Internal dissonance
- Isolation and/or self reliance

1. Noticing difference

Describes the people and systems involved in identifying difference in the early years, and the initial responses to it.

- Health professionals/early years settings attribute difference to potential autism and/or neurodiversity and refer for assessment.
- Family- response and understanding of difference relates to cultural beliefs and autism awareness levels.
- Parent- Initially unsure or unaware of 'differences' due to limited knowledge of autism or have 'a gut feeling' that there might be additional or different needs.

Family/Community Response

Hetherington (2012)
Theme 1: 'Acknowledging the Impact of Autism'- **Coping with others' reactions**
- Excluded from family events
- Stigmatised by family for child's 'inappropriate' behaviours
- Family suggesting they are ineffective parents/ blamed behaviour on parents
- Parents 'kicked out of church' due to child's behaviours

Professionals

Pearson & Meadan (2018)
Facilitators to obtaining diagnosis- **Concerns and referrals initiated by others**
- Special education teachers
- Primary care providers

Debabnah et al., (2018)
Facilitators to early screenings and referrals
- Some healthcare workers who listened and made the necessary referrals for screening and early intervention. The children of caregivers who had attentive primary care workers were all diagnosed before the age of 4.

Family/Community Response (continued)

Debabnah et al., (2018)
Theme 3: 'Stigma in the Black Community'- **Resistance from family members**
- Prayer and discipline suggested as the best approach
- Some parents reported that some friends and family from the black community encouraged them to seek developmental assessment for their child

Lovelace et al., (2018)
Theme 3: 'Family Dynamics'- **Family Interpretations**
- Shame and blaming the parent
- Lack of autism understanding
- Spiritual advice/ 'Pray it away'

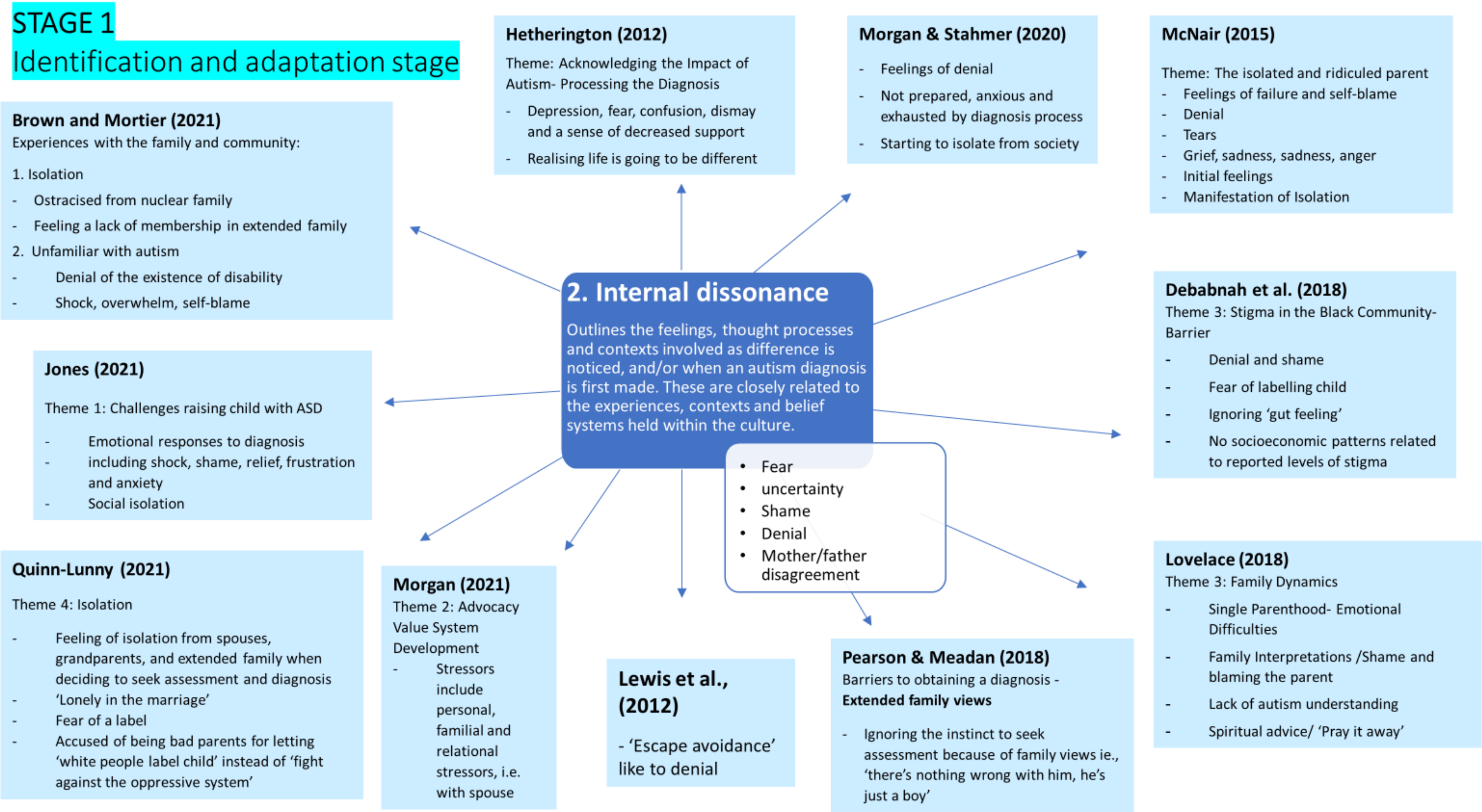
Theme 4;' Community Dynamics'- **Community interpretations**
- Negative interpretation
- Bad parenting assumed
- less understanding and acceptance

Pearson & Meadan (2018)
Theme: Barriers to obtaining a diagnosis- **Extended family views**
- Avoid the subject
- Dismissive 'There's nothing wrong with him' or 'he's a boy'

Morgan and Starmer (2020)
Grandparent encourages mother to make a referral

Brown and Mortier (2021)
Experiences with the family and community
Theme 1: Isolation
- Ostracised from nuclear family
- Feeling lack of membership in extended family
- Lack of inclusion in the community
- Some drew strength from the church community

Quinn-Lunny (2021)
Theme 4: Isolation- **Judgement and lack of understanding**
- Temptation to 'hide' child to avoid judgement



STAGE 1
Identification and adaptation stage

Brown and Mortier (2021)
Experiences with the family and community:

1. Isolation
- Ostracised from nuclear family
- Feeling a lack of membership in extended family

2. Unfamiliar with autism
- Denial of the existence of disability
- Shock, overwhelm, self-blame

Hetherington (2012)
Theme: Acknowledging the Impact of Autism- Processing the Diagnosis
- Depression, fear, confusion, dismay and a sense of decreased support
- Realising life is going to be different

Morgan & Stahmer (2020)
- Feelings of denial
- Not prepared, anxious and exhausted by diagnosis process
- Starting to isolate from society

McNair (2015)
Theme: The isolated and ridiculed parent
- Feelings of failure and self-blame
- Denial
- Tears
- Grief, sadness, sadness, anger
- Initial feelings
- Manifestation of Isolation

2. Internal dissonance

Outlines the feelings, thought processes and contexts involved as difference is noticed, and/or when an autism diagnosis is first made. These are closely related to the experiences, contexts and belief systems held within the culture.

- Fear
- uncertainty
- Shame
- Denial
- Mother/father disagreement

Jones (2021)

Theme 1: Challenges raising child with ASD
- Emotional responses to diagnosis
- including shock, shame, relief, frustration and anxiety
- Social isolation

Debabnah et al. (2018)
Theme 3: Stigma in the Black Community- Barrier
- Denial and shame
- Fear of labelling child
- Ignoring 'gut feeling'
- No socioeconomic patterns related to reported levels of stigma

Quinn-Lunny (2021)

Theme 4: Isolation
- Feeling of isolation from spouses, grandparents, and extended family when deciding to seek assessment and diagnosis
- 'Lonely in the marriage'
- Fear of a label
- Accused of being bad parents for letting 'white people label child' instead of 'fight against the oppressive system'

