

***“Who am I? More than autism!”***

**Race, Ethnicity, Culture and Autism:**

**An auto/biographical unpacking of intersectional identities  
among Black British children and young people with autism in  
English special schools**

A thesis submitted for the degree of Doctor of Philosophy

by

**Donna-Marie Holder**

Supervised by Dr Nic Crowe and Dr Ellen McHugh

Department of Education

Brunel University London

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- Brunel University London Graduate School Poster Conference 2021, 2023
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- 2<sup>nd</sup> Annual Online Doctoral Researchers' Conference 2021
- University College London's Centre for Inclusive Education Inclusive and Supportive Education Conference 2021
- University of Brighton Department of Education Conference 2021
- Brunel University London Department of Education Conference 2021, 2022, 2023
- Education Equity Services Annual Conference 2021
- Festival of Education 2022
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- Whole Education SEND Leadership Conference 2024

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## Abstract

The nexus between race, ethnicity, culture, identity and autism is a significantly under-researched area. Moreover, studies that explore the depth of Black British children and young people's experiences and others at the intersection of special needs education in England is equally underexplored, despite large numbers of children and young people from Black Caribbean and African backgrounds (by birthright or ancestry) populating special schools. A crucial gap currently exists in English research that examines how children and young people with autism from Black backgrounds understand their racial, ethnic and cultural identities, and how these identities are influenced by home and school.

This research study is made up of two parts. The first involves auto/biographical accounts of my life as the mother of a young Black British man with autism, as well as my experiences as a special needs' educator. The second part of this critical work is an investigation into the intersections of racial, ethnic and cultural identities among Black British children/ young people with autism attending English special schools. This qualitative study utilises data from over 40 semi-structured interviews to gather the first-hand experiences of those who can provide such insight and information to help better close this gap. They are Black British children/ young people with autism, their families and educators, exposing how the intersected characteristics of race, ethnicity and culture influence identity among children/ young people with autism in England.

Key findings from the study include *Black British children/ young people with autism can understand their multiple identities; implicit and explicit ethnic-racial socialisation takes place predominately in the home; children and their families have experienced combined racism and ableism in special schools and other settings; and special school staff have experienced and witnessed racism in their provisions*. Findings from this research have implications on special education in England.

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# Introduction

## Introduction

The nexus between race, ethnicity, culture, identity and autism is a significantly under-researched area. Moreover, studies that explore the depth of Black British children and young people's experiences and others, at the intersection of special needs education in England is equally underexplored, despite large numbers of children and young people from Black Caribbean and African backgrounds (by birthright or ancestry) populating special school provisions. In this opening chapter, I will briefly layout the structure of this thesis beginning with the research rationale, research questions, background, and current context. Next, I will define several key terms that are used throughout this study, followed by an outline of each chapter and conclude with a summary.

## Research Rationale

While there is a large body of existing research that explores the relationship between race and special educational needs and disabilities (SEND) including *intersectionality* (Blanchett, Harry and Klingner, 2009; Richards, 2015), *over-representation* (Dyson and Gallannaugh, 2008; Strand and Lindsay, 2009), *race and class* (Tomlinson, 2014), *racial disparity* (Fish, 2019), *socioeconomic disadvantage* (Roman-Urrestarazu, *et al.*, 2021) and *inclusion and discrimination* (Thomas and Loxley, 2022) a crucial gap currently exists in English research that examines disability and identity formation. Explicitly, how children and young people with autism from Black backgrounds 'understand' (are aware of, interact/ engage with and recognise) their racial, ethnic and cultural identities, and how these identities are influenced by home and school.

This study utilises the first-hand experiences of those who can provide such insight and information to better help close this gap. They are those impacted by autism: children/ young people with autism, as well as their families and educators, exposing how the intersected characteristics of race, ethnicity, and culture influence identity development among Black British children/ young people with autism in England. This study centres around three main research questions:

- *In what ways have my own lived experiences of raising a young Black British man*



*with autism helped construct his racial, ethnic, and cultural identities?*

- *To what extent do Black British children and young people with autism 'understand' (are aware of, interact/ engage with and recognise) their racial, ethnic and cultural identities through exposure at a) home and b) school?*
- *How do special schools in England incorporate race, ethnicity and culture into all aspects of their pedagogy and wider school community.*

This thesis is a research study that is made up of two parts. The first involves auto/biographical accounts of my life as the mother of a young Black British man with autism, helping him understand his racial, ethnic and cultural identity/ identities, as well as my vast experience as a special needs' educator, navigating the nuances of race and culture in English special schools. I deem that these personal reflections will form the roots of this research that will in turn extend into the second part of this critical work: an investigation into the intersections of race, ethnicity, culture, identity and autism (involving Black British children/ young people with autism, parents and staff) in special schools in England. By using my personal narratives within this research, my aim is to translate my lived experiences (Kinouani, 2021) with my son and my experience as a special school practitioner into a wider discussion about intersections of race, ethnicity, culture, identity and autism in special education.

From a personal perspective, as a Black woman mothering a son diagnosed with autism and additional learning difficulties and needs, I am constantly trying to grapple with how I see my son, through some of the distinct parts of who he was, is, and will always be: *Black, Male and Differently- Abled* ('Dis/abled'). I intentionally use the term different ability or separate dis/ability instead of disability because of the negative undertones of the word that I have grown up around, which I explain later in the next two chapters. I have a heightened sense of concern that regardless of my son's special educational, behavioural and emotional needs, he will most often be viewed in society as a Black man first, which in these uncertain and unprecedented times is always a legitimate worry. Sadly, my worry, positioned at the convergence of both his race and gender, needs no further justification when all we have to do is say their names: Stephen Lawrence and George Floyd (Bowling,

2011; Mercer, 2021; Wu *et al.*, 2023). The added lens of disability against race and ethnicity is equally distressing with the cases of police violence against Black individuals with disabilities in the United Kingdom (Philip, 2022) and overseas (Levin, 2024).

This intersected space of race, ethnicity and dis/ability research, however, is still extremely limited, which this thesis aims to address within the confines of a more specialised study. I consider this research to be both timely and critical given not only the current global climate of racial divide in relation to persistent issues of racial injustice but also historical connotations of systemic racism and inequity in English schools (Gillborn, 2008; Tomlinson, 2021). I am extremely passionate about encouraging my son's development of a positive self-image (and that of other Black children/ young people with autism) which cannot be separated from his racial, ethnic and cultural identities. In the same way, I am committed to unpacking issues surrounding race, ethnicity, identity and culture within special education and special schools in England, which is lacking in empirical research.

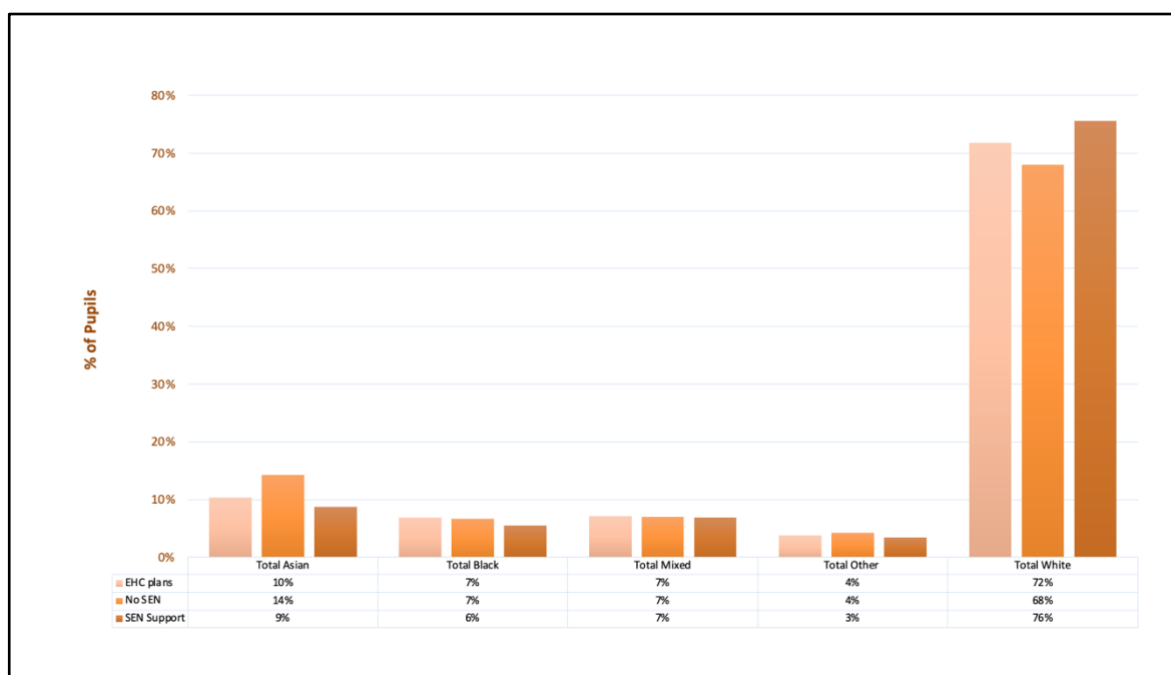
Professionally, as a SEND educator with more than 12 years' experience of teaching and working with children/ young people with acute needs, difficulties and dis/abilities, predominately autism in special schools, the absence of race, culture and diversity that I have witnessed within special education provisions in England is concerning. Although, I dive deeper into a few of my personal stories in the next chapter, the unavailability of research that explores the ways that race, SEND, and English special schools connect besides the plethora of studies identifying *disproportionality* (Lindsay, Panther and Strand, 2006; Strand and Lindorff, 2018; Demie, 2019) and the areas already mentioned reinforces the cruciality of why further research is needed. Particularly whether children/ young people with autism 'understand' their multiple identities and if race, ethnicity, and culture features within strategies, policies, and pedagogy to name but a few areas in shaping the identity of Black British children and young people across the autism spectrum in English special school environments. While race remains a contested topic in historic and contemporary educational research, there are stark areas within this wide-ranging theme that research has yet to uncover, a disparity that this study intends to challenge.

## **Background and Current Context**

According to the most recent data from the Department for Education (2024a) over 1.6 million pupils in England in 2023/2024 were identified as having Special Educational Needs (SEN). These figures have increased by over 101,000 since 2023 and include state-funded schools from nursery to secondary and special schools, as well as non-maintained special schools (which are neither state-funded or maintained), pupil referral units and independent schools. 4.8% of these pupils have an Education Health Care (EHC) plan, a document from the local authority that sets out the level of specialist support a child/young person requires, typically more than having only SEN support. An EHC plan requires a statutory assessment to be conducted of SEN and also includes health and social care support. Autistic Spectrum Disorder (ASD) is the most prevalent need for those with an EHC plan with just over 400,000 plans (288,144 boys and 112,269 girls) issued in 2023/2024.

Pupil characteristics from the school census and other sources (Department for Education, 2024a) highlight that pupils with an EHC plan from Black backgrounds (where ethnicity data was provided) are just over 27,700, made up of mostly Black African (18,563) followed by Black Caribbean (5040) and finally other Black backgrounds (4164). Figure 1 that I created below from the government data, illustrates the varying levels of SEN in English schools according to total ethnicity groupings, such as pupils that have SEN support indicating that they do not have an EHC plan, and the support offered is in addition to or varies from help given to an individual of the same age. Pupils with SEN support are often in mainstream provisions and have been identified as having a learning disability or difficulty and require more support outside of that offered by the school's curriculum (Department for Education, 2024a).

**Figure 1: Ethnicity by type of need in England 2023/2024**



**Source:** Department for Education (2024a)

While White British and White other backgrounds respectively make up the largest number of pupils with EHC plans in England, individual ethnicity data shows that Black African pupils are the next most common group followed by Asian Pakistani with Black Caribbean pupils in 13<sup>th</sup> place, as seen below in Table 1.

**Table 1: Top Ten EHC Plans Ranked by Ethnicity**

Ethnicity	EHC plans	Ranking
White - White British	239,262	1 <sup>st</sup>
White - any other White background	19,957	2 <sup>nd</sup>
Black - Black African	18,563	3 <sup>rd</sup>
Asian – Pakistani	16,352	4 <sup>th</sup>
Mixed - Any other mixed background	11,237	5 <sup>th</sup>
Asian – Indian	8,492	6 <sup>th</sup>
Mixed - White and Black Caribbean	8,121	7 <sup>th</sup>
Any other ethnic group	7,670	8 <sup>th</sup>
Asian – Bangladeshi	7,667	9 <sup>th</sup>

Asian - any other Asian background	7,454	10 <sup>th</sup>
Black - Black Caribbean	5,040	13 <sup>th</sup>

**Source:** Department for Education (2024a)

Due in part to their educational, emotional, behavioural, health and care needs, pupils with an EHC plan are predominately taught in special school environments. Skiba *et al.*, (2008); Strand and Lindsay (2009; 2012) and Strand and Lindorff's (2018; 2021) research findings suggest that there is a constant ethnic disproportionality within SEN settings whereby Black Caribbean pupils are over-represented for Moderate Learning Difficulties (MLD) and in some cases considerably over-represented for Social, Emotional and Mental Health (SEMH) and other learning and behavioural needs. This information coincides with multiple historic data sources that indicated children/ young people from Black Caribbean backgrounds (more than any other Black group) as being disproportionately identified as having SEND and other learning needs in England.