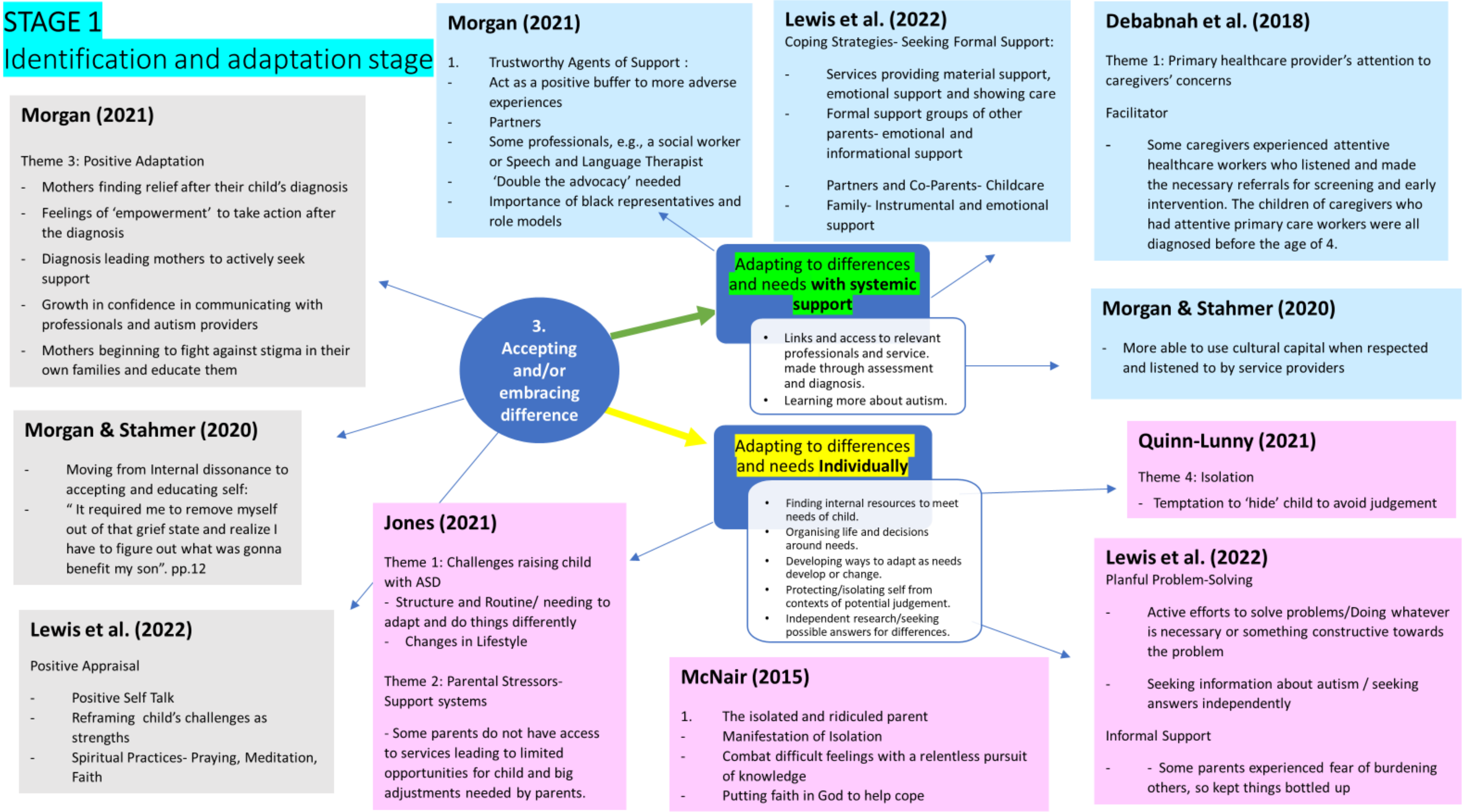
Morgan (2021)
Theme 2: Advocacy Value System Development
- Stressors include personal, familial and relational stressors, i.e. with spouse

Lewis et al., (2012)

- 'Escape avoidance' like to denial

Pearson & Meadan (2018)
Barriers to obtaining a diagnosis - **Extended family views**
- Ignoring the instinct to seek assessment because of family views ie., 'there's nothing wrong with him, he's just a boy'

Lovelace (2018)
Theme 3: Family Dynamics
- Single Parenthood- Emotional Difficulties
- Family Interpretations /Shame and blaming the parent
- Lack of autism understanding
- Spiritual advice/ 'Pray it away'



STAGE 1
Identification and adaptation stage

Morgan (2021)

Theme 3: Positive Adaptation

- Mothers finding relief after their child's diagnosis
- Feelings of 'empowerment' to take action after the diagnosis
- Diagnosis leading mothers to actively seek support
- Growth in confidence in communicating with professionals and autism providers
- Mothers beginning to fight against stigma in their own families and educate them

Morgan & Stahmer (2020)

- Moving from Internal dissonance to accepting and educating self:
- " It required me to remove myself out of that grief state and realize I have to figure out what was gonna benefit my son". pp.12

Lewis et al. (2022)

Positive Appraisal

- Positive Self Talk
- Reframing child's challenges as strengths
- Spiritual Practices- Praying, Meditation, Faith

3. Accepting and/or embracing difference

Morgan (2021)

1. Trustworthy Agents of Support :
- Act as a positive buffer to more adverse experiences
- Partners
- Some professionals, e.g., a social worker or Speech and Language Therapist
- 'Double the advocacy' needed
- Importance of black representatives and role models

Lewis et al. (2022)

Coping Strategies- Seeking Formal Support:

- Services providing material support, emotional support and showing care
- Formal support groups of other parents- emotional and informational support
- Partners and Co-Parents- Childcare
- Family- Instrumental and emotional support

Debabnah et al. (2018)

Theme 1: Primary healthcare provider's attention to caregivers' concerns

Facilitator

- Some caregivers experienced attentive healthcare workers who listened and made the necessary referrals for screening and early intervention. The children of caregivers who had attentive primary care workers were all diagnosed before the age of 4.

Adapting to differences and needs **with systemic support**

- Links and access to relevant professionals and service. made through assessment and diagnosis.
- Learning more about autism.

Morgan & Stahmer (2020)

- More able to use cultural capital when respected and listened to by service providers

Adapting to differences and needs **Individually**

- Finding internal resources to meet needs of child.
- Organising life and decisions around needs.
- Developing ways to adapt as needs develop or change.
- Protecting/isolating self from contexts of potential judgement.
- Independent research/seeking possible answers for differences.

Quinn-Lunny (2021)

Theme 4: Isolation

- Temptation to 'hide' child to avoid judgement

Jones (2021)

Theme 1: Challenges raising child with ASD

- Structure and Routine/ needing to adapt and do things differently
- Changes in Lifestyle

Theme 2: Parental Stressors- Support systems

- Some parents do not have access to services leading to limited opportunities for child and big adjustments needed by parents.

McNair (2015)

1. The isolated and ridiculed parent
- Manifestation of Isolation
- Combat difficult feelings with a relentless pursuit of knowledge
- Putting faith in God to help cope

Lewis et al. (2022)

Planful Problem-Solving

- Active efforts to solve problems/Doing whatever is necessary or something constructive towards the problem
- Seeking information about autism / seeking answers independently

Informal Support

- Some parents experienced fear of burdening others, so kept things bottled up

STAGE 2
Activation advocacy stage

4. Activation

Events and experiences with systems (mainly schools and local authorities) that activate the necessity to persistently advocate for child. This is mainly set across compulsory education age.

Treatment of parent
- Questions and queries not taken seriously
- Labelled ‘intimidating’ or ‘trouble’ for showing concern
- Requests for assessment ignored

Treatment of child at school
- Differential treatment
- Recommendations and support not put in place
- School staff lack of autism awareness
- Not recognising needs as SEND
- Adultification and ‘chosen behaviour’
- Internal exclusions
- Exclusions, managed moves, and PRUs

Organisational dysfunction
- Inflexible
- Biased processes
- Misinformation
- Inexperienced staff

‘Activation’ in the studies includes experiences with the healthcare system, school districts and educational settings.

Lovelace (2018)

Theme 1: Racial Discrimination

- Covert and overt racism in medical and educational spaces
- Directed at the mother and/or child

- Mother's knowledge about child dismissed or not believed

- “Each stage, from diagnosis to receiving proper services, was fraught with difficulty”. pp.8

Theme 2: Complex Collaboration

- Overwhelmed with negative experiences and emotions
- Child’s needs not being met
- Difficult Interactions with school Personnel and Service Providers
- Child’s needs not being met
- Outnumbered and not listened to at meetings

Brown and Mortier (2021)

Experiences while navigating school communities:

1. Disempowering Experiences

- Poor implementation/ quality of service
- Tense communication and lack of cultural awareness
- Errors and difficulties caused by school district/ requests ignored, stalled, shelved

Hetherington (2012)

Hazards and obstructions that mothers and children must overcome:

Microaggressions and actual aggression (towards parents and children)
- Hostile treatment, ignored, pressured to accept ‘mentally retarded’ or ‘emotionally disturbed label, given incorrect information, Physical aggression and harsh treatment against children

School Assumptions about the mothers and children
- Parents treated as dangerous and aggressive, Children not seen for their gifts and strengths

Debabnah et al. (2018)

Barrier to diagnosis:

- Primary healthcare workers not attentive to the concerns of some caregivers- ‘let’s wait and see’ approach.

These children were all diagnosed between the ages of 4 and 8 (later than those who had more attentive HCPs).

- Theme 2: Perceived racism and poor caregiver-provider interactions- Barrier

- Majority of caregivers reported unease with interactions and perceived this as racism
- Incorrect assumptions made about the caregiver
- Some thought that it was due to the reputation of the neighbourhood that they were from or their economic status.