The current data, however, shows that there has been a shift within the Black groups and Black African children now hold more EHC plans than Black Caribbean children, which is likely connected to migration and immigration changes, which has seen an increase of African populations coming to, and settling in the UK, as opposed to those from the Caribbean, as had previously been the case of the Windrush generation (Grant, no-date). Therefore, I have chosen to exclusively focus on Black Caribbean (mine and my son's heritage) and Black African groups (children/ young people and parents) in this study, for which my reasons will be further explained in the methodology chapter. The participants will include Black British pupils and students in special schools, SEN further education and colleges in England that have an autism diagnosis to explore how the intersected themes of race, ethnicity and culture influence the construction of their identities at home and school.

Substantial literature has examined the position of race when educating Black children, from the importance of *mentoring* (Majors, Wilkinson and Gulam, 2001) and perceptions of *Black masculinity* (Sewell, 1997) to the influence of *culture* in learning (Davidson and Alexis, 2012). Equally, education for learners with SEND and other difficulties has also been

a popular discourse when it comes to *inclusion* (Norwich, 2008), *partnership working* (Patterson, 2011), and *pedagogy* (Farrell, 2012). The crossroads of educating Black learners with SEND in special schools, particularly in the UK context is where an inconsistency lies. There is a scarcity of work probing *if* and *how* race, ethnicity and diversity are taught in English special schools or the intersectionality between race, culture and different abilities (Blanchett, Klingner and Harry, 2009) which is important to the general discussion of dis/ability and education. Several studies have covered these as broader topics for example teaching diverse students in mainstream and Higher Education settings and how to deliver a multicultural curriculum to Black and ethnic students (Cochran-Smith, 1995a; Cochran-Smith, 1995b; Ladson-Billings, 1999; Maylor, 2010) but more research is needed.

Bhopal and Ramie (2014) conducted a qualitative study on trainee teachers who took part in a series of interviews that investigated their views on race and diversity, personal identity, their preparedness for tackling issues of race in the classroom and other such issues related to the topic of race. Their findings suggest that student teachers require more in-depth training and support in developing their awareness of diversity and tackling racism in the classroom. Another important finding from the study was that the participants were acutely aware of their own identities, including race and gender and how they affect student learning. However, what findings would such a study present in a special school in England? The perspectives of English special school personnel in education discourses about race and culture are largely void from literature or focus on mainstream, further or higher education.

The accounts and interactions related to this study's themes shared by English special school staff (and all participants) reflect the need for and value of their experiences, and if we are to learn more about the intersectionality of race, ethnicity, identity and autism within specialist institutions in England then we must lift the lid on the pedagogy and philosophy within these spaces and dig deeper. It is not enough to simply assume that special schools recognise the importance of race, ethnicity and culture in their settings or that they understand the complexity that these interconnected identities have on Black children/ young people with autism and their families. I strongly believe that education, which includes special education, has a duty of care to ensure that their ethos, teaching

practices, curriculum, environment and overall work is equitable and diverse, which can have a significant impact on the ways that children/ young people see themselves and others, which must not be the responsibility of the family alone.

Parents and the family are typically characterised as the primary agents of socialisation (Anastasiu, 2011; Kuczynski, Parkin and Pitman, 2015; Bæck, 2017), the first to teach a child about the ways of being, morals and life in general before they are instructed and socialised further through school and other modes, such as their peers, and begin to make their own meanings of life and the world around them. Despite the prominence of the role of parents and families in shaping the lives of their offspring there is a lack of research and literature available that captures the views and thoughts of Black parents that have children/ young people in special schools in England and more globally. This shortage of research includes whether these parents and carers of Black children/ young people with autism teach them about race and culture for example, and if they do, how and why are they doing this. In chapter three, I will review some of the literature around racial and cultural socialisation in greater detail and some of the ways parents are tackling important issues of racism and diversity in today's society with their children/ young people.

One of the aims of this research, which will be explained further in both the auto/biographical chapter (chapter two) and the methodology chapter (chapter four) is to understand how my role as a mother has influenced my son's racial, ethnic and cultural identity/identities. By analysing the experiences of participants with a similar positionality as me: *parents* (i.e., parents from a Black Caribbean or African background with a child/ young person with an autism diagnosis, who is attending or has attended a special school in England) and *special school personnel* (i.e., experience of teaching, working with children/ young people with autism in an English special school), I was able to not only critically reflect on my own experiences but also the personal accounts of these participants so as to begin to gain a deeper understanding of race, identity and autism as discussed in chapters five and six.

To further contextualise the purpose of this study, as mentioned in the introduction of this chapter, research that involves participants with different abilities and other marginalised

groups remains sparse. Their perspectives are the missing piece of a larger puzzle that provides personal knowledge and experiences with which to develop a more profound understanding of any subject. In recent years, there has been an increase in studies that involve the active participation of people with different abilities, especially children. Farmer and Macleod (2011) provided comprehensive guidance on involving disabled people in social research that included how to do so, as well as the benefits of having their involvement. The document was produced by the Office of Disability Issues and utilised academic and empirical literature and research as a foundation for the guidance. Although it was produced over a decade ago, there is some useful information that remains helpful today, such as the barriers to involvement, types of research that disabled people could take part in and different ways to include disabled groups in research. Despite the usefulness of this guidance, however, it does not make explicit reference to research that involves those who have multiple modes of marginalisation, such as ethnic minority groups and children/ young people with different abilities and needs (e.g. non-speaking communicators), which could be an indication of society's view during that moment in time.

In more recent times, however, there has been a shift in recognising individuals with different abilities as they themselves, along with numerous allies have been championing and advocating for their rights. Such action not only includes taking part in more research (as a participant) but also being involved in the research processes themselves (participatory research) as an affected member of the community being researched, best suited to identify issues and solutions (Bailey *et al.*, 2015; Rios *et al.*, 2016; Macaulay, 2017). In this study, Black British children with autism, with differing abilities and needs were significant participants whose involvement provided invaluable, personal experiential information beneficial to better understand this important research. I provide a more in-depth explanation about my intention for including vulnerable Black children/ young people with autism in this study in the chapters that follow.

## **Key Terms**

There are a few key terms used across this thesis, which I have contextualised below. Although often used interchangeably, *race* and *ethnicity* are not the same. Across time, the



argument has developed from them being fixed characteristics (e.g., race: biological, physical attributes such as skin tone) to being more fluid (e.g., ethnicity: belonging to a social group because of shared commonalities such as heritage, culture, or language). While race and ethnicity are both socially constructed notions, this social construction manifests itself differently in everyday life, relationships, and social issues based on the varying inequality that exists within them (Gillborn, 1990; Hall, 1992; Lewis and Phoenix, 2004; Valdez and Golash-Boza, 2017). Meanwhile, *culture* is also defined as a shifting process whereby people are linked together because of shared values, traditions, customs, ways of life, or belief (Egede, 2006). In this thesis, I acknowledge race, ethnicity and culture as separate constructs and considered them through an intersectional lens. However, it was recognised through several of the interviews with the different adult participant groups, as well as some studies and literature, that race and ethnicity were understood and utilised as similar, or the same concepts, as were ethnicity and culture.

*Special Educational Needs and Disabilities (SEND) or Special Educational Needs (SEN)* is an overarching name given to disabilities and difficulties that impact a child or young person's ability to learn and requires provisions to be made for education and health (Department for Education, 2015; NHS England, no-date a).

*Special Schools or Special Educational/ Special Needs Schools* are a provision that specifically caters to learners whose educational and other needs cannot be met within a mainstream school (Queen Margaret University, 2023; Twinkl, no-date; The School Run, no-date).

*Dis/ability, different ability.* These are my preferred terms for disability, which I have quickly touched on earlier in this chapter and will expand on further in the next two. I have used these terms interchangeably. However, where I refer to existing literature and information, I use the term that is used (e.g. 'disability').

Due to the varying needs and cognitive abilities of children and young people with autism, knowledge is constructed in diverse subjective ways. Therefore, when referring to the children and young people with autism that took part in this study, I have used the term '*understanding*' as a blanket term to include awareness, engagement, interaction, and

recognition.

I refer to the *institution* as structures and groups within society that establish and maintain rules and customs within society. They hold varying positions of power with particular functions that can include upholding order and laws, or socialisation, examples include the family and education (Laslett, 1973).

Finally, I have used *gender* in this study to define the sex (i.e., male/ female) assigned at birth of the children/ young people with autism who took part in this study, as both self-identified themselves and designated by parents and school personnel.

## Chapter Outline

Because of the auto/biographical lens with which this study is partially founded on there are more chapters than that of a traditional thesis, which includes the voices of several central participants. In order to make these contributions more visible, I have intentionally colour-coded only the main participants comments as seen here: *myself*, *children/ young people with autism* (including my son), *parents* and *school personnel*.

*Chapter one* provides the introduction to the thesis, the rationale for the research, research questions, background, and current setting of the themes of the study, as well as key terms regularly used throughout and a chapter-by-chapter overview.

In *chapter two* I share some personal and sensitive reflections of my life as a Black mom from a Caribbean background to my young Black son with autism, which includes some of his own accounts, shared in his own way as a non-speaking communicator, as well as my lived experiences as a SEND professional working in a special school in England. Using a few of my private journal entries and public autism blog posts, I provide an intimate look at a life affected and inspired by autism intersected with race, ethnicity and culture in stories titled “*mothering autism... while Black*” and “*just go back where you came from, you Black...*”. While chapter two predominately focuses on the auto in this auto/biographical study, it establishes the basis with which the experiences of the participants that took part in this study were analysed and reflected upon and connect to my stories in chapters five and six. This chapter also serves as the beginning of the literature review related to some

of this study's main themes: race, ethnicity, culture, identity and autism, which spans both this chapter and the next.

The literature review continues into *chapter three* as I further discuss more of the empirical studies pertaining to my research. I will critically examine existing literature to help investigate my research questions in the areas of *autism and identity formation* and *racial, ethnic, cultural socialisation*. The literature review in both this and chapter two subsequently provides a basis for the discussions of the results in chapters five and six.

I provide a comprehensive rationale for this study in *chapter four's* methodology. I explain my justification for the entire research process from the methods used and how the research was conducted to how the data was analysed using thematic analysis. The methodology chapter is extremely detailed because of the inclusion of vulnerable children and young people with autism as participants in this study.

Chapters five and six contain the results and discussion of the analysed data from over 40 interviews with Black British children and young people with autism, parents of Black British children/ young people with autism, school personnel with experience teaching, supporting, and working with minority ethnic children/ young people in special schools in England. Findings in chapter five focus on 'identity' and covers themes that include: *Awareness/ understanding* and *identity formation/ empowerment*, while chapter six explores the 'institution' and themes of *teaching and curriculum challenges* and *school socialisation*. The institution refers to school and education overall, but also touches on the role of the family as an institution in its own right. Each theme across the two results chapters are analysed against literature and theoretical perspectives of Intersectionality and Disability Critical Race Theory (DisCrit).

These two chapters bring the auto/biographical focus in chapter two full circle, as I reflect on the results from the study through my unique positionalities: *mother to a young Black son with autism, SEND professional and researcher*. In this space, I carefully ponder the experiences of the participants in this study and how they interconnect with my own stories in the construction and co-production of knowledge of self and others. Knowledge that is both subjective and unapologetic for bringing to life the lived experiences and voices of

marginalised groups through an auto/biographical perspective.

The conclusion is chapter seven, a summary of the thesis. It comprises of a recap of the study and the key highlights as well as the study's limitations, my reflection as a researcher, and recommendations for further study. The chapter is followed by a full reference list and appendices.

### **Chapter Summary**

In this introductory chapter I have provided an outline of this study that explores the intersection of race, ethnicity, culture and identity among Black British children/ young people with autism. I have explained the rationale for this research study, as well as a brief background and the current context that the main themes are situated within. In addition, key terms that are used consistently throughout this study are defined, finally ending with a short chapter outline of each the seven chapters. The next chapter is where this study begins with an intimate auto/biographical look at my own experiences as the Black mother of a young Black man with autism and SEND education professional trying to make sense of race, ethnicity, and culture in our autistic lives.