Morgan & Stahmer (2020)

Parent and child experiences-

- Mothers told they are difficult and adversarial in the IEP process
- Not listened to
- Settings not seeing child for their strengths
- School refuse to refer child for assessment and want to exclude them

- Example of crises breaking internal dissonance and leading to action

Morgan (2021)

Theme 2: Advocacy Value System Development

- Active resiliency needed to navigate oppositional agencies, policies and people
- Stressors create the development of advocacy
- Stressors include being ignored and dismissed by professionals compounded by personal, familial, financial and relational stressors, i.e. with spouse

Quinn-Lunny (2021)

Theme 2: Face Many Challenges

- School Districts preferring to label black child with ADHD or ‘behavioural problems’ unless child is non-verbal
- Difficulties getting interventions
- Paediatricians failing to screen for ASD at assessment/ perceived as prejudice or cultural barrier
- Parent ignored and dismissed
- Lack of knowledge and understanding about autism by paediatricians, therapists and educators
- Professionals thinking because a child is verbal, they cannot have autism
- Lack of resources and evidence-based treatments
- Difficulties getting interventions
- Teachers not trained in ASD
- Concern about the impact of delays and rejection on child

Theme 3: Unequal Treatment of parent seeking ASD identification

- Not listened to, rushed, or treated unfairly by professionals
- Stereotyped assumptions made,
- Judged as ‘welfare mums’
- Parents needing to push against biases
- Professionals more likely to just see ‘behavioural issues’ rather than autism
- Parental passion seen as ‘anger.’
- Difficulty trusting institutions because of biases

Jones (2021)

Theme 2: Parental Stressors:

- Doctors and HCPs having little knowledge and understanding of autism

Pearson & Meadan (2018)

Barriers to obtaining a diagnosis:

- HCPs Ignoring Parental concerns

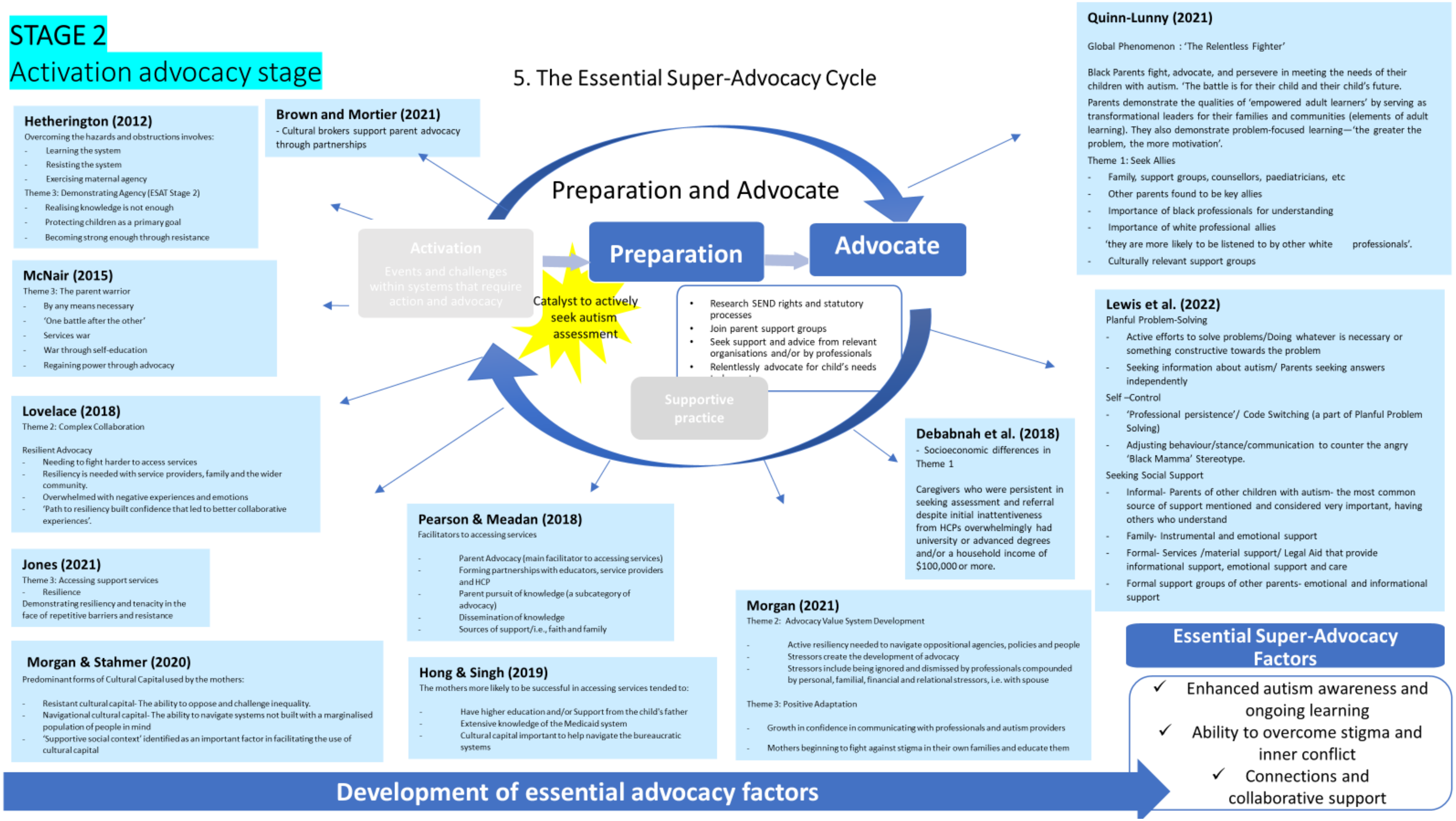
McNair (2015)

1. The isolated and ridiculed parent:
- Micro-insults and aggressions from school staff and personnel
- Misunderstandings
- Powerlessness and Withheld information
- Prevalence of racism

Hong & Singh (2019)

Limited therapeutic services:

- Complex and confusing bureaucratic processes
- Navigating systems including process delays, long waiting lists, e.g., 1 year for appointment
- Out-of-pocket expenses for services Medicaid does not cover
- Frustration with the bureaucracy involved in IEPs
- Lack of timely provision of the right provisions for children in school.



STAGE 2
Activation advocacy stage

5. The Essential Super-Advocacy Cycle

Preparation and Advocate

Activation

Events and challenges within systems that require action and advocacy

Catalyst to actively seek autism assessment

Preparation

Advocate

- Research SEND rights and statutory processes
- Join parent support groups
- Seek support and advice from relevant organisations and/or by professionals
- Relentlessly advocate for child's needs

Supportive practice

Hetherington (2012)

Overcoming the hazards and obstructions involves:

- Learning the system
- Resisting the system
- Exercising maternal agency

Theme 3: Demonstrating Agency (ESAT Stage 2)

- Realising knowledge is not enough
- Protecting children as a primary goal
- Becoming strong enough through resistance

Brown and Mortier (2021)

- Cultural brokers support parent advocacy through partnerships

McNair (2015)

Theme 3: The parent warrior

- By any means necessary
- 'One battle after the other'
- Services war
- War through self-education
- Regaining power through advocacy

Lovelace (2018)

Theme 2: Complex Collaboration

Resilient Advocacy

- Needing to fight harder to access services
- Resiliency is needed with service providers, family and the wider community.
- Overwhelmed with negative experiences and emotions
- 'Path to resiliency built confidence that led to better collaborative experiences'.

Jones (2021)

Theme 3: Accessing support services

- Resilience

Demonstrating resiliency and tenacity in the face of repetitive barriers and resistance

Morgan & Stahmer (2020)

Predominant forms of Cultural Capital used by the mothers:

- Resistant cultural capital- The ability to oppose and challenge inequality.
- Navigational cultural capital- The ability to navigate systems not built with a marginalised population of people in mind
- 'Supportive social context' identified as an important factor in facilitating the use of cultural capital

Pearson & Meadan (2018)

Facilitators to accessing services

- Parent Advocacy (main facilitator to accessing services)
- Forming partnerships with educators, service providers and HCP
- Parent pursuit of knowledge (a subcategory of advocacy)
- Dissemination of knowledge
- Sources of support/i.e., faith and family

Hong & Singh (2019)

The mothers more likely to be successful in accessing services tended to:

- Have higher education and/or Support from the child's father
- Extensive knowledge of the Medicaid system
- Cultural capital important to help navigate the bureaucratic systems

Debabnah et al. (2018)

- Socioeconomic differences in Theme 1

Caregivers who were persistent in seeking assessment and referral despite initial inattentiveness from HCPs overwhelmingly had university or advanced degrees and/or a household income of $100,000 or more.

Morgan (2021)

Theme 2: Advocacy Value System Development

- Active resiliency needed to navigate oppositional agencies, policies and people
- Stressors create the development of advocacy
- Stressors include being ignored and dismissed by professionals compounded by personal, familial, financial and relational stressors, i.e. with spouse

Theme 3: Positive Adaptation

- Growth in confidence in communicating with professionals and autism providers
- Mothers beginning to fight against stigma in their own families and educate them

Quinn-Lunny (2021)

Global Phenomenon : 'The Relentless Fighter'

Black Parents fight, advocate, and persevere in meeting the needs of their children with autism. 'The battle is for their child and their child's future.

Parents demonstrate the qualities of 'empowered adult learners' by serving as transformational leaders for their families and communities (elements of adult learning). They also demonstrate problem-focused learning—'the greater the problem, the more motivation'.

Theme 1: Seek Allies

- Family, support groups, counsellors, paediatricians, etc
- Other parents found to be key allies
- Importance of black professionals for understanding
- Importance of white professional allies

  'they are more likely to be listened to by other white professionals'.
- Culturally relevant support groups

Lewis et al. (2022)

Planful Problem-Solving

- Active efforts to solve problems/Doing whatever is necessary or something constructive towards the problem
- Seeking information about autism/ Parents seeking answers independently

Self –Control

- 'Professional persistence'/ Code Switching (a part of Planful Problem Solving)
- Adjusting behaviour/stance/communication to counter the angry 'Black Mamma' Stereotype.

Seeking Social Support

- Informal- Parents of other children with autism- the most common source of support mentioned and considered very important, having others who understand
- Family- Instrumental and emotional support
- Formal- Services /material support/ Legal Aid that provide informational support, emotional support and care
- Formal support groups of other parents- emotional and informational support

Development of essential advocacy factors

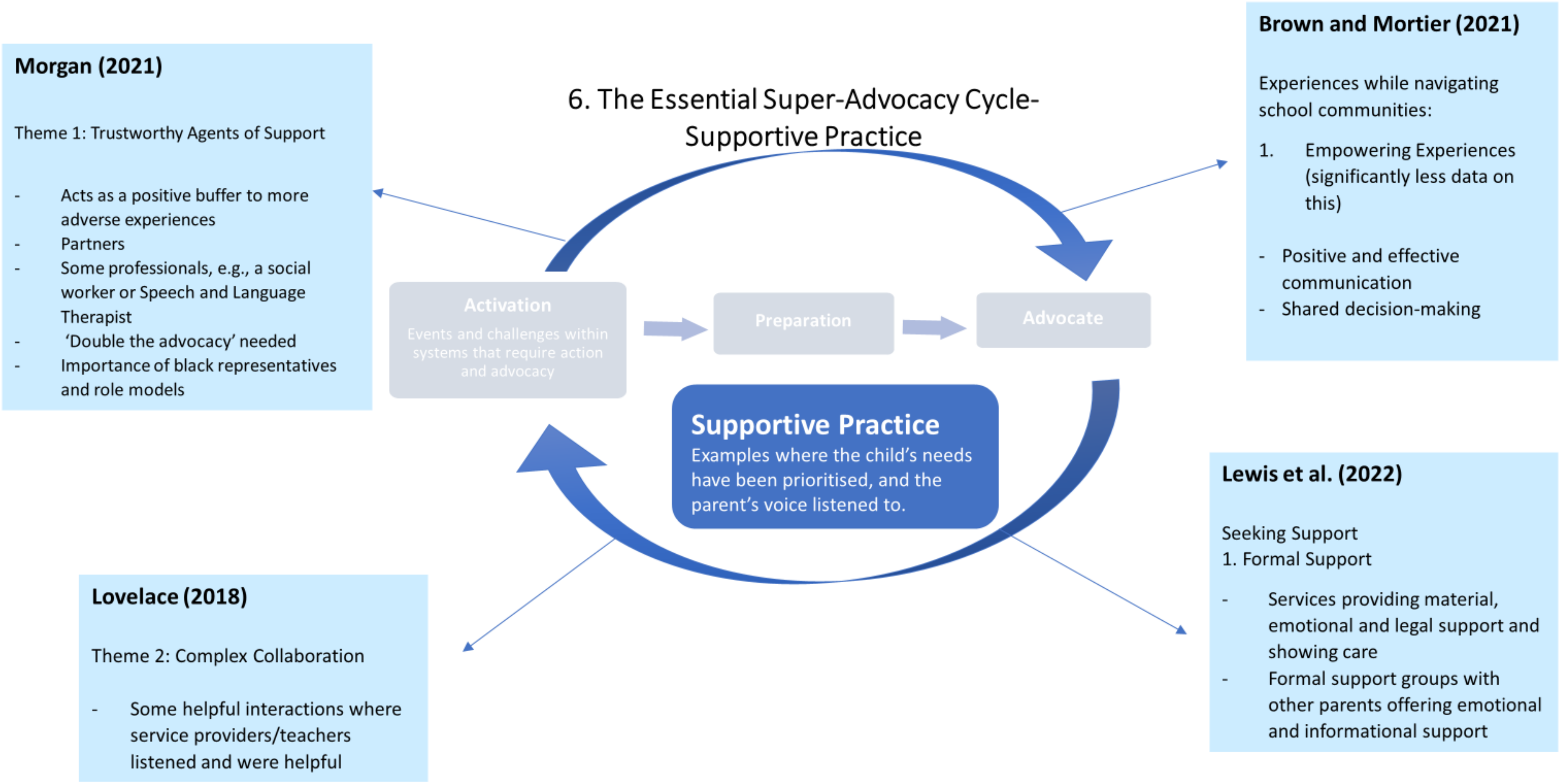
Essential Super-Advocacy Factors

✓ Enhanced autism awareness and ongoing learning

✓ Ability to overcome stigma and inner conflict

✓ Connections and collaborative support

STAGE 2
Activation advocacy stage



6. The Essential Super-Advocacy Cycle- Supportive Practice

Morgan (2021)

Theme 1: Trustworthy Agents of Support

- Acts as a positive buffer to more adverse experiences
- Partners
- Some professionals, e.g., a social worker or Speech and Language Therapist
- 'Double the advocacy' needed
- Importance of black representatives and role models

Brown and Mortier (2021)

Experiences while navigating school communities:

1. Empowering Experiences (significantly less data on this)

- Positive and effective communication
- Shared decision-making

Supportive Practice
Examples where the child's needs have been prioritised, and the parent's voice listened to.

Lewis et al. (2022)

Seeking Support
1. Formal Support

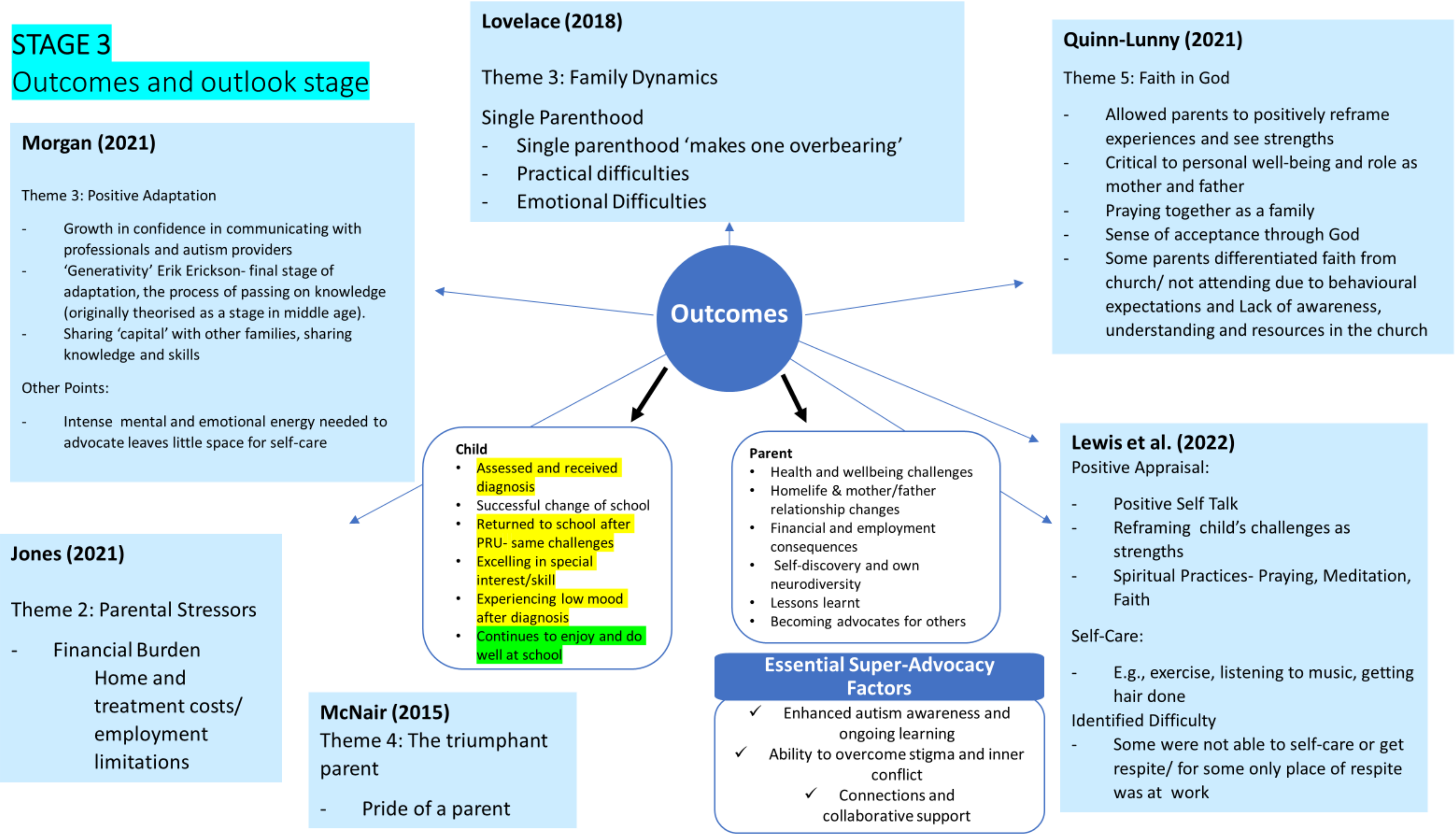
- Services providing material, emotional and legal support and showing care
- Formal support groups with other parents offering emotional and informational support