## **Chapter Two: The ‘me’, ‘he’ and ‘we’: Using Auto/Biography to explore how my distinct identities and lived experiences influence my son’s identities**

### **Introduction**

Watching my son develop his own sense of identity, as a young Black man with autism has been the major catalyst for this research as I try to understand how he understands who he is compared to who I, and even society see him as. I have been forced to confront, relive, and reflect on the ways in which my own racial, ethnic and cultural identities have been constructed and reconstructed over time, as I watch him navigate his place in the world. A world that does not always accept or respect the diverse nature of his different and connected identities. In this chapter, I explain my rationale behind using auto/biography as a methodological approach. In addition, I share some personal accounts as a mother and SEND professional, which are central to my ‘insider/outsider’ positionality in this study, both of which influence my role as a researcher and my identity. I will discuss positionality here in this chapter, the methodology chapter and also in the results chapters (five and six), which will be used to reflect on the findings from the different participant groups connecting our stories and experiences together through auto/biography.

The brief stories that follow have been shaped by one or more of the themes of this study (i.e., race, ethnicity, culture, identity, and autism) and connect to notions of ‘identity’ and ‘institution’. They begin with my accounts including the journey of my migrant parents from the Caribbean to England; parts of my childhood and schooling; becoming a parent to a Black child with autism and working in an English special school. Next, I will share some of my son’s experiences as a young Black man in England with autism, not only as I have experienced them as his mother, but also communicated in his own words. As a non-speaking young person my son uses a mix of augmentative and adaptive communication (AAC) tools, such as symbols and pictures, which will be explained in the methodology chapter. This chapter begins to relate much of the literature available on the broad themes of this study through a personal lens, which in turn allowed me to self-reflect on the experiences of the participants in this study and my own positionality, as will be seen later

in this thesis in chapters five and six.

### **Auto/Biography as our story, and our story as research**

So why Auto/Biography? Why is sharing my story, my son's story, in our own words important? How does it help to make meaning of the experiences of others and their stories? And, what has our story got to do with intersecting race, ethnicity, identity and autism? Well, it has taken me many years to come to terms with my son's different abilities. I personally try to refrain from using the word 'disability' because of the prejudicial origins of the word that I have grown up around and witnessed, which would immediately situate his ability as being detrimental or harmful. While in more recent times the negative constructions of the term disabled are being reframed as some disabled people and groups positively reclaim the word (Fitzgerald, 1997; Andrews *et al.*, 2019; Andrews and Forber-Pratt, 2022), the word disability still conjures up painful reminders of my own childhood and teenage experiences of how people with different abilities were ridiculed and treated unfairly.

It was not until I started working in special schools that I realised that the feelings that I had as a parent of a young person with autism were like those of other parents of children with autism and SEND. Feelings of guilt, shame, hurt, anger, and a plethora of other emotions and thoughts that have parents and carers often questioning "*why our child*" or "*what did I do wrong*"? These human exchanges or stories seemed only to be discussed within what felt like a secret society for fear that people would judge and not understand us. I started to feel as though there were often racial, and cultural undertones at play in many of the interactions that I had with schools and professionals charged with supporting my son's acute needs or even random people in the street and so I sought to learn more. Learning more would involve not only our experiences but that of others; in the search for answers of a wider phenomenon, which is typically auto/ethnographic in nature.

While auto/ethnography is a more established research method, it is not the only one and I chose auto/ biography because it resonated with me and the ways in which I wanted to write this thesis. What initially appealed to me about using auto/biography as the foundation of this research was its ability to allow me to be both reflexive and critical of

my various positionalities, but also draw on the perspectives and stories of others (Parsons and Chappell, 2020). I have kept a personal journal since my early teenage years as a therapeutic release of emotions that has aided my mental and emotional wellbeing (Riddell *et al.*, 2020) and more so to express my inner thoughts and feelings about life and the many roads that I have travelled as it happens, which includes my roles as a mother and SEND professional. However, in my capacity as a researcher that sits separate to these identities, I have had to critically evaluate these stories from others and my own meanings. I believe that if this research were devoid of some of my personal stories of race, ethnicity, identity and autism, which are at the very heart of it, how could anyone connect and understand the relevance and cruciality of the study. However, I acknowledge that sharing my lived experiences would require me to be vulnerable and share intimate details of not only my life, but also my son's, who as a young person with autism is already considered vulnerable. I chronicled the inner monologues of my decision to include our stories within the research study, in my journal, writing:

*Do people really wanna hear stories about a Black woman teaching her son with autism about his racial and cultural identities? I can't seem to find them anywhere in research... girl, have you just answered your own question? I gotta be honest and share what life is really like for us, because honey, it ain't nothing like the stories told by the white women on TV. [sic]*

Journal entry, (Holder, 2021a)

I am a Black woman, of which I am incredibly proud. That pride, however, juxtaposes the reality of being a Black woman today whereby a Black woman's pride and ambition is often perceived negatively as aggression or worse still (Collins, 1986; Griffin, 2012; Chigwada, 2013; Bryan, Dadzie and Scafe, 2018). I am inherently connected to such a powerful yet racialised history that polices everything from my hairstyles to my vernacular, my parenting skills to my academic ability and all that lies between (Kinouani, 2021). Personally, I feel the weight of such incessant judgement. Moreover, it impacts all areas of my life in ways that I am often afraid to share, again because of that fear I spoke of earlier, fear of being criticised further for being too emotive and sensitive. Evidence suggests that such an onerous weight can lead to the autoethnographic stories, experiences of Black women

being ignored, deemed irrelevant, and undervalued in research particularly, with the risk of not being heard at all (Thomas, 2004; Hill, 2019; Davis *et al.*, 2021). Although in recent times, as evidenced by the works of Davis (1974, 2023) and bell hooks (2015) to name but a few, once unheard voices, invisible faces and vacant narratives of Black women across disciplines, within empirical research and wider society have started to unapologetically emerge, disrupting Whiteness and Eurocentricity as a singular story, highlighting the importance of Black and indigenous representation in stories as a right and necessity (Reynolds, 2002; Bloom and Erlandson, 2003; Adichie, 2009; Ross and Godwin, 2015; Ireland *et al.*, 2018).

My earlier journal entry gives rise to the ways in which my thoughts and feelings seek to challenge the westernised hierarchy of philosophy that has albeit erased any other view as valuable. Kovach (2021) argues that indigenous research and methodologies have their own identities and significance that are central to greater understanding and creating outcomes relative to these groups. I cannot ignore or escape my racial and ethnic roots and their influence on my identity, not that I would want to, but I use this statement to argue that I cannot either erase myself, history, nor my lived experiences from this research, as I am both an insider and outsider, closely linked to the themes central to this study. I am the auto/ but the story does not come full circle without the biography, some of which we explore here but also in the latter results chapters.

My research also focuses on the experiences and accounts of others in their own words, as they understand and feel them, which I have used to interpret what we can learn about developing racial, ethnic and cultural identity in Black British children and young people with autism. By using experiences from an auto/ biographical perspective the research develops through the reciprocity of experiences from self and others. There is a relatability in auto/biography that not only adds to human knowledge but elicits empathy through the sharing of stories that can resonate with people living through similar experiences. Chappell and Parsons (2021) assert that stories give rise to contesting assumptions we hold true and afford opportunities to delve into the ways we are both alike and unlike. Equally, personal stories disclose problems that are still present, which may have been forgotten, misunderstood, or even ignored. Beyond the knowledge that auto/biography in research



provides, it also opens the 'what is behind closed doors' to the public sphere, necessary for co-construction, transformation, interpretation and solution-based discourse, no different to other types of research. By laying bare the private challenges of life that we contend with on a micro level, we can explore how they are inherently linked to the wider, macro-type of injustices and problems embedded in our society (Plummer, 2016).

In this study, the auto (my)/ biographical (others) stories illuminate the impact of structural inequalities such as racism and discrimination on the personal lives of individuals, families and others to better analyse and learn from their experiences. I was surprised at the similarities between some of my own stories and the lived experiences of the parents and school personnel participants explored in chapters five and six, emphasising the power in using auto/biography in research. Another perspective about auto/biography is provided by Brown (2020) who asserts that auto/biography can be used to delve into the complexities of race and culture and how they connect to a society that is constructed on power and difference. She further suggests that auto/biographical study encapsulates layered dimensions such as race and racism by those who experience it in a social world. Likewise, Rogers (2020) offers that the unique perspective of the insider captured through auto/biographical life stories requires researchers to engage with their positioning throughout the research process, as she has done in her work exploring disability and social justice. Both authors have highlighted strengths in auto/biographical research, operating within some of the themes that my own thesis is investigating, race, culture and disability.

So how does auto/ biographical stories and storytelling translate into research? Lewis (2011) suggests that there is life in stories that elicits human qualities and has an identity of its own, although this approach is underutilised in research. In his enquiry of how stories/ storytelling sits within research, he suggests that they have an important role of amplifying silenced and invisible voices and by continually utilising stories in this way we open ourselves to limitless new findings. Similarly, Gallagher (2011) champions the value of stories in educational research while also cautiously warning that due diligence should be given in accepting the provocation that they can cause and openings they close. In addition, personal storytelling in research whether through *narrative accounts* (Wang, Koh and Song, 2015), *autoethnography* (Adams and Manning, 2015), or *auto/biography* (Letherby, 2000)

extends the reach to a wider audience, provides insider perspectives, and contributes to underexplored fields. Thus, utilising auto/biography in this research study allowed me to connect with the research on a deeper level, learning from my own reflections and the experiences of others. I know that I am not the only Black mother raising a young Black adult with autism. My lived experiences as not only his mother but also as a SEND educator for over 12 years allows me intimate and unique access inside his world (and that of the participants in this study), both as a participant and observer, which as a researcher is a privileged yet delicate space to occupy.

## **Part 1: Identity**

### **Generational wealth: Stories from the first generation shaping the next generation**

I recognise that my son is a product of his environment, which primarily includes my own upbringing. I only have to look back at the primary agents of socialisation in my own life, my family, to understand where most of my racial, ethnic and cultural identity/identities come from, which then extends to my son. I am who I am largely due to the struggles, sacrifices, and successes of my parents, first generation migrants from the Caribbean. I consider myself rich with generational wealth that money cannot buy, overflowing with my parents' treasured tales of life from another land and time. I am blessed to have grown up with the stories of their journey to England or "*the strange land*" as my Daddy called it when he first landed on cold British soil on the morning of October 19<sup>th</sup>, 1967. Their intimate accounts of leaving behind the sun-soaked, calypso-infused, clear sea small islands of Barbados and St. Vincent respectively, provide a resonant historical and social perspective of diaspora and migration through their eyes.

My Daddy has not forgotten any of the detail in his migration storytelling. From his 'Sunday best clothing' that he was wearing (which he only wore to church or for special occasions) when he was leaving Barbados to the smell of the big metal airplane full of Bajan men and women in search of their new tomorrow. He even speaks of the conflicted looks of worry which they tried to hide amid the happy ones from the family that they were leaving behind. At 21 years old, my Daddy was a young unmarried man in his prime, a high-school

graduate and avid player of the Barbadian national sport, cricket. The oldest son of nine, but he says *"those are the ones I knew about"* with a slight chuckle. He explained that representatives from British transport came to Barbados to recruit personnel for buses, trains, and hospitals (London Transport Museum, no-date). The main requirement was that those applying understood *"pounds, shillings, and pence"*. He saw the British recruitment search as an opportunity to better his own life and that of his mother and siblings in Barbados. When he arrived in Britain, he recalled that he was often told, *"this was your new home now"* but in truth it was nothing like home for him, certainly not at first glance. Hard grey pavements replaced the loose gravel and sandy sidewalks that he was familiar with. The air was cold, colder than he had ever known and the large trees with fallen autumnal leaves replaced the palm and coconut trees that he was able to scale in seconds. *"Everyone looked at us funny for a while... I don't think they saw many Black people before"* he exclaimed with a laugh, *"some treated us as humans too, but not many"*. When I asked why, he told me *"because we were Black and foreigners"* accused of *"taking their jobs"* by White British people, and that statement has never left my mind.

He has told me that he put much of the racial abuse and discrimination that he suffered as a bus driver for London Transport to the back of his mind because in *"those days you just had to deal with it... it wasn't nice, but you just had to take it"*. My Daddy is a cool and soft-spoken man that still has his strong Bajan accent. He has been my hero from the time I knew what the word meant and probably before that. I am most like my daddy of both my parents: resilient, determined, and studious and the Black and Bajan pride he brandishes like a badge of honour was instrumental in enriching my own racial, ethnic and cultural identity in my childhood. In 1970, my Daddy returned to Barbados, three years after his arrival in England to marry my mother who he had been dating for a few years. They both returned to Britain the following year to start their new lives together as husband and wife or in employment terms, bus driver and nurse.

My mom was, we are, descendant of 'Amerindians' (the term my mom was taught and used), proud indigenous people of the Americas. Before her passing, she told me some stories of her *"fair-skinned, long black curly haired"* indigenous American Indian grandmother, who was a *"disciplinarian and loved nice things"*, an equally apt description

that I would use for my mother. Through the years my mom has guarded much of her lived experiences, those related to her racial and ethnic identity specifically, conditioned by the notion that Black women must have a thicker skin and be strong (Baker-Bell, 2017; West, Donovan and Daniel, 2016). Some of the tales that she has shared with me are harder to swallow. I have questioned whether this is because I am now older and a Black woman with a son of my own, although I cannot begin to fathom how she must have felt when she was constantly taunted during her nursing days to *“turn around and show us your tail”*, like she was some sort of animal or someone to be fetishized and objectified over as Sara ‘Saartjie’ Baartman tragically was centuries prior (Henderson, 2014).