Lovelace (2018)

Theme 2: Complex Collaboration

- Some helpful interactions where service providers/teachers listened and were helpful

STAGE 3
Outcomes and outlook stage



Outcomes

Morgan (2021)

Theme 3: Positive Adaptation

- Growth in confidence in communicating with professionals and autism providers
- 'Generativity' Erik Erickson- final stage of adaptation, the process of passing on knowledge (originally theorised as a stage in middle age).
- Sharing 'capital' with other families, sharing knowledge and skills

Other Points:

- Intense mental and emotional energy needed to advocate leaves little space for self-care

Lovelace (2018)

Theme 3: Family Dynamics

Single Parenthood

- Single parenthood 'makes one overbearing'
- Practical difficulties
- Emotional Difficulties

Quinn-Lunny (2021)

Theme 5: Faith in God

- Allowed parents to positively reframe experiences and see strengths
- Critical to personal well-being and role as mother and father
- Praying together as a family
- Sense of acceptance through God
- Some parents differentiated faith from church/ not attending due to behavioural expectations and Lack of awareness, understanding and resources in the church

Child

- Assessed and received diagnosis
- Successful change of school
- Returned to school after PRU- same challenges
- Excelling in special interest/skill
- Experiencing low mood after diagnosis
- Continues to enjoy and do well at school

Parent

- Health and wellbeing challenges
- Homelife & mother/father relationship changes
- Financial and employment consequences
- Self-discovery and own neurodiversity
- Lessons learnt
- Becoming advocates for others

Essential Super-Advocacy Factors

- ✓ Enhanced autism awareness and ongoing learning
- ✓ Ability to overcome stigma and inner conflict
- ✓ Connections and collaborative support

Jones (2021)

Theme 2: Parental Stressors

- Financial Burden
  Home and treatment costs/ employment limitations

McNair (2015)

Theme 4: The triumphant parent

- Pride of a parent

Lewis et al. (2022)

Positive Appraisal:

- Positive Self Talk
- Reframing child's challenges as strengths
- Spiritual Practices- Praying, Meditation, Faith

Self-Care:

- E.g., exercise, listening to music, getting hair done

Identified Difficulty

- Some were not able to self-care or get respite/ for some only place of respite was at work

STAGE 3
Outcomes and outlook stage

Outlook
Questions, thoughts and hopes about the future

- How do you tell your child they are autistic? Post-diagnosis care
- How do you prepare a black autistic child for the world outside?
- Male black vulnerability and autism
- School not recognising autism traits in my daughter
- Post 18 opportunities?
- Black autistic role models?

Brown and Mortier (2021)

Desired support and the role of cultural brokers for parents-school partnerships:

1. Specifically designed support for African American families Culturally specific support groups and clubs
- Receiving information and resources to support advocacy
- Advocates present at IEP meetings to ensure rights are not violated

2. Create measures to improve autism awareness/acceptance in school communities

- Raise awareness of staff, administrators, students and their teachers to develop understanding
- Develop ways to increase representation and trust, e.g., someone trustworthy and ready to support on the school site.
- African American representation

someone who understands and can educate others about the needs of African American parents

Pearson & Meadan (2018)

Mother's Recommendations to Service Providers and HCPs

- Specialised training on autism for educators and HCPs
- HCPs dedicated to supporting parents in navigating services
- HCPs being more responsive to parent concerns

Mother's advice to and for other parents

- Train yourselves/ learn about autism and available resources
- More parent education and training around autism for African American parents

Questions, thoughts and recommendations for the future were found in the individual stories of many parents but this theme was only in the main findings of two studies.

Appendix 10: Summarised findings of literature review studies

Summary of Literature review studies

The Essential Super-Advocacy Theory (ESAT) Key		
Stage 1 **Identification and Adaptation Stage**	**Stage 2** **Activation Advocacy Stage**	**Stage 3** **Outcomes and Outlook Stage**
Noticing Difference- **ND** Noticing Difference (Professionals)- **NDP** Noticing Difference (Family)- **F** Noticing Different (Parents) **NDPA** Internal Dissonance-**ID** Accepting and/or Embracing Difference - **AED** Adapting with Systemic Support- **AWS** Adapting Individually- **AI** **Undeveloped Essential Super-Advocacy Factors (at the beginning of Stage 1)** Limited Autism Awareness- **LAA** Internal Dissonance- **ID** Self-Reliance and/or Isolation- **SRI**	Activation- **A** Activation(Treatment of Child)- **TC** Organisational Dysfunction - **OD** Activation (Treatment of Parent)- **TP** Preparation- **P** Preparation (Research SEND Rights and Processes)- **R** Preparation (Join parent support groups/collaborative support)- **CS** Preparation (Seek advice from relevant organisations and/or other professionals)- **SA** Advocate- **AA** Supportive Practice- **SP** **SuperAdvocacy Cycle- SAC** **Catalyst- C** **Developed Essential Super-Advocacy Factors** Enhanced Autism Awareness and Ongoing Learning- **EAA** Ability to Overcome Stigma and Inner Conflict- **OS**	Outcomes Child- **OC** Outcomes Parent- **OP** Outlook- **O**

	Connections and Collaborative Support- **CS**	

	Authors/ Year of publication	**Main Research Question/s**	**Type of Source**	**Research Design**	**Participants**	**Conceptual/ Theoretical Framework/s**	**Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)**
Paper 1 ***"They think we don't have the knowledge:" The Intersection of Autism and Race***	Hetherington (2012)	How do the dual oppressions of race and disability impact African American mothers of children with autism and their relationship with the schooling process?	Doctoral Thesis Education	Qualitative Semi-structured Interviews, a focus group and field notes Grounded Theory analytical process	5 African American Mothers of 7 children with autism (pg.6) All of the children were diagnosed by 2 years old, apart from one who was diagnosed at eight years old.	Feminist Disability Theory	The intersection of 'African American mother' and 'child with autism' presents a 'complex labyrinth of hazards' within institutional structures and the special education system. These hazards must be overcome so that mothers can support and protect their children with autism (pg. 134). The hazards and obstructions were found to be 'regulatory' or 'interactional'. These are: - Assessments, Diagnosis and Committees on Special Education (Stage 1- LAA /Stage 2- A, TP, OD) - Microaggressions (towards parents and children) Hostile treatment, ignored, pressured to accept 'mentally retarded' or 'emotionally disturbed label, given incorrect information, Physical aggression and harsh treatment against children (Stage 2- A, TC, TP)

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							- Lack of knowledge and Privileged knowledge (Stage 1- LAA) - School Assumptions about the mothers and children Parents treated as dangerous and aggressive, Children not seen for their gifts and strengths (Stage 2- A, TP, TC) Overcoming the hazards and obstructions involves: - Learning the system (Stage 2- R, P, CS) - Resisting the system (Stage 2- AA, SAC, SA) - Exercising maternal agency (Stage 2- SAC) Themes and theoretical concepts of the Grounded Theory (pg. 136): Acknowledging the Impact of Autism (ESAT Mainly Stage 1) - Processing the diagnosis (Stage 1- LAA, ND, ID) - Coping with others' reactions (Stage 1- ND, ID, AI/ Stage 2- TP, SRI) Understanding the power of the special educational system (ESAT Stage 2) - recognising the subjugation of their own knowledge (Stage 2- A, TP, OD) - Wanting the system to change (Stage 2- TC, P, R, CS, SA)

	Authors/ Year of publication	**Main Research Question/s**	**Type of Source**	**Research Design**	**Participants**	**Conceptual/ Theoretical Framework/s**	**Main Themes/ Findings** **And Links with The Essential Super-Advocacy Theory (ESAT)**
							Demonstrating Agency (ESAT Stage 2) - Realising knowledge is not enough (Stage 2- TC, TP, OD) - Protecting children as a primary goal (Stage 2- TC, R, P, CS, SA, AA, SAC) - Becoming strong enough through resistance (Stage 2- R, P, CS, SA, SAC, EAA, OS)
Paper 2 ***My life, my son, our journey***	McNair (2015)	What roles must African American parents play to access appropriate classroom accommodations, modifications, and support services for their sons?	Doctoral Thesis Leadership for Education Justice	Qualitative Narrative inquiry Online questionnaire and interviews	5 families, all of whom include a biological parent and a son with autism (from preschool to 8th grade/13 years old). The age of diagnosis is not specified for all children	Critical Race Theory (CRT) (Delgado & Stefanic, 2001) Social Justice	The roles identified that African American Parents play in order to help their children access appropriate classroom accommodations, modifications, and services are (pg. 66): 1. The isolated and ridiculed parent (pg. 66-75) (ESAT Stage 1 & 2) - Feelings of failure and self-blame (Stage 1- ID) - Denial (Stage 1- ID) - Micro-insults and aggressions from school staff and personnel (Stage 2- TP) - Initial feelings (Stage 1- ID) - Misunderstandings (Stage 2- TP) - Powerlessness and Withheld information (Stage 2-TP & OD) - Manifestation of Isolation (Stage 1- ND, ID & AI) - Prevalence of racism (Stage 2- A)

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							2. The parent advocate (pg. 76-82) (ESAT Stage 2) - ‘Knowing the lingo’ Language and knowledge needed to navigate the system (Stage 2- P) - Consulting a professional advocate (Stage 2-SA) - Family Advocates (Stage 2- CS) - Journey to Advocacy (Stage 2-P) - Regaining power through advocacy (Stage 2-P, R & SS) 3. The parent warrior (pg. 83-90) (ESAT Stage 2) - By any means necessary (Stage 2- SAC) - Initially Denied ‘One battle after the other’(Stage 2-SAC) - Services war (Stage 2- SAC) - War through self-education (Stage 2- P, R, EAA) 4. The triumphant parent (pg 91-93) - Pride of a parent Two of the parents only experienced roles 2,3 and 4.

	Authors/ Year of publication	**Main Research Question/s**	**Type of Source**	**Research Design**	**Participants**	**Conceptual/ Theoretical Framework/s**	**Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)**
Paper 3 ***''We Had to Keep Pushing'': Caregivers' Perspectives on Autism Screening and Referral Practices of Black Children in Primary Care***	Debabnah et al. (2018)	What are the barriers and facilitators to ASD screening and referrals in primary care? Are there socioeconomic differences in primary caregiver-reported experiences?	Peer-reviewed paper	Qualitative Semi-structured interviews 'Grounded Theory approach' (Strauss & Corbin, 1990)	22 female caregivers (18 mothers, 4 'other' including grandmothers) of Back American Children with ASD.	Public Health Critical Race Framework (PHCRF) (Ford & Airhihenbuw, 2010)	Four themes were identified, some of which included both facilitating and hindering aspects to the early screening and referrals of Black American children with autism. Theme 1: Primary healthcare provider's attention to caregivers' concerns (ESAT Stage 2) Barrier - Primary healthcare workers were not attentive to the concerns of some caregivers by repeatedly giving other explanations for concerns or having the 'let's wait and see' approach. The children of caregivers who had this experience were all diagnosed between the ages of 4 and 8 (later than those who had more attentive HCPs). (ESAT Stage 2- A, TP, OD) Facilitator - Some caregivers experienced attentive healthcare workers who listened and made the necessary referrals for screening and early intervention. The children of caregivers who had attentive primary care workers were all diagnosed before the age of 4. (Stage 2- SP) Socioeconomic differences in Theme 1

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							- Socioeconomic status was not found to determine who was and was not listened to. Caregivers from all education and income levels were found in both groups. - Caregivers who were persistent in seeking assessment and referral despite initial inattentiveness from HCPs overwhelmingly had university or advanced degrees and/or a household income of $100,000 or more. Theme 2: Perceived racism and poor caregiver-provider interactions- Barrier (ESAT Stage 2- A, TP, TC) - The majority of caregivers reported unease with interactions and perceived this as racism - Incorrect assumptions made about the caregiver - Some thought that it was due to the reputation of the neighbourhood that they were from or their economic status. Socio-economic differences in Theme 2 - There were no socioeconomic differences in the caregivers who reported racism as influencing their interactions with HCPs, but those with a higher economic and educational level were more likely to

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							identify and link the specific assumptions that were made about them to racism. Theme 3: Stigma in the Black Community- Barrier (ESAT Stage 1- ND, F, ID) - Denial and shame - Fear of labelling child - Resistance from family members - Prayer and discipline suggested as the best approach Family and friends as a facilitator - Some caregivers reported that some friends from the black community and family encouraged them to seek developmental assessment for their child. Socioeconomic differences in Theme 3 - There were no socioeconomic patterns related to reported levels of stigma Theme 4: Legal and Custodial Issues- Barrier - Those who were not biological guardians or had negative experiences with the welfare or legal systems had difficulties following up and/or trusting the healthcare

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							services, causing delays in the child being assessed and receiving intervention. Socioeconomic differences in Theme 4 - The majority of those who mentioned these barriers had incomes below $25,000 or an education at or below high school (secondary school) level.
Paper 4 ***Experiences of African American Mothers of Sons with Autism Spectrum Disorder:***	Lovelace et al. (2018)	What is the impact of race on the lived experiences of African American families who have boys with ASD? What caregiving experiences do	Peer-reviewed paper	Narrative Inquiry Grounded Theory Framework Codes were identified from existing literature and used as initial	3 African American mothers of sons with ASD (one son had a diagnosis of Pervasive Developmental Disorder-Not Otherwise Specified).	None Specified	Four main themes emerged from Lovelace and colleagues' study, which suggest race does impact the lived experience of African American mothers who have sons with ASD: Theme 1: Racial Discrimination (ESAT Stage 2- A, TC, TP) - Covert and overt in medical and educational spaces - Directed at the mother and/or child - Mother's knowledge about child dismissed or not believed - "Each stage, from diagnosis to receiving proper services, was fraught with difficulty". (pg. 8) Theme 2: Complex Collaboration (ESAT Stage 2- A, TP, TC, AA, SAC)

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
Lessons for Improving Service Delivery		participating African American Mothers of children with ASD attribute to race? Do participant reports provide evidence of a unique experience for African American families of children with ASD?		codes to start the analysis. Prospective codes from the data were then added and included in emerging themes.			- Resilient Advocacy Needing to fight harder to access services Resiliency is needed with service providers, family and the wider community. Overwhelmed with negative experiences and emotions 'Path to resiliency built confidence that led to better collaborative experiences'. - Difficult Interactions School Personnel and Service Providers Child's needs not being met Outnumbered and not listened to at meetings Some helpful interactions where service providers/teachers listened Theme 3: Family Dynamics (ESAT Stage 1, ND, F, ID, AI) - Single Parenthood (Stage 1- AI, ID) Support groups not supportive of the needs of the single-parent

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							Single parenthood 'makes one overbearing' Practical difficulties Emotional Difficulties - Family Interpretations (ESAT Stage 1- ND, F, ID) Shame and blaming the parent Lack of autism understanding Spiritual advice/ 'Pray it away' Theme 4: Community Dynamics (ESAT Stage 1- ND, F, ID, AI) The African American community, Autism community and the intersection between the two. - Community Interpretations- African American community/ negative, non-supportive interpretation, Bad parenting assumed, less understanding and acceptance - Lack of resources- ASD programmes not locally available, ASD communities out of the area, absence of educational information about autism (have to educate self and others personally).

	Authors/ Year of publication	**Main Research Question/s**	**Type of Source**	**Research Design**	**Participants**	**Conceptual/ Theoretical Framework/s**	**Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)**
							- Lack of connection- Distance of ASD communities/groups, not a lot of African American families at summer camps and other activities/services - Extended family was found to provide connection and support
Paper 5 ***African American Parents' Perceptions of Diagnosis and Services for Children with Autism***	Pearson & Meadan (2018)	What are the perceived factors that facilitate and impede early diagnosis and access to services among African American parents who have children with ASD?	Peer-reviewed paper Education and Training in Autism and Developmental Disabilities Office of Special Education Programmes, U.S.	Qualitative questionnaires and semi-structured interviews Grounded Theory	11 Black American mothers of 13 children aged 4-11 with ASD Age at diagnosis ranged from 1.5- 6 years old. Five children were not diagnosed until four years old or older (pg.22)	None Specified	Perceived factors that facilitate and impede obtaining a diagnosis and accessing services: Facilitators to obtaining a diagnosis: - Concerns and referrals Initiated by others (ESAT Stage 1- NDP, F) - News and Media Barriers to obtaining a diagnosis (ESAT Stage 1 & 2) - Extended family views (ESAT Stage 1, ND, F, ID) - Parental lack of knowledge of development and disability - (Stage 1- LAA)