Thinking back, she was always more reluctant than my Daddy was to share some of her experiences with me, especially when I was younger. She has since told me that she wanted very much to protect me from the racial, gendered, ethnic experiences and ill-treatment she received in the same way that I want to protect my son (Brown, 2020). Her sad eyes used to avoid mine when she talked about what it was like to be the one of two only Black nurses in a British hospital in a new country. These experiences were further intensified because her melanin skin was the deeper, darker, blacker of the two. Although, if my mom was considered dark-skinned in comparison to her colleague, her peer must have been almost white, as to look at my mom was to look at someone more ‘red skin’ in complexion. I remember how much she would lather my brown skin with cocoa butter *“black girls, don’t go out with dry skin”* as she would always say, and slick down my natural hair with grease. Although she has since passed away, I still think of my mother as a typical Caribbean woman: strong (by choice and condition), traditional, and proud. My parents had to overcome countless sacrifices and toils to raise my brother and I during the ever-changing landscape of political, economic, and social 1970s England, where they were constantly reminded by some that as Black migrants from the Caribbean, *“this isn’t your home, don’t forget that!”* [sic].

The migration of people from the Caribbean to the UK is well documented. My parents, like many other families from the West Indies during that time are representative of the Windrush Generation (Peplow, 2019; Taylor, 2020; Royal Museums Greenwich, no-date). Individuals and families from across the Caribbean migrated to the UK in response to direct

recruitment and personal invitation by the British government to help rebuild the country in the wake of the devastation and turmoil of World War II (Gmelch, 1992; McDowell, 2020). This poignant moment in History, charts the migration course of Caribbean passengers who first arrived in Britain on the Empire Windrush in the 1940s over 30 years (Wardle and Obermueller, 2018; Grant, no-date). Their symbolic journey to the land that once colonised their islands was not without trial and tribulation, as powerful stories in their own words tell of racial prejudice and hardship back then (Matthews, 2018; Grant, 2020) moreover tainted by a scandal of rejection and abandonment in present day (Gentleman, 2020; Hewitt, 2020). By briefly sharing and reflecting on parts of my father and mother's journey in this research I can connect their biographical stories to those of my son and I, and their relevance in helping to shape our identities.

The gendered migration narratives of my parents intersected with their racial, ethnic and cultural identities are credited with shaping much of who I was as a child and indeed who I evolved into and continue to be as an adult today. A Black woman who is mothering her son with the same cultural and ethnic traditions, expectations, and values that she was raised with, in ways that are appropriate to his needs and understanding. Because an autism diagnosis should not disconnect him from knowing and taking pride in his distinct characteristics, especially if society will in turn disadvantage him because of some of those same traits, more so the visible ones (i.e., gender and race). The stories of my parents are as precious and invaluable as treasures from the lands of their birth. I did not truly understand or appreciate all that they endured so that my brother and I would have what they believed would be a better life, determined to ensure we did not lose sight of our rich Caribbean heritage, even if at times we were judged because of it.

I still use the term West Indian, as it is what I was called growing up and still today. My West Indian heritage is such an important part of my history and identity. It unites the different fibres of my identities, not just my ethnicity, but my gender, religion and cultural beliefs. It has become reconstructed and continues to change over time. Levitt (2009) asserts that second-generation children of migrants who are deeply raised and connected to their ancestral roots will naturally become socialised into their ways and customs. My Daddy always says that *"the West Indies is not just where I'm from, but it's who I am"*. Both

of my parents are immensely proud of where they are from and always planned to permanently return in their golden years. I recall my many visits to Barbados as a child being spoilt by my paternal granny, aunts, and uncles without a care in the world. We played outside with bare feet until it was dark, chased lizards on the veranda and the ocean was our bath water. The sounds of sweet soca music filled the air along with the melodic accents and enunciations that were the Bajan and British blends for many migrants that were able to visit home. As cliché as it sounds, my siblings and I were always reminded that it was important to never forget where we came from. We understood the context of that statement as not forgetting 'our Caribbean roots' as it made our parents, who made us, intricately linked.

Both of my parents made sure to keep that connection alive, especially my mom. She made sure that the family was connected to our Caribbean roots in every way possible like through both the Bajan and Vincentian *food* that we ate (e.g., cuckoo, conkies, roasted breadfruit, curry chicken, and roti); *music* that we listened to (calypso, soca, country, and gospel on Sundays); *events* we attended (Caribbean cricket matches as my Daddy was a star player, parties, West Indian community celebrations) and even the *area* that we lived in, a largely populated Caribbean borough in London. Our home was also a visual reminder of their home islands with the flags of both Barbados and St. Vincent and the Grenadines all over the house, along with countless other souvenirs and trinkets. Cultural traditions and values were introduced to my brother and I very early on such as cleaning the whole house on Saturdays, church every Sunday in your well-ironed Sunday best, followed by a big family dinner cooked without fail by my mom.

The only gender-specific element in my early childhood that I remember was that my mom mainly did all the cooking and cleaning, girls played with dolls and boys had action-figures, my gendered identity was developed more when I went to school. We addressed friends of our parents as 'aunty' or 'uncle', you did not talk back and if you did, then your punishment would involve 'licks' with the belt, wooden spoon, or whatever was nearby. Everything we did, said, how we behaved and who we were around as a family was because of their engrained deep ethnic and cultural upbringing. These values have remained passed down through the generations and have been embraced by me, embedded as fundamental

parts of my home and life, which have served as a foundation to disrupt the racism and inequality experienced by my parents (Sutherland, 2006). Both of my parents would say *“everyone in the West Indies is Black, we didn’t even think about race until we came here”*, here being England. The colonial chains that England had over the Caribbean impacted them differently when they lived there. Therefore, the racial elements of their identity, which then formed part of my identity was to always be proud to be Black, that was until I started to become conditioned in and by environments outside of their control.

### **Why don’t I look like Lucy Ewing?... I don’t wanna be Kunta Kinte!**

I lived in innocent bliss unaware of the lasting, detrimental effects of racism that I would soon experience as a young impressionable girl. My parents did all they could to shelter my brother and I from the harsh reality that was beyond the safety of our home, although I will share two brief stories that impacted my racial identity forever. Television programmes that portrayed Black people in a positive light were rare. Everything from commercials to cartoons, soap operas to dramas represented Black men and women as either enslaved, criminals, orphans, servants, in need of help/ saving by White people, sexual objects with grossly exaggerated features and other characters beside. I do not remember ever seeing us as doctors, lawyers, teachers or wealthy housewives until later in the 80s when I first watched The Cosby Show. I lived in the fantasy world of Charlies Angels and Dallas always represented by glamorous white women and girls. Even the poor white people on TV had it better than Black people when I was a child.

One evening while watching TV with my mom and brother, I became mesmerised by Lucy Ewing, a character from the TV drama Dallas (Britannica, no-date). She was a little older than me at the time with beautiful blonde, shiny hair, perfect white smile, and cool clothes. I was glued to the screen and at one point pouted and shouted, *“why don’t I look like Lucy Ewing?”* to which my brother shouted back, *“because you’re Black, dummy, we don’t look like them”* [sic]. I could not let it go and my rebuttal was quick, *“well where were the Black girls like Lucy Ewing then”*, my brother kissed his teeth, and my mom said nothing. I sat and stewed for most of the evening until my daddy came home. I figured that if anyone would tell me where those girls were, it would be him. I pounced on him as soon as he got home, not even giving him time to put down his money tray from the bus or take off his uniform.

I first asked him my initial question about looking like Lucy Ewing, and he smiled before responding, *“because you’re not supposed to look like anyone else, God made you my beautiful brown girl”*, he went on to say *“you’re the most beautiful girl in the world, you don’t wanna look like anyone else”* [sic]. He then started to explain that Black people were treated differently because of the way we looked and pulled out some of his old Britannia encyclopaedias to tell me more. There were discussions that I had overheard between the grown folks at events we attended when I was younger about what I later learned was racism but this discussion with my daddy was different, because at the time, I really wanted to be like Lucy Ewing, and did not understand why being Black meant that I could not.

I was momentarily transfixed on Lucy and the glamour of Dallas before becoming traumatised by the harsh reality of ‘Roots: the miniseries’ (Havens, 2013), which felt like a baptism of fire into the worst of racial injustices, slavery. To this day, I have not been able to watch Roots again as seeing Kunte Kinte being whipped and beaten as an enslaved Black male in the era of slavery in the United States. I remember crying uncontrollably saying *“I don’t wanna be Kunte Kinte”* and telling my daddy and brother that *“I don’t want us to become slaves”*. I was too young to grasp the magnitude of what I had witnessed on the small colour tv screen, but it left a lingering pain that stayed with me until early adulthood that made me ponder whether being Black was truly something to be proud of as my parents had always taught us. I did not have much time to wonder, as the next structure to fan the flames of doubt over my racial, ethnic and cultural identity/identities was waiting, education.

### **West Indian migrant children and the British education system**

As a second-generation immigrant born in England in the mid-1970s, education was different for me, as it was for parents in the Caribbean, and is now for my son. Such changes in teaching and learning practices is to be expected as education has political, cultural and social connotations that are relevant of place, time, status, and more. Even though we were born in England, we were still considered West Indian children due to our parental ancestry. My parents, brother, and I all recall obvious racial and gender discrimination when it came to the British education my older brother and I received related to how we wore our natural hair, the home cooked meals we had at lunch, and not omitting our



academic ability. I remember witnessing my brother and other Black boys being shouted at and labelled as 'troublemakers' by White faculty members, as their White peers who were often the real culprits were ignored and even praised. I enjoyed school mostly, which could have been because I did not receive the same treatment as my brother or the other Black males. Girls, irrespective of race, depending on the situation, seemed to get away with more, although I do remember that when I sat with my Black friends, we were told off more, even though the White girls were often louder. My mom liked to remind me that I once said to a teacher *"don't shout at me when you're not shouting at the white girls"*. That was the first and last time she got a call from the school about me, but at home, she told me that she was proud that I stood up for myself.

We, the Black pupils, also did not get the same academic attention and support as that of the other group of White kids, I remember that vividly. Even the Indian children and the few Chinese pupils at the school received more preferential treatment. While I consider myself as someone who is academically focused, I was very much pushed towards sports and other subjects like cookery, while the White, Chinese, and Indian girls and boys were heavily encouraged toward Science, Technology, Engineering and Maths (STEM) subjects. At the time I did not grasp the racial, class, gender and stereotypical practices at play at school, even within the broader minority ethnic groups (McDonald and Hayes, 2003; Archer and Francis, 2007), which often transferred from the adults (teachers and school staff) to the children into all areas imaginable like playgrounds and friendship groups.

Taunts like *"you can't play with me because you're Black"*, *"your hair is funny and rough"*, *"why is your skin so dark, did you get burnt"*, *"Black girls are ugly with big lips and noses"*, *"ewww, you smell like curry"* and more than I want to revisit, were routine at primary school. I can remember running crying to my big brother the first time a White boy said that he would not play with me because I was a Black girl, *"I don't want your dirt on my skin"*. My brother was two years older than me but was extremely tall and had a heavy build. Most kids at school were afraid of him but he was my big bro and would not let anyone mess with me. Although big, he was gentle and told the boy in no uncertain terms to say sorry and not to talk to me again if he was not going to be nice.

Because of my big brother I did not have to deal with many cruel racial jabs when younger and only remember a handful of incidents where kids were mean to me because of my race, ethnicity or both. However, once was enough to leave a lasting impression on my early childhood identity that being a Black girl meant that I was not considered smart enough, pretty enough, or worthy of being treated the same as everyone else. It also made me think that for my brother who was always around to save the day, being a Black boy meant that for some he was considered scary, not smart, and a problem. Parallels that I have experienced with my son, who resembles my brother in his youth. Not everyone had an awesome brother like mine, and he was not always going to be around. So, like I had seen my parents do, particularly my mother, I developed a thick skin that in some ways protected me when at school, pushing the pain that I associated with being Black in that space, at that time, deep within (Kinouani, 2021).

All of our teachers were White in primary school. The lack of Black teaching staff at all levels that is still evident in English education today (Callendar, 2018; Gorard *et al.*, 2023) was noticeable and my pre-teen mind could not comprehend why even though there were lots of Black people in my area, none of them were teachers or headteachers but rather the custodial or kitchen staff. When my brother and I have reflected on our time in school, he remembers being told that he was always “underachieving”, “*not good enough*” or called names such as “*stupid*” and “*dunce*” when he asked for help. I have heard the term ‘underachieving’ used in current times in relation to my own son and Black boys more generally in British education including special schools.