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
			Department of Education, funded				- HCP lack of autism knowledge (ESAT Stage 2- A, OD) - HCPs Ignoring Parental concerns (ESATStage 2- A, TP, TC) Facilitators to accessing services (ESAT Stage 2- AA, P, R, CS, SA, SP, SAC) - Parent Advocacy (main facilitator to accessing services) - Partnerships with educators, service providers and HCP - Parent pursuit of knowledge (a subcategory of advocacy) - Dissemination of knowledge - Sources of support/i.e., faith and family Barriers to accessing services - Employment - Family life events - Health care costs and insurance - Geographical location of services

	Authors/ Year of publication	**Main Research Question/s**	**Type of Source**	**Research Design**	**Participants**	**Conceptual/ Theoretical Framework/s**	**Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)**
							Mother's Recommendations to Service Providers and HCPs (ESAT Stage 2- OD, Stage 3- O) - Specialised training on autism for educators and HCPs - HCPs dedicated to supporting parents in navigating services - HCPs being more responsive to parent concerns Mother's advice to and for other parents (ESAT Stage 2- A, AA, P, SAC, EAA, OS, CS) - Train yourselves/ learn about autism and available resources - More parent education and training around autism for African American parents
Paper 6 ***Contextualising the social and structural***	Hong & Singh (2019)	What are the social and structural factors that place children and their families	Peer-reviewed paper	Qualitative, Semi-structured Interviews	21 single Black American female caregivers of children with ASD who rely on state Medicaid	Adapted 'Cycle of Environmental Health Disparities Framework'	Factors that place these mothers, their children and their families with limited resources at risk of: Late Diagnosis: (ESAT- Stage 1- LAA) 1. Low income and parental education associated with late diagnosis 2. Lack of autism awareness

	Authors/ Year of publication	**Main Research Question/s**	**Type of Source**	**Research Design**	**Participants**	**Conceptual/ Theoretical Framework/s**	**Main Themes/ Findings** **And Links with The Essential Super-Advocacy Theory (ESAT)**
constraints of accessing autism services among single Black female caregivers in Atlanta, Georgia		with limited resources at risk of delayed ASD diagnostic services and limited therapeutic services?			health Insurance in Atlanta 16 mothers 5 Grandmothers		3. Complicated scheduling coordination 4. Long waiting lists Limited therapeutic services: (ESAT Stage 2- A, OD) 1. Medicaid - Medicaid provision not available in some geographical locations - Complex and confusing bureaucratic processes - Navigating systems including process delays, long waiting lists, e.g., 1 year for appointment - Out-of-pocket expenses for services Medicaid does not cover 2. Further frustrations with the bureaucracy involved in changing a child’s IEP and the lack of timely provision of the right provisions for children in school. 3. Locations of ASD service unaccessible The mothers more likely to be successful in accessing services tended to: (ESAT Stage 2- EAA, R, and CS- was key in ESAT) - Have higher education and/or - Support from the child's father - Extensive knowledge of the Medicaid system - Cultural capital important to help navigate the bureaucratic systems

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							Compounding Factors to Barriers: (ESAT Stages 1, 2 and 3 Underlying all points) - Intersection of race and gender (and associated inequalities) - Single parenthood - Socio-economic and low-income status - Limited employment options, e.g., not offering enough flexibility - Stressful environments on a day-to-day basis, e.g., relying on public transport - Being the primary caregiver and 'breadwinner'
Paper 7 **Narratives of single, black mothers using cultural capital to access autism**	Morgan & Stahmer (2020)	What forms of cultural capital are used by single Black mothers to advocate for their children with autism in schools?	Peer-reviewed paper British Journal of Sociology of Education	Qualitative Semi-structured interviews Thematic Analysis	Single Black Mothers	Critical Race Theory (CRT) Community Cultural Wealth Model (Yosso, 2005)	Predominant forms of Cultural Capital used by the mothers in this study: (ESAT Stage 2- A, P, AA, SAC) 1. Resistant cultural capital- The ability to oppose and challenge inequality. 2. Navigational cultural capital- The ability to navigate systems not built with a marginalised population of people in mind.

	Authors/ Year of publication	**Main Research Question/s**	**Type of Source**	**Research Design**	**Participants**	**Conceptual/ Theoretical Framework/s**	**Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)**
interventions in schools						Bourdieu's 1973 Theory of Social Reproduction Cultural Capital Theory (CCT)	Key Finding: Mothers have to engage in systems that are institutionally racist, sexist, and ableist. This leads to misdiagnosis, deferred diagnosis, and poor quality of service. Parent and child experiences- (ESAT Stage 2, A, TP, TC) - Mothers told by settings and school district that they were difficult and adversarial in the IEP process - Feeling of not being listened to motivated mothers to become advocates themselves - Settings not seeing child for their strengths (ESAT Stage 2, P, CS) - Parent felt that they could develop advocacy and a voice once matched with other parents like herself - Preschooler without diagnosis at risk of being excluded from preschool showing signs of developmental difficulties not referred for assessment by preschool who still want to exclude. Mother writes to principal- a form of cultural capital (ESAT Stage 2, A, TC, P, AA)

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							(ESAT Stage 1, ID, SRI, AI) - Parent experiencing denial and starting to isolate from society - Some examples of supportive practice/ being listened to by setting (ESAT Stage 2- SP) - Example of crises breaking the dissonance and leading to action by parents (ESAT 2- A, C) - Mother leaves job to turn attention to care for her daughter (ESAT Stage 3- OP) - Parent committed to helping other parents (ESAT Stage 2- CS, Stage 3- OP) (ESAT Stage 1- AED, ND, F) - Quote demonstrating moving from Internal dissonance to accepting and educating self. - Parent’s mother identifying difference and recommending referral (ESAT Stage 2- CS) - ‘Supportive social context’ identified as an important factor in facilitating the use of cultural capital

	Authors/ Year of publication	**Main Research Question/s**	**Type of Source**	**Research Design**	**Participants**	**Conceptual/ Theoretical Framework/s**	**Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)**
							(ESAT Stage 2- SP) - Examples of mothers feeling more able to use their cultural capital when they were respected and listened to. - (ESAT Stage 2, A, SAC) - Examples of mothers fighting for individualised services for their children against the recommendation of 'experts'
Paper 8 **"Watch Your Tone" The Experiences of African American Parents of Students on the Autism**	Brown & Mortier (2021)	What are the experiences of African American parents of children on the autism spectrum within the family and community? What are the	Peer-reviewed paper	Qualitative Semi-structured interviews with parents Focus group with cultural brokers	7 African American mother and 2 couples 6 Cultural Brokers 3 of which have children with autism	Communities of Practice (Wenger-Trayner, E. & Wenger-Trayner, 2002)	Experiences with the family and community: 1. Isolation (ESAT Stage 1- ND, F, SRI, ID) - Ostracised from nuclear family - Feeling lack of membership in extended family - Lack of inclusion in the community - Some drew strength from church community 2. Unfamiliar with autism (ESAT Stage 1- LAA, ID) - Unfamiliar with the impact of autism - Denial of the existence of disability Experiences while navigating school communities:

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
Spectrum in Parent-School Partnerships		experiences and needs of African American families with children on the autism spectrum while navigating school communities?					1. Empowering Experiences (ESAT Stage 2- SP) - Positive and effective communication - Shared decision-making - (Significantly less data on this) 2. Disempowering Experience (ESAT Stage- A, TP, TC, OD) - Poor implementation/ quality of service - Tense communication and lack of cultural awareness - Issues with school district Desired support and the role of cultural brokers within parents-school partnerships: 1. Specifically designed support for African American families (ESAT Stage 3- O) - Culturally specific support groups and clubs - Receiving information and resources to support advocacy - Advocates present at IEP meetings to ensure rights are not violated

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							2. Create measures to improve autism awareness/acceptance in school communities (ESAT Stage 3- O) - Raise awareness of staff, administrators, students and their teachers to develop understanding 3. Develop ways to increase representation and trust, E.g., someone on the school sight that ise trustworthy and ready to support. (ESAT Stage 3- O) 4. African American representation - someone who understands and can educate others about the needs of African American parents
Paper 9 **African American Parents' Experience Accessing**	Jones (2021)	What are the experiences of African American parents in Philadelphia accessing and maintaining	Doctoral Thesis Human and Social Sciences	Qualitative generic study (Cooper & Endacolt) used to explore attitudes, beliefs and	10 African American parents/ 5 Mothers and 5 fathers	Resilience Theory (Zimmerman, 2013) Behavioral Health Model	The experiences, barriers and facilitators that affect parents maintaining and accessing autism services for their child: Theme 1: Challenges raising child with ASD (ESAT Stage 1- ID, AI) - Emotional responses to diagnosis Examples of a mixture of emotions including shock, shame, relief