Like my parents, my big brother has stories of his own that tell of the trauma that has been retold in literature about Black boys being treated *unfairly and disciplined harshly* (Crozier, 2005), *treated different to girls including Black girls and other minoritised groups* (Gillborn, 1997), *experiencing racism* (Graham and Robinson, 2004; Ochieng, 2011), *inequitable access to opportunity* (Osborne, 2001), underachieving and with lower ability (Sewell, 1997; Crozier, 2005; Demie, 2022) and masculine identities (Davis, 2001; Sewell and Majors, 2001) because of the colour of their skin. In fact, my brother and I also experienced some of these issues in other contexts, when we were schooled internationally, in the United States and the Caribbean, which were constructed in systemic racism, religion, and

colonialism. In England at the time, learners who were children of the Windrush generation and Caribbean migrants were endemically depicted as substantially inferior and mentally incapacitated (Graham, 2001; Sewell, 2001; Pheonix, 2009; Hamilton, 2017).

Coard's (1971) critical report on the disproportionality of West Indian children in schools for the "Educationally Subnormal" (pg.49) was one of the first of its kind to expose racist and discriminatory ways in British schools. This disturbing period in British history was recently revisited as the subject of a BBC documentary, 'Subnormal: A British Scandal' (BBC, no-date). A Black Caribbean national himself, who previously taught in his native Grenada, Coard found that West Indian children were being unfairly placed in special schools because of their ethnicity and dialect with teachers failing to recognise their capability and skills. They were singled out as being different, labelled as academically inadequate, which not only impacted their education but their employment opportunities, well-being, and identity. In addition, according to Coard, the Black Caribbean children who remained in mainstream schools still had to contend with low teacher expectations and the ramifications of systemic racism that led to their low self-esteem and lack of confidence.

The misidentification of academic deficiency and special educational needs of West Indian children based on racial discrimination, as amplified by Coard, has been supported and repeated in various studies and government reports. Tomlinson's (1981) study investigated the decision-making processes involved in determining children unsuitable for mainstream schools instead "educationally subnormal" (pg.3), by way of inaccurately classifying them as "handicapped" (pg.1) (a term commonly used during that time) typically under a façade of challenging behaviour and learning issues. Her work substantiated much of Coard's findings, specifically the overrepresentation of West Indian children deemed to have learning disabilities which she argued was constructed as a social practice built upon structural ideals of order and power. The Rampton Report (1981), which concluded as The Swann Report (1985), was instructed to inquire about the academic performance of West Indian children. Specific reference and recognition was made to Coard's seminal book, and his findings regarding the disproportion of Black West Indian children in special school provisions.

The miseducation, misrepresentation and misidentification of Black Caribbean learners abilities, highlighted by Coard (as well as other Black ethnic groups) in English education, still today remains under scrutiny with scholars investigating *school exclusion* (Graham *et al.*, 2019; Demie, 2021), the *attainment gap* (Arday, Branchu and Boliver, 2022) and *SEND* (Strand and Lindorff 2018) a major focus of this thesis. Coard's groundbreaking book provides a substantial historical background of the institutional depiction of the Black West Indian child in British education. However, while Coard's work contends with the intentional prejudiced placement of Black West Indian children in schools for the "educationally subnormal", this thesis draws reference to both his rationale (2005) in chapter four, as well as deploys a contemporary, contextual lens inspired by his work, which explores the persistent systemic barriers and factors influencing attainment, discrimination, ableism and racism among Black British children and young people with autism in English special schools today, later in the institution section of this and later chapters.

Being born British did not mean that my brother and I were exempt from the negative classifications applied to Black children of Caribbean descent. My brother in particular, was always under academic watch, which led him and other Black boys to constantly being singled out as, labelled as delinquent. This scrutiny was only amplified further at home, as our parents, as theirs had been with them were strict with our education. If we got in trouble at school, whether it was justified or not, we got in even more trouble at home, that was their culture, harsh punishments and high expectations. They constantly told us that we had to "*work harder than everyone else because we were Black*" and that was not a choice. We saw for ourselves, how hard they both worked yet how much we struggled financially compared to many of my White friends and their families, my parents' peers.

I look back now and see how those struggles also impacted the family physically, emotionally and mentally, but they dared not show it because their racial, ethnic and cultural identities would not allow it. They were expected to not show signs of weakness, only strength was allowed. I have carried this mantra throughout my life and did not start to make sense of how damaging this outlook has been (Watson-Singleton, 2017; Brown, 2020) until I became a parent myself, a young Black mother with my own set of mountains

to climb and to conquer.

### **Mothering ...while Black**

Collins (2000) critically engages with Black Feminism to explore motherhood outside of the White woman's perspective but rather at the crossroads of race and class. While predominately written through the explicit lens of the African-American mother, many of their ideas can be considered in a UK context, although I would assert that the American political, social, economic backdrop through which race, class and gender are viewed cannot be easily generalised in this country. The author suggests that Black motherhood must be contextualised in the historical connotations of oppression and inequality to comprehend the profound nature of this role. Much like the US, injustice is engrained and deep-rooted in the UK through colonialism and slavery (Horne, 2017; Gamsu, Ashe and Arday, 2024). For the Black woman, motherhood is both a distinctive and shared learning experience with other women but equally a journey of liberation and growth. The author describes motherhood through different domains from the representation of power in motherhood to mother-daughter dynamics and the criticality of socialisation between them, which drew instant parallels with my relationship with my Black Caribbean mother and her authoritative yet protective manner. The bond between mother and child holds deeply personal meaning, which I recognised from the very moment a little test indicated two big blue positive lines.

As soon as I was aware that I was pregnant with my son and after he was born, I worried about his future as a Black man living in a world where he might be considered dangerous because of the colour of his skin or his ethnic makeup. I have personally witnessed Black males in my family and friendship groups being harassed and treated unjustly, as well as the prejudicial media and societal portrayal of Black boys and men as hyper-masculine, gangsters, thugs or villains (Sewell, 1997; Brown, 1999; Smiley and Fakunle, 2016). I wrote quite passionately about the fears that I had for my son in my journal throughout my pregnancy and have continued to document them across the 21 years of his life, with an excerpt from his formative years reading:

*What if he gets into a gang, stopped and searched by Police just because he was hanging*

*on the block like I used to when I was a kid...what if he is racially abused like [family members name] how am I supposed to help him... make it right?*

Journal entry, (Holder, 2004)

In Britain during the era of the 2000s, I recall constantly hearing about the rise of gun, knife and gang-related deaths/ murders, which alone filled me with fear for the life my son would live, in much the same way it worried me for my Black father, brother and partner. I could not ignore the institutional racism embedded in the structures he would become socialised by, based on my own lived experiences and what I read and saw, like *school* (Handel 1988); *media* (Genner and Süß, 2017); or *government* (Banks and Roker, 1994) and their influence on his identities. Statistics continue to direct the narrative that crime and criminality is predominately a problem in Black communities (Gilroy, 2008; Parmar, 2014; Home Office, 2024). Systemic racism highlights the ways in which race, especially Blackness is constructed and positioned throughout society in damaging and adverse narratives, along with the subsequent effects thereof (Doane, 2006; Feagin, 2013; Gillborn, 2018; Demie, 2021). The murders of George Floyd and Breonna Taylor by American police in 2020 saw global demonstrations, protests and movements calling for an end to racial injustice. Recently, calls to action in this country, the United Kingdom, against racial inequity were initiated as a result of the *Windrush Scandal* in 2018 (Lidher, McIntosh and Alexander, 2020; Griffiths and Yeo, 2021); the *Grenfell Tower tragedy* (Preston, 2019; Coxshall, 2020); and the *COVID-19 pandemic* (Davison, Forkert and Grayson, 2020; Clarke, 2021), a glaring reminder of how deep-seated institutionalised racism runs, from immigration to housing, and health to education.

The theoretical foundations of Critical Race Theory (CRT), identify the examination of institutionalised racism and historical poor academic performance of Black Caribbean pupils in British schools as significant and entrenched barriers and obstacles in British education (Bradbury, 2014, Gillborn, 2015). Although the use of CRT in schools has been under fire both here in the UK and US due to fears that it aligns with radical political beliefs. I staunchly disagree with this position. A huge amount of the literature related to race and racism in education is contextualised within CRT (Gillborn, 2005; Annamma, Connor and Ferri, 2013; Lander, 2014; Johnson 2018; Joseph-Salisbury, 2019) and much can be learnt

from CRT, from inception to present about race and education, from the barriers to the lessons, which is key to moving in the direction of change. Therefore, reiterating the significance for a more in-depth look into the relationship at the margins of special education, race and identity. I stress, however, that CRT alone does not fully provide the most suitable framework to critically analyse the deeper intersections of race, ethnicity, identity, and autism. I would raise a similar argument for other singular concepts such as Critical Theory (Held, 1990); Critical Pedagogy (Kincheloe, McLaren and Steinberg, 2011); Social Identity Theory (Huddy, 2001) and others not mentioned.

Theoretically, intersectionality allows the cyclical processes at play in the production and reproduction of racism and other inequalities to be challenged in diverse ways providing greater depth to the themes in this study (Cho, Crenshaw and McCall, 2013). This study, therefore, embraces both Intersectionality and Disability Critical Theory (DisCrit) as a theoretical stance, which will be discussed in chapter four. As although the paradigms of critical theories are valuable, the overlapping themes of race/ ethnicity, culture and dis/ability connected to this work are beyond a singular area and therefore require a theoretical toolkit, built upon more than one idea. Making meaning of the social constructions of race and further extensions of the term, including racism, microaggressions and Whiteness is necessary in understanding an individual strand of this research, but it also requires an intersectional understanding alongside ethnicity, culture, identity and autism.

### **Mothering autism... while Black**

A brief search of the literature on 'mothering children with disabilities' results in an overwhelming number of studies covering everything from *sex and intimacy* (Rogers, 2010) to *COVID-19* (Pozniak and de Camargo, 2021). More explicit searches such as 'mothering Black children with disabilities' include *feminist activism* (McDonald, 1997; Lawson, 2018), *health and wellbeing disparities* (Lewis and Craddock, 2019) and *racialised discourses of deficiency, cultural capital, and socialisation* (Blum, 2011; Turner, 2020; Morgan and Stahmer, 2021), all of which provide some insight to the sentiments of concern I have raising a young man with autism both for him and myself, although they do not entirely capture all of my concerns. For while there is mothering children with disabilities, by simply

adding the strand of race and/or ethnicity these children become more vulnerable, necessitating teaching, and safeguarding on the existence of racism and bigotry (Turner, 2020).

Interestingly, Stuart (1992) disputes disability and race as a “double oppressor” (pg.177) that instead should be categorised as a solitary happening. I partially agree with this view in much the same way I expressed earlier that I cannot separate my racial, ethnic identities from any other part of who I am. For example, although I am a woman, my experiences as a Black woman, a Black-British Caribbean woman, take on different racialised meanings, which can enact multiple forms of discrimination (Uccellari, 2008; Cho, Crenshaw and McCall, 2013; Harnois, 2015; Atrey, 2018). However, as will be discussed later in this chapter, my experiences of working in a special school show that disability is often the primary concern, ignoring and excluding the influence of race, ethnicity and culture, which I consider to be problematic (Vernon, 1999). Moreover, I argue that unconscious bias, and Whiteness are also factors that mask the influence of discrimination based on race, ethnicity and culture in special schools. Therefore, research that explores the implications of intersectionality is essential to arguments that compound binary or more experiences, characteristics, and identities, such as gender and disability, or race, disability and gender, as only singular entities (Moodley and Graham, 2015; Banks, 2018; Berghs and Dyson, 2022). Conversely, there are still arguments that position marginalised identities, (e.g., gender and disability) as individual problems, warranting their own enquiry in isolation from the other (Kondro, 2012).

I am sure that many people would declare that motherhood is one of the most difficult jobs in the world, regardless of race, however, I would contend that the intersections of race, ethnicity, culture, class, gender, socio-economic status and marital status add various dimensions that present trials and barriers that most non-Black mothers do not have to consider (Elliott, Powell and Brenton, 2015; Smith, 2016; Kinouani, 2021). I have previously explained that as a Black woman mothering a Black son with autism, I am heavily focused on his various identities and my role in helping him make sense of them, influenced by the views of society. Now that he has become a young adult, I realise that I cannot always protect him or keep him safe from the dangers in the world no matter how much I may try.



I recognise that I must allow him to live autonomously, as much as he is able to, which means helping him develop positive narratives of his dominant, evident identities, like his race, ethnicity and culture, daily.