	Authors/ Year of publication	**Main Research Question/s**	**Type of Source**	**Research Design**	**Participants**	**Conceptual/ Theoretical Framework/s**	**Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)**
Support Services for Their Autistic Child		autism services for their child (barriers and facilitators)?		experiences		(Anderson, 1995)	- Structure and Routine Needing to adapt and do things differently - Changes in Lifestyle Impact on careers and employment Financial implications (ESAT Stage 3- O) (ESAT Stage 1- SRI, ID) - Social Isolation Restricting time with friends, losing friends, shame Theme 2: Parental Stressors - Financial Burden (ESAT Stage 3- OP) Home and treatment costs/ employment limitations - Limited providers In terms of those made available through insurance - Support systems (ESAT Stage 1- AWS, AI) Some had access to services, and others did not; some had social support from family (ESAT Stage 1- LAA, Stage 2- A, OD)

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							- Awareness and understanding of child's diagnosis Parents lacked awareness, but they also experienced doctors and HCPs not knowing much about autism Theme 3: Accessing support services (ESAT Stage 2- A, P, AA) - Waiting lists Waiting up to 2 years for intervention, availability of services not possible for parent schedule - Insurance Limited services and treatments available on Medicaid unless can pay for private insurance - Resilience (ESAT Stage 2, A, P, AA, SAC) Demonstrating resiliency and tenacity in the face of repetitive barriers and resistance

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
Paper 10 **The Developmental Process of Parent Advocacy for Black Mothers of Children on the Autism Spectrum**	Morgan (2021)	What are the pathways to becoming an autism parent advocate? What variables are associated with parent advocacy?	Doctoral Thesis Human Development	Mixed methods, surveys, focus groups and interviews. Thematic Analysis Narrative enquiry Phenomenological qualitative methods Self Portraiture	7 Black mothers across 4 states Parent-peer coaches so trained in advocacy	Critical Race Theory (CRT) Double ABCX Model	The key factors in positive adaptation and advocacy development: 1. Trustworthy Agents of Support (ESAT Stage 2- CS, SP) - Act as a positive buffer to more adverse experiences - Partners - Some professionals, e.g., a social worker or Speech and Language Therapist - 'Double the advocacy' needed - Importance of black representatives and role models 2. Advocacy Value System Development (ESAT Stage 1- ID, Stage 2- A, P, AA, SAC, Stage 2- O P) - Active resiliency needed to navigate oppositional agencies, policies and people - Stressors create the development of advocacy - Stressors include being ignored and dismissed by professionals compounded by personal, familial, financial and relational stressors, i.e. with spouse 3. Positive Adaptation (ESAT Stage 1- AED, Stage 3- OP)

	Authors/ Year of publication	**Main Research Question/s**	**Type of Source**	**Research Design**	**Participants**	**Conceptual/ Theoretical Framework/s**	**Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)**
							- Mothers finding relief after their child's diagnosis - Feelings of 'empowerment' to take action after the diagnosis - Diagnosis leading mothers to actively seeking support - Growth in confidence in communicating with professionals and autism providers - Mothers beginning to fight against stigma in their own families and educate them - 'Generativity' Erik Erickson- final stage of adaptation, the process of passing on knowledge (originally theorised as a stage in middle age). - Sharing 'capital' with other families, sharing knowledge and skills Other Points (ESAT Stage 2- SAC, Stage 3- OP) - Intense mental and emotional energy needed to advocate leaves little space for self-care
Paper 11 ***A Phenomenologic***	Quinn-Lunny (2021)	What are the lived experiences of black parents through	Doctoral Thesis Education	Qualitative Semi-structured interviews,	16 Parents 15 mothers, 1 father	Phenomenological study No theories	Findings include broad themes of barriers or facilitators, with one overarching theme or 'global phenomenon' as described by the author: Global Phenomenon: The Relentless Fighter (ESAT Stage 2- SAC and the theory title)

	Authors/ Year of publication	**Main Research Question/s**	**Type of Source**	**Research Design**	**Participants**	**Conceptual/ Theoretical Framework/s**	**Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)**
al Study: Lived Experiences of Black Parents Through the Autism Spectrum Disorder Identification Process		the ASD identification process, including barriers and facilitators? What are parent training needs to assist in effective identification?		questionnaires and parent journalling Phenomenological	11 African American 1 Jamaican 1 Haitian 1 Native American	or models specified	Black Parents fight, advocate, and persevere in meeting the needs of their children with autism. 'The battle is for their child and their child's future. Parents demonstrate the qualities of 'empowered adult learners' by serving as transformational leaders for their families and communities (elements of adult learning). They also demonstrate problem-focused learning—'the greater the problem, the more motivation'. Theme 1: Seek Allies (ESAT Stage 2- CS, Essential Advocacy factor, Stage 3- O) - Family, support groups, counsellors, paediatricians, etc - Other parents found to be key allies - Importance of black professionals for understanding - Importance of white professional allies- 'more likely to be listened to by other white professionals'. - Culturally relevant support groups

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							Theme 2: Face Many Challenges (ESAT Stage 2- A, OD, TP, TC, Stage 3- OC) - Lack of knowledge and understanding about autism by paediatricians, therapists and educators - Professionals thinking because a child is verbal, they cannot have autism - Lack of resources and evidence-based treatments - Pediatricians failing to screen for ASD at assessment/ perceived as prejudice or cultural barrier - IGnored and dismissed - School Districts prefering to label black child with ADHD or behavioral problems unless child is non-verbal - Difficulties getting interventions - Teachers not trained in ASD - Concern about the impact of delays and rejection on child

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							Theme 3: Unequal Treatment of parent seeking ASD identification (ESAT Stage 2, A, TP) - Not listened to, rushed, or treated rudely by professionals - Stereotyped assumptions made, - Judged as ‘welfare mum’ - Parents needing to push against biases - Professionals more likely to see behavioural issues rather than autism - Parental passion seen as ‘anger.’ - Difficulty trusting institutions because of biases - Professionals needing training in cultural awareness Theme 4: Isolation (ESAT Stage 1- ND, F, ID, SRI, AI) - Feeling of isolation from spouses, grandparents, and extended family when deciding to seek assessment and diagnosis - Judgement and lack of understanding

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							- Temptation to ‘hide’ child due to avoid judgement - ‘Lonely in the marriage’ - Fear of a label - Accused of being bad parents for letting ‘white people label child’ instead of ‘fight against the oppressive system’ Theme 5 Faith in God - Allowed parents to positively reframe experiences - Critical to personal wellbeing and role as mother and father - Praying together as a family - Providing strength to fight - Sense of acceptance through God - Parents differentiated faith from church/ none were attending due to behavioural expectations of child Lack of awareness, understanding and resources in the church - Faith-based community not in favour of seeking medical support

	Authors/ Year of publication	**Main Research Question/s**	**Type of Source**	**Research Design**	**Participants**	**Conceptual/ Theoretical Framework/s**	**Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)**
Paper 12 **The creator did not give me more than I can handle: Exploring coping in parents of Black autistic children**	Lewis et al. (2022)	What coping strategies are used by black parents who have children with autism? What role does culture play in the use and effectiveness of coping strategies?	Peer-reviewed paper	Mixed Methods Questionnaire and semi-structured interviews Grounded Theory Methods	Twenty parents of African American children, all women. Children aged 3-17 All boys	Black Family Stress and Coping Model (BFSC) (Massey et al., 2018) ABC-X Model (McCubbin & Patterson, 1982) Mundane extreme environmental stress (Peters & Massey, 1983)	Findings found that the following coping strategies were used: Planful Problem-Solving (ESAT Stage 1- AI, Stage 2- P, R, SA) - Active efforts to solve problems/Doing whatever is necessary or something constructive towards the problem - Seeking information about autism/ Parents seeking answers independently Self -Control (ESAT Stage 2- AA) - ‘professional persistence’/ Code Switching - A part of Planful Problem Solving - Adjusting behaviour/stance/communication to counter the angry ‘Black Mamma’ Stereotype. Seeking Social Support (ESAT Stage 2- P, CS) Informal Support (ESAT Stage 2- AI- opposite) - Partners and Co-Parents- Childcare responsibilities, positive support

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							- Family- Instrumental and emotional support - Parents of other children with autism- the most common source of support mentioned and considered very important, having others who understand Identified difficulty - Some parents experienced fear of burdening others, so kept things bottled up Formal Support (ESAT Stage 1- AWS, Stage 2- SP) - Services and providers- material support/ Legal Aid emotional support and showing care - Formal support groups of other parents- emotional and informational support Identified difficulty Organised parent groups not representative/ unwelcome/different struggles and concerns Some online groups also caused distress/ discrimination perceived as racism Positive Appraisal

	Authors/ Year of publication	Main Research Question/s	Type of Source	Research Design	Participants	Conceptual/ Theoretical Framework/s	Main Themes/ Findings And Links with The Essential Super-Advocacy Theory (ESAT)
							(ESAT Stage 3- O, OC, OP, No spiritual practice) - Positive Self Talk - Reframing child's challenges as strengths - Spiritual Practices- Praying, Meditation, hETH Self Care (ESAT Stage 3- OP, mainly difficulties) - E.g., exercise, listening to music, getting hair done Identified Difficulty - Some were not able to self-care or get respite/ for some only place of respite work