When my son was diagnosed with autism around 18 months old, a new set of worries unrelated to his race and ethnicity dominated my thoughts. With no knowledge or experience of autism, I questioned in different journal entries, *“what would his life be like?”*, and *“what did I do wrong in my pregnancy?”*. Upon reflection, these questions may have been relative to that of any parent receiving news of a medical diagnosis for their child. Although, at the same time, I also experienced what I would describe as a strange state of calm, whereby I fleetingly had a sense of relief that because of his autism he would likely be with me forever and I could protect him from the perils of the world and society. The perils of being a Black British boy of Caribbean descent in a society that has been known to be prejudiced against such identities. How misguided and naïve. When I began to develop my research proposal for this study, I reflected on why his autism diagnosis became an overriding thought in my mind, writing again in my journal:

*What about autism made me forget about his race and ethnicity... he’s still gonna be a black boy, now with autism, and that’s a whole other ball game. [sic]*

Journal entry, (Holder, 2020)

My son’s racial and ethnic identity as it intersects with his ability was not at the forefront of my mind, but it was not far away either at certain times. At first, I was overwhelmed with how much there was to contend with, like trying to process and understand what autism meant and would mean for our family. I shared the following thoughts about this in my online autism blog that I wrote to explain what it was like to live with autism by people who lived it:

*If he had an outburst, he would tear up whatever was in his sight. He would break things, grab clothing and rip it, scream in your face, scratch and shout. I would wait for the Police to show up every day for fear that the neighbours would think we were harming him because you could hear his screams blocks away. Although we told our neighbours our son was autistic, you never knew what was going on in their minds and that scared me. I just*

*didn't think anyone would understand.*

Our Autistic Lives, (Holder, 2013)

I did not admit this in the blog but rather in the safe space of my private journal that what scared me the most about the police coming to our house, was that my son was Black, and I have a mistrust for them when it comes to Black people, especially males, and that still petrifies me now (Jackson, 2024). During his schooling, his racial identity came into play when things were not going right, often propelling it to the front of my thoughts thanks to comments about the underachievement of Black boys being raised at one of his performance meetings as a teenager. It took me back to my own education but more so the experiences of my brother and other Black male friends I knew. I did not expect, nor was I prepared for the stereotypical conversations of black boys and underachievement (Coard, 1971; Graham and Robinson, 2004; Crozier, 2005; Demie, 2022; Wallace and Joseph-Salisbury, 2022) in a special school. At that time, I was just a parent who wanted the best for their child despite the challenges that came with his different abilities, however I soon recognised that unconscious and conscious bias, discrimination, and systemic racism was not exclusive to mainstream education in England, it was something that I had to fight against on my son's behalf in special education.

I wondered what the conversations with White parents of children with autism were like. Was ethnicity or race a factor in those conversations as it had been mine? All this time, I was acutely aware that racial inequality existed in my professional corporate world but somehow was oblivious to the workings of it within special education. My mind began to wonder whether this was the experience of other Black parents of children and young people with autism, or if I was alone, or like earlier contemplations, whether anyone cared. Would sharing our experiences help or hinder others. I pondered the notion of sharing our personal accounts with caution in a journal entry that reads:

*I can't be the only mom trying to figure out how to share their racial, cultural identity with their child. Just because he has autism, it doesn't mean that he doesn't have an identity besides ability. But what if people don't get it? What if they don't understand our story? I know someone else needs this...*

### **The Formidable Black Mother**

I was not the only mom! And it seemed as though someone else did need it, and they were the parents who took part in this study. They needed the opportunity to share their experiences as parents of Black British children and young people with autism in special schools, which I will discuss through the findings of the study. I was not the only parent of a Black child with autism that had such concerns. In fact, all the parents who took part in this study shared stories of wanting to teach their child/ young person about their diverse identities and share the traditions and customs that were integral parts of their upbringing with them. However, it was the mothers who were the real drivers of racial and cultural socialisation and fierce advocates for encouraging and promoting diverse individual and intersected identities among their children. They were evident in the ways they raise their child/ young person with similar and sometimes unique fears and hopes that I had, as we will later explore. As to, were the experiences of discrimination, ableism, and racism against their child/ young person which they shared, including instances at school and how they coped with such issues. Thus, for me the role of the Black mother became immortalised through sacrifice and success, pain and joy and other such antithesis not only through my own experiences and that of my mother before me, but also the mothers in this study.

Empirical literature, stories, blogs and more about the Black mother is abundant. According to Hintz-Zambrano (2021) Black motherhood is synonymous with raising children with cultural pride, protecting their rights and empowering them, meanwhile educating them of the dangers of being Black. In 2009, Reynolds argued for the complexity of the Black mother to be understood beyond the peripheries of White Eurocentric experiences of motherhood and patriarchy that chose to ignore the dominance of racism and race. She further highlighted the plight of disparity that Black and minority ethnic mothers suffered at the margins of race, class and gender in gaining access to vital health care, social and cultural capital and running single-parent households. Traditionally, Black mothers were not just mothering their own broods, but they were the community mothers for those outside of her household: the other mother (Collins, 2000).

The author revisited their initial piece ten years later (Reynolds, 2020) maintaining that Black mothering is now even more concerned with not only protecting and nurturing their children in a world that seeks to depreciate them but also challenge racism, teaching children about *“the impact of racist and identity politics so that they can successfully navigate the environment and institutions that place them at a disadvantage”* (pg. 5), which concurs with my own experiences and the mothers that I interviewed, covered in the findings chapters. This synopsis of Reynolds work on Black motherhood begins to exemplify the intersectional complex characteristics of identity providing recognition of the significant role of the Black mother. A role that is far too often snubbed and disregarded dismissing the invaluable contribution to civilisation beyond solely their own family. Thus, raising a Black boy with autism was not only going to be a challenge for me when it came to education but also the big world outside of home and school.

**“...just go back where you came from, you Black...!”**

The day that my son first experienced racial and ableist abuse is firmly etched in my journal and mind. As a non-speaking young person with autism, it has been my principle aim in life to ensure my son’s peace is always safeguarded. I am his ‘identity armour’, his protection from those around him who chose to see him as less than because of any his protected characteristics (Equality Act, 2010). Because he has Black colour skin and different abilities and needs to what many in the world deem as ‘normal’ or ‘typical’. While there have been many instances prior to the one detailed below where he was subjected to microaggressions and discrimination because of his race, this was the first time I felt that he was aware that something was wrong.

As we left our local supermarket after a weekly shop, my son and his dad were walking arm in arm laughing as we headed to the exit. They were a few steps ahead of me with the bags and I was trying to keep up. There was an older White couple walking towards the exit doors, so my son and his dad walked around them towards the car park. Without intention or realising it my son’s bag accidentally touched the older gentleman. As I saw this happen, I immediately went over to apologise, I was able to only express *“I’m so sorry”* to the man before he started shouting towards my son that he should *“go back to where he came from”*. He was so nonchalant and flippant that he caught me off guard. I was stunned. My

internal dialogue started to bold-type thoughts loudly in my mind, *'did he say what I think he just said?'*, *'I know he wasn't talking to my child'* [sic]. The burn started to form behind my eyes, and stinging immediately followed but I was holding onto those tears like I was my dignity. I was not about to be seen as the angry Black woman, not here, not now. I could feel my body shaking and hear my heart pounding. I was convinced everyone else could hear it too. I mumbled through a mix of defeat and frustration that my son had autism and could not speak and was truly sorry on his behalf. Well, my apology and explanation seemed to infuriate him more as he then screamed, *"then he shouldn't be allowed out"*, repeating again, *"why don't you all go back to where you come from you Black..."* [sic]. He stopped short at whatever name he was going to call us. I was now ready to abandon said dignity and my calm Black woman exterior because I was going to protect my son's innocence at all costs.

At this point, I yelled out for my partner, who, like some superhero with the hidden power of speed was already in front of us, with our son looking perplexed. My partner had heard what the man shouted and asked him to repeat it. A small crowd had also gathered, including the store's security who wanted to call the police on the man, (thankfully not us) accusing him of racist and ableist abuse. All I could do was look at my son, who was looking at me confused and anxious. It was not about me, yet I felt as though I failed him. I had in a way unbeknownst to me, let him down. Even with the crowd defending my son, and my partner trying to comfort me, all I could see was darkness, the same colour of our skin. The day I had always feared had finally come. My son was not seen as a person but as a Black man, a Black disabled man, a threat. Was it really time to start having the discussion about race with him, please no, I was not ready!

When we returned from the store, I wanted to understand how my son felt about what happened and if he understood any of it. However, I was too emotionally drained and wanted to be sure that I did not influence how he may have felt. The following day, I asked him a series of simple questions, using a mix of images, symbols, and verbal language, that I knew that my son could understand. I used random objects and places in the discussion to assess my son's understanding. Below are my son's thoughts and feelings in his own words the day after the event, that I scribbled in a notebook.

**Me:** *Where did [name of son] go yesterday?* [Shows images of aeroplane and the grocery store] *Plane or store?*

**Son:** Points to grocery store

**Me:** *Did you have fun at the store?* [Shows symbols for 'yes' and 'no']

**Son:** Taps on yes and no

**Me:** *[Name of son] happy or sad at store?* [Shows symbols of 'happy' and 'sad']

**Son:** Taps on happy and sad

**Me:** *Happy because...* [Shows symbols and images of 'store', 'mommy', 'daddy', 'chocolate', 'aeroplane', 'horse', 'shouting man']

**Son:** Points to chocolate, daddy, and mommy. Gives me symbol of chocolate

**Me:** *Snack later. [Name of son] sad because...* [Shows symbol and images of 'store', 'mommy', 'daddy', 'chocolate', 'aeroplane', and 'shouting man']

**Son:** Points to shouting man and pushes it away

**Me:** Puts the shouting man image back with the rest and asks again *[Name of son] sad at...*

**Son:** Points at shouting man image again and pushes it away again. Gets up and gestures towards the door.

**Me:** *Ok, it is ok. Shouting man is finished. You are a good boy. [Name of son] is a happy boy, no more shouting man.*

Once my son left the room, I did not know how to feel. I was unsure about how he felt now and whether I should have asked him those questions. I am sometimes torn between my role as a mom and utilising my skills as a SEND professional always ready with a contingency and solution. If this happened with a child at school, I would want to check they were ok, so as a mom, I needed to know that my son was ok. But as I heard him laughing as he went down the stairs, I reminded myself that he has the right to feel what he feels in the same way everyone else does, and that incident was a turning point in me wanting to help him see himself, his racial, ethnic self in a positive light, even if there were others who saw these same identities, individual or combined as negative.

### **Racism, Discrimination, and Ableism: All of the above**

Let me provide some additional context to the above incident and its relevance to this research study. My son was a teenager at the time and this incident happened, a few years

after the murder of Trayvon Martin in 2012, a young Black teenager killed on his way from the store by George Zimmerman (History, 2013) and before the murder of George Floyd (BBC News, 2020) by American police. The Black Lives Matter (no-date) movement and much of society was calling for a response, and most importantly, justice, for the senseless murders of Black men and women and police brutality across the US, UK, but equally the world over, as they continue to do (Oluo, 2019; Joseph- Salisbury, Connelly and Wangari-Jones, 2021; Adeniyi, 2022; Mozie, 2022). If I was worried about my son's racial identity at any point, I was now besides myself, terrified even, whenever he was not by my side. This incident where my son was abused because of his race and ability at our local grocery store enhanced my awareness that his racial identity is often the most dominant characteristic that he is judged by first, as his autistic traits are not always visible. Such experiences and others have led me to question correlations and causations of racial and ethnic identity formation for children and young people with acute needs, like my son. And, what the intersectionality of these themes means for this research.

Accounts, data and literature about racism and discrimination is immense and with the inclusion of dis/ability, new emerging information is taking shape. Davis, Solomon and Belcher (2022) examined the connection between autism and race as they surveyed thirty-two (32) autistic and thirty (30) non-autistic young adults about their experiences of discrimination, psychological empowerment, racial (Black) identity and stress. Demographically, the participants self-identified as Black or African American, and their age range was between 18-65. While gender detail was not specified, the results indicate responses based on gender, suggesting both male and female participation. Several different measures were used to assess suitability and check the understanding of participants, particularly those who identified as autistic, along with other tools to quantify and evaluate stress and racial identity, such as the Perceived Stress Scale (Cohen, Kamarck and Mermelstein, 1983) and the Multidimensional Inventory of Black Identity Regard (Sellers *et al.*, 1997).

The findings reported that for both groups race was the primary source of discrimination, although for the autistic participants experiences of discrimination were also because of autism. They also suggested that there was frequent discrimination due to the binary

identities of race and autism. There was little difference between the groups in relation to stress, but the identity measures proposed that the autistic participants felt more positive about their racial identity and being Black. According to the results of the Black Identity Regard scale, autistic participants reported higher on the private regard sub-scale, which explores whether individuals have positive or negative feelings and thoughts associated with being a member of the Black community, it was also considered an indicator of perceived stress.

The author asserts that the study provides a foundation with which to explore the intersectionality of race and disability further, which I agree with. The findings provide a helpful picture of the intersection between race, autism and relevant to this thesis, identity, which as I have already stated, limited research exists. However, there are limitations here, as with any quantitative study the findings are statistical and thus the depth of their experiences and feelings is not expanded on. The why's, what's, and how's that qualify certain responses would be beneficial in such as study to contextualise how the participants have made meaning of their experiences, which then can be used to develop a better subjective understanding of the relationship between race and autism.

Equally, recognising the broad spectrum of autism requires the inclusion of participants across the spectrum, whose experiences are unique to them because of their needs and abilities. By excluding or not acknowledging interconnected identities, there is a danger of further marginalisation and discrimination of individuals that already face such because of the ways their individual characteristics are judged by an ableist, racist society. The findings highlight that these young autistic adults are navigating a world where their identities connected to race and autism, as well as other characteristics, such as gender are regularly scrutinised by themselves and others, therefore the roles of education and home becomes a fundamental element in the intersectional identity socialisation process.

Selman *et al.*, (2017) carried out a UK study of social stigma experienced by Black Somali parents of children with autism. Mostly mothers made up the 15-strong participant group (aged between 28-56) whose children were between 4-13 years old. They were interviewed in person and asked to discuss their experiences from before their child received an autism



diagnosis to present-day, as well as the services they received and life in general. Results indicated that the children and families faced significant discrimination from being labelled, judged, stereotyped to shunned and excluded, including within their own community. They found ways to cope through family and community support and religion. Many of these results mirror that of my study and the experiences participants and their child/ young person have encountered with out in the community, as well as some of the ways that they have coped with them.

I consider my son as multi-ethnic, Black-British and Caribbean (by way of his grandparents' descent) and so I have actively engaged with the subjects of race and ethnicity with my son (individually and collectively), in a way that is both accessible and appropriate for his ability. Some examples of these interactions include learning about Caribbean history, the islands, food, culture, famous people and similarly learning about Britain. We have mostly focused on his Caribbean identity as it features heavily in our household as already explained and is not likely to feature in his Eurocentric education at school, that will construct his Britishness at the omission of wider Black history (Arday, 2021). I use symbols that I create on specialist programmes with Black/ Brown faces when communicating with him about himself (Figure 2) although they are not always easily accessible because the default skin tone on most programmes is White.



**Figure 2: Examples of communication symbols**

We also work on repeating positive affirmations daily that celebrate and empower his racial, ethnic and cultural identity development and understanding. The affirmations were a direct response to the incident at the grocery store and my attempt at some of the strands of ethnic-racial socialisation, such as racial pride, cultural socialisation, and self-worth (Huguley, *et al.*, 2019) discussed in the next chapter. Is this an accurate and reliable measure of racial and ethnic identity formation, however? Is he truly able to fathom the ways in which his racial and ethnic identity are considered inferior across societal structures and does he need to understand this? I realised that these questions could not be answered with a simple yes or no but rather over time as we consistently worked together to develop meaningful connections to who he is, who he understands that he is by what he sees and feels, what he engages and interacts with, what he is exposed to and what we show him, and I further understood that these constructions may change and become reconfigured over time and experiences (Woodward, 1997).

Reflecting on my son's appalling brush with racism and ableism often leads me to think of Harvey Price. Harvey is the mixed-ethnic son of British celebrity Katie Price who is White,

and Black Trinidadian former footballer, Dwight Yorke, although it has been heavily reported that Yorke has been noticeably absent from Harvey's life. While Harvey is of mixed Black/ White heritage, it would appear much of the racial abuse aimed at him identifies him as Black. Harvey who has been diagnosed with autism along with other challenges has been subjected to horrific online abuse and trolling because of his race and ability (BBC News, 2019). What makes some people see and judge his racial, ethnic, and abled identities in such cruel and spiteful ways? What lasting damage is caused to Harvey's racial identity formation through the regular torrent of abuse he receives? And how much of it does he understand?

In the past, Harvey has been interviewed on tv alongside his mother talking about how the trolling makes him feel (Loose Women, 2016) and it has been predominately his mother Katie that has fought and campaigned tirelessly on Harvey's behalf against internet trolls and even the Police, accused of sharing racist, ableist, and sexist messages about Harvey (Alexiou, 2020; Doherty-Cove, 2020; Gregory, 2023). Although it is mostly Katie's voice advocating for Harvey against trolling, I felt the impact of hearing things from Harvey's perspective, as he understands it, which continues to encourage me to not only be an advocate for my son, but ensure his voice, thoughts and feelings are heard too. In wanting to amplify another voice of young people with autism, there is also a striking blog written by Tré Ventour-Griffiths (2022) who bravely speaks of his experiences of ableism, racism, and other sensitive topics. Being able to read Tré's stories as a Black autistic male provides an intimate account that explains first-hand the intersectionality involved through his own experiences which he shares in 'autism, while Black'. He openly shares the battles he has had to endure and how he has to continually fight because of his multiple identities.

The racism and ableism experienced by Tré along with the incessant abuse that Harvey has faced because of his race and ability are hate crimes. Hate crime statistics look at different identity characteristics including race, disability and religion (Zayed and Allen, 2024). According to Home Office statistics (2023) for England (not including Devon or Cornwall) and Wales, racially motivated hate crimes were the most commonly reported in 2022/2023 with just over 100,000 offences. While there were 13,777 reported Disability related hate crimes. 5% of the total hate crimes at the end of March 2023 (145, 214) were estimated to

have more than one motivating factor (i.e. race and disability), although detailed information about the intersecting strands was not available at the time of writing this thesis. Evidence of racism against Black and minority ethnic people and groups across various contexts including health, work, and school are firmly established (Kushnick, 1988; Joseph-Salisbury, 2020; Danso and Danso, 2021; Demie, 2021; Osborne, Barnett, and Blackwood, 2023; Arday, 2022a, Berghs and Dyson, 2022). Racism, discrimination, and ableism are hugely contested topics, which I will continue to expand upon in the next section and other chapters. It is an aim of this research study to provide some new and additional perspectives from parents and special schools connected to autism and SEND in England.

### **The centrality of racial-ethnic socialisation and identity through the lens of autism**

In chapter three, I discuss the concept of racial and ethnic socialisation (RES) as a practice to teach children about race and ethnicity (Hughes *et al*, 2006). Through this study and my own experiences with my son, I suggest that in much the same way that neurodiverse children are taught about maths, science or how to dress independently, a fundamental life skill would be to also include discussions and teaching about race and ethnicity: the good, bad and ugly. In all cases, teaching would be done in ways appropriate to a child or young person's needs and abilities, at home and school and in any other space that they occupy. I maintain that this is of vital importance, especially as we prepare children and young people with autism and other SEND for the realities of the multi-diverse world that they are active members of.

#### **“Who is a smart Black man?”**

As my son has become older and his awareness of himself and the world around him grows, I have thought about how I could counteract any negative connotations that my son may or may not be aware of in relation to his race, ethnicity, culture, gender and ability suitable for his needs and understanding. When I am down or troubled, I give myself a pep-talk and manifest positive thoughts to reset the adverse ones (such as the experience of racism and ableism I discussed earlier) and so I wanted to find a way to do that for my son. As a young person with autism who is non-speaking and uses gestures and pictures and symbols to

communicate or PECS (Picture Exchange Communication System), a communicative aid often used by those with autism (Charlop-Christy *et al.*, 2002), our daily declarations allow me to help my son connect with his racial, ethnic identity and sense of self in a positive and powerful fashion. Thus, I decided to create ‘symbolated affirmations’, as shown in figure 2.2 below for him, us, to affirm together on a daily basis.



**Figure 2.1: Affirmation communication boards**

He has a selection of different affirmations to choose from, which lets him remain in control of the practice. There have been some mornings that he does not want to engage in the affirmations and that is ok, because it is his choice, but they have been very few in the six years since we have been doing this and it has evolved substantially since then. On the occasions where his engagement is limited, I chose my own for him and say them in my head and smile at him. Our morning ritual involves me asking him to choose an affirmation, “[son’s name] is”, using symbols with Black faces and a range of diverse adjectives and statements including, smart, funny and friendly. The process remains the same although I may also show him another symbol alongside what he chose, depending on his mood or if I have noticed something, such as “[son’s name] looks sad today, is [son’s name] sad or something else?”.

I then use the affirmations that he has chosen to check his understanding and reaffirm his choice. These questions include, “Who is a smart Black man?”, “Who is a strong Black man?” and “Who is a happy Black man?”. My son points at himself, with an air of confidence that I am sure he gets from me and laughs most days or on a few occasions hurries me along so he can get out the door to school or to whatever he is doing next. I

used to wonder if I was imposing who I want him to be through these affirmations. But I reminded myself, that he has a choice of affirmations which he selects from. Furthermore, he is already all those things, *smart, strong* and *happy* and I am simply reminding him.

Racial inequity in schools, dis/ability discrimination, the senseless murders of Black men and women and fight for social justice have often left me scared for my son's future. Scared is not an adequate adjective to describe the way my stomach churns, heart cries, and mind races when I think of his future in this current world. Especially as my grey hair begins to multiply and our birthdays seem to come around quicker than 365 days. I often ask myself "*Who will look after him when I am no longer around?*" or "*Who will do his daily affirmations with him?*" and "*Who will protect him?*". Crying no longer remedies those questions and if it does it is only for a fleeting moment, and I must force myself to come back to the present. Not for me but for him. He is not fully aware that the structural eyes of society produce and reproduce inequality fundamental to who he is, Black, differently-abled and male, which is what they see. And I cannot truly convey how deep these thoughts hurt my soul, especially because it often robs me of time with my son in the here and now, which is deeply precious.

Therefore, I consider it my duty as his mother to reset those narratives in ways that allow him to be an active member of society, proud of his race, ethnicity, abilities and culture. Not ashamed of any part of who he is and his multiple identities. Hall (1990, 1996) explores the intricacy of identity through transformation, whereby identity is as much the state of 'being' as it is 'becoming' (1990, pg.225). Much of Hall's identity work and that of other sociologists rejects identity as permanent. Hall implies that identity is interwoven in the stories of the past and the hopes of the future, which is bound by historical references of power and cultural, racial inequality. His personal experiences as a Black man from Jamaica, living in England forced Hall to explore, reconstruct and dissect his identity and positionality within the binary lens of past and future, which took place over the course of his life. Thus, identity can evoke internal thoughts and questions about what it means to be male or female, Black, Caribbean, British, combinations of both and the many more characteristics which are used to define and label, notwithstanding the context which these attributes are situated. What makes us different from or like others and how does this otherness develop

our identity and how we are seen and see ourselves?

Using some of Hall's work as a basis for the racial and ethnic work that I do with my son would be to explore how he understands his identities, which at present is mostly at an exterior, physical level, as a Black-British man with Caribbean roots living with autism. Hall's views of race, ethnicity, culture and identity argue that the notion of identity, whether cultural, or ethnic for example are based on experiences, understandings, interactions, and representations that are intertwined in history, politics and society. Identity is intricate, and being Black British has a different meaning to being Black Caribbean, and once gender, class or other characteristics are involved, the understanding takes on yet again another meaning. While I am raising my son to embrace the different sides of those racial, ethnic identities and the cultural nuances that comes along with it, I recognise that for a neurodivergent young person, his understanding of identity is predominately influenced by me and society, and in some instances, it may not go beyond a surface-level view depending on his ability.

When identity intersects with race, ethnicity and different abilities these additional layers create a more complex picture of identity, which I will continue to explore in the next chapter. Although there is a shortage of research into the intersectionality of race, identity and dis/ability there are studies that connect the themes on a broader scale, such as identity and disability or race and identity. Children and young people with acute needs and abilities experience challenges in developing identity because of their limited awareness of social cues and behaviours (Fletcher and Lawrence, 2018) and the ability to engage with other significant characteristics, such as ability (Müller, Schuler and Yates, 2008). Furthermore, developing identity where a disability exists is influenced by the *level of ability* (Rękosiewicz, 2020), *integration with others* (Gill, 1997) and *type of disability*, such as intellectual or physical (Forber-Pratt *et.al.*, 2017). Additionally, trying to categorise identity alongside race and disability is complex for reasons that are built upon notions of supremacy, difference, and inequality (Stuart, 1992; Shakespeare, 1996). Thus, identity becomes a two-way mirror, on the one side how the individual sees/ understands themselves and on the other side how they are perceived by the outside world.

As my son is now a young adult, I have explicitly developed discussions around race, ethnicity and culture, to help support his awareness of self and others, especially as he is out in the community more without me, experiencing the diverse world that he is a part of. The final exchange shared below between my son, and I is one of our more recent (in June 2023) longer affirmation sessions that we do every couple of months that continue to explore who he is, communicated in his own words, using symbols, images and objects.

Me: *Affirmation time please.*

Son: [Gets affirmation folder and hands it to me]

Me: Thank you, rabbit, [pet name I have called my son since he was born]. [Points to folder] *whose book is this?*

Son: [Points to self and taps on his chest a few times, makes vocalisations]

Me: *Well done! Yes, it is [name of son] book.* [Opens folder and takes out random pictures and symbols including 'Black boy', 'rabbit', 'bus', 'egg', 'Indian boy', 'Chinese boy', 'Black girl', 'White girl', 'picture of me']. *Who is [name of son]?*

Son: [Vocalises and gives me the picture of the Black boy]

Me: [Picks up picture of the rabbit in one hand and picture of Black boy in other hand] *Who is [name of son]?*

Son: Taps on picture of Black boy.

Me: *Good boy.* [Shows page with colour symbols including 'black', 'brown', 'red', 'green', 'yellow'] *What colour is [name of son]?*

Son: [Flicks some of the symbols] and then points to brown. Takes the brown symbol and gives it to me. Starts flapping and laughing.

Me: *Well done [name of son]! Umm, can you help mommy please?*

Son: Vocalises to indicate 'yes' and nods head

Me: *What colour is mommy?*

Son: [Starts flapping again and begins to clap, making vocalisations and looks at me]

Me: *Mommy is...?*

Son: [Selects the brown symbol and puts it on my face]

Me: *Mommy is brown. Well done. Three more then finished. Let's do some matching.* [Shows picture of Grandad and flags from Barbados and Somalia]. *Grandad from...?*



Son: [Quickly gives me Barbados flag].

Me: *Yes, Grandad from Barbados.* [Puts picture of son and picture of grandad next to each other alongside 'same' and 'different'. *Grandad and [name of son] same or different?*

Son: [Taps the same symbol and picks up the brown symbol that is on the colour page and hands it to me]

Me: *Yes, grandad and [name of son] are brown, the same. Good work. One more and finished.* [Chooses subject, verb, and object communication board and picture of himself to identify what he sees in the picture]. *I see...?*

Takes my finger and points while I say what he points to

Son: *I see Black boy*

Me: *I see Black boy. Good boy. [Name of son] is a smart Black boy. Good work rabbit. Affirmations have finished.*

I am not overly pedantic with the black/ brown colour selections that my son selects when doing affirmations- sometimes he chooses black and on this day it was brown. I have seen him look intensely in the mirror before choosing the colour sometimes. While racially we are categorised as 'Black', which I identify as, I appreciate that our skin colour is various shades of brown and that is what he sees and recognises. The goal is to learn more about how my son sees and understands his identity in an accessible way. By consistently helping him to interact with his culture, ethnicity and race he continues to develop and make his own meaning of who he is, which sometimes changes depending on his mood or understanding of the questions asked for example. One thing that is certain from our sessions is that he always has a big smile when I ask who is a smart Black man.

Seeking to understand how my son sees and understands himself and engages with his different identities has fuelled my desire to carry out this research study. I recognise that he has primarily developed his identities based on how I see them and the ways that I have exposed him to them. Through the years, I have actively tried to help him to connect to our rich Caribbean heritage and find pride in his racial identity, as I have learnt to do throughout my life, by exposing him to different aspects of our history, values, traditions, and culture. Admittedly, much of the racial, ethnic, cultural and social constructions (e.g., being a Black male of West Indian descent) that he has learned have come from home and our family

through our lived experiences, music, food, stories and more in ways that are suitable for his needs. Furthermore, these constructions have also developed through the ways in which other structures, such as school and also society view my son, as a young Black male with autism, which has not always been positive due to the prevalence of institutional racism and inequality.

While I have always tried to respect his autonomy when encouraging him to interact with his identities, I recognise the importance of this independence even more so now as he becomes a young adult, developing a sense of self formed through social interactions and experiences with different people and structures, not just the home. Due to his vulnerability as a young man with autism and acute needs, I still believe that it is crucial that I support him in empowering racial, ethnic and cultural pride to counteract the negative inferences in society, which I have seen to boost his confidence and create a sense of belonging and awareness of how unique and special he is.

At home, in much the same ways that I was continuously exposed to elements of my race, ethnicity and culture to develop my identities as a child the traditions and values continue with my son. My son's father is Black British and also of parental Bajan descent, with similar stories of our cultural upbringing, which we instinctively raised our children with. Caribbean food is at the heart of our home as both my son's grandmothers are regularly cooking him traditional Vincentian, Barbadian and other Caribbean dishes, which he started eating as soon as he could manage solids. He often heads straight for their kitchens to see what delicacies they have waiting for him, especially on a Sunday for the big family dinner. My son loves soca music, almost as much as I do, which could be because of how much of it I played while I was pregnant with him. He sometimes requests his favourite soca and calypso beats with symbols or finds soca artists or songs on YouTube. We have Caribbean flags in our home, which if you ask him *"who this is for"* and show him pictures of his immediate family members, he can proudly match *"Barbados for Grandad and Granny"* (on his Dad's side) and *"St. Vincent is for Nan-Nan"*, which he knew my mom as. And when he visits his grandparents on both sides, there are lots more artifacts and souvenirs of the Caribbean isles to connect him to his heritage. Some of the ethnic and cultural references that we use with our son are in figure 2.3 below:



**Figure 2.2 Examples of ethnic and cultural references at home**

We recognise that some of the Caribbean influences stem from West Africa during slavery as well as Britain during the colonial reign. I have created social stories about Caribbean history for my son as an accessible way to learn about his roots. We also read books and share West Indian stories like Ananse or Anansi the spider, originally West African folklore (Marshall, 2007) that was adapted in Caribbean storytelling, watch movies like Black Panther and shows like Desmond's, The Fresh Prince of Bel-Air, and even children's shows like JoJo and Gran Gran, Doc McStuffins, and more. Positive Black media representation has certainly improved since I was growing up. My son has enjoyed attending or watching Caribbean events and celebrations, such as Crop Over, Notting Hill Carnival, Barbados Independence, and other Caribbean country's independence days, National Windrush Day, birthdays and weddings with a heavy Caribbean influence. Like any parent we filter what our son watches and is exposed to, as a vulnerable young person, but we actively celebrate

and are proud of our Black culture, not only during the month of October because Black History is all year round in our home. At school, however, that is a different story.

## **Part 2: The Institution**

Race and racism in special education in England (and more globally) may not always be as obvious as the encounters that I have shared in the previous section within communities or indeed mainstream settings, which are discussed below because society is constructed upon abled ideologies whereby individuals and groups that are dis/abled are expected to adapt (Scope, no-date). As has been discussed across this thesis, Black children and young people with autism and SEND have been overrepresented in special schools/ education for decades, are subjected to persistent attainment disparities, they have been denied access to specialist support and care, have suffered unfair treatment and discrimination from education and other professionals and have in some cases been on the receiving end of blatant racism and ableism (Coard, 1971; Tomlinson, 1983; Walters, 2012; Tomlinson, 2014; Gilborn, 2015; Tomlinson, 2016; Harry and Klinger, 2022; Perepa, Wallace and Guldberg, 2023). The constructions of race and racism are not only felt by these pupils but also their parents and school staff and are manifested across policies and pedagogy.

### **My lived experiences in English special schools: “All lives matter...not just Black ones”**

An incident occurred in 2021 where disparaging and racist comments were left in a staff suggestion box at the school that I was working at that left me and another Black teacher distraught. Like many other institutions at the time, my school wanted to respond to the murder of George Floyd and global racial injustice and inequality in a tangible way, so they created a ‘multi-cultural group’. Some of the main functions of the group were to assess diversity across the school in relation to race and ethnicity, which included establishing an open dialogue about race, providing race-related training, and diversifying the school curriculum. The group was made up of staff from different ethnicities, genders and nationalities, all with the commonality of wanting to improve the diversity of the school.

Both the national and specialised curriculum utilised in the pedagogy of the school, was significantly Eurocentric, minimally diverse at best. There was an inconsistent approach to

culture and diversity. Black History Month was led by the few Black staff members working at the school and celebrated sporadically some years, not every year, meanwhile training on racial issues was non-existent. There was very little attempt to incorporate pupil's identities and experiences aligned to their race, ethnicity and culture consistently and sustainably into the activities of the school and classroom and when it was, it felt tokenistic. Aspects of educational learning, particularly multicultural events, and topics, which fall outside of the core subjects, English, Maths and Science have long been viewed through a critical lens regarding their academic significance especially when they are delivered irregularly, lending itself to feelings of tokenism and exclusion (Bernardy, 1995; Kivel, 2017; Odena, 2017). I reaffirm once again, as part of this research that if children and young people with SEND are taught curriculum subjects and life skills in appropriate ways, then why are their racial, ethnic and cultural identities not included in the same way? Why are these pupils not actively provided with opportunities to engage with activities/ content reflective of their diverse identities and that of others, including the multiethnic, multicultural world that they are members of, in ways relevant to their needs and understanding, which could help to negate any associations to racism and prejudice.

Over the course of several months one of the newly appointed senior leaders, the only person of colour in the leadership team, along with members of the multi-cultural group constructed a plan to tackle racism, racial inequity, lack of diversity within the curriculum, and cultural representation in our special school setting. I sent an email to the senior leader thanking them for a whole-school race-related training session that was organised, which I captured in a journal entry:

*Finally, someone gets what I have been talking about... the Black kids and staff don't have to keep being victims of microaggressions and blatant racism... STOP IGNORING AND INVALIDATING OUR BLACKNESS! [sic]*

Journal entry (Holder, 2021c)

The multi-cultural group was putting plans into action rapidly. We went from having little to no school-based content relating to race and ethnicity to having a prominent Black Caribbean professor in race studies deliver training to all staff on race, racism and

education. However, feedback highlighted that the training lacked specific relevance to special education as the information pertained to mainstream schools. By the professor's own admission, he struggled to find adequate research and material on race and special education that would best support the training. To me, it was clear that you could not simply apply race training, interventions/ models from other practices to special schools without understanding the needs of those individuals and tailoring it accordingly. Special education is certainly not a one-size-fits-all model. There were also focus groups held at school exploring the thoughts and feelings of staff about race and racism, although noticeably, only the senior leader of colour attended. Black History Month was back on the calendar and celebrated the same year and an afternoon of staff development time was dedicated to curriculum enhancement, specifically around race and diversity.

Subsequently, there was resistance to change from the very beginning, as many staff members declared *"there was no racism at the school, why were we talking about race"*. Yet the small minority of Black teaching staff (one teacher and three teaching assistants) relayed feeling the need to regularly defend themselves against daily microaggressions. There was a shift in some people's attitudes and behaviours towards staff of colour, as some of the White staff members felt they were being accused of racism. Things came to a head when the group led a presentation on all the work that had been done and encouraged staff to feedback. While most of the responses were positive, there were written and verbal comments that stated: *"why do we need to celebrate anything to do with Black people, who cares!"* and *"all lives matter, not just Black ones, what about White and Brown lives!"*. I even had a White colleague who I had worked closely with for several years, tell me that *"no-one here is racist, and that it [racism] wasn't real anyway"* [sic].

My initial reaction to what the colleague said to me personally and the other comments was emptiness. I was not surprised, as this had been my experience for many years when I tried to initiate conversations about race in this space. However, these feelings soon moved to hurt and anger because I felt that I had to substantiate to people that I had worked closely with why not only did my Black life matter, but so too did the lives of all the Black, Brown and minority ethnic children and young people we teach, support and care for. Despite the prolonged disparity and prejudice against Black people that was making global

news, I still had to validate to my colleagues, some of whom I had worked with for years that: BLACK LIVES DO INDEED MATTER!

### **But do you really want to talk about race and racism in special education?**

As explained in the opening chapter, my interest in special education has been fuelled by my personal life and my son's diagnosis of autism. Consequently, my desire to empower my son's racial, ethnic and cultural identity has needed to expand beyond my home into my professional environment, as a SEND practitioner. For over 12 years, I have worked with children and young people with a range of SEND and difficulties, predominantly those on the autistic spectrum and others with mild to severe learning needs. My interactions with these amazing individuals have broadened my understanding of neurodiversity and improved mine and my family's relations with my son. However, during my time in English special schools, I have experienced racial discrimination first-hand, witnessed conscious and unconscious bias against Black staff, children and their families and other challenges associated with race and ethnicity and cultural difference, independently and intersectionally. In the first chapter, I described that most of the studies investigating race in special education or special schools have drawn attention to broad issues such as large numbers of Black students in special and alternative education provisions (Blanchett, 2006; Strand and Lindsay, 2009; Strand and Lindorff, 2021) but there are missing links and more research is needed that considers how race and ethnicity might influence special education teaching and learning, student attainment, discrimination and more of these Black groups in special education.

One such example of the intersection between race, autism and attainment follows. Using data from one local authority in London, Demie (2022) investigated disproportionality in attainment of over 3000 pupils with SEN once their primary school education in England ended. The data in the study comprised of school census and Key Stage 2 results and was analysed using descriptive statistics. The findings have implications that are relevant to pupil performance, discussed in chapter six. The results indicate that pupils with SEN in England are less likely than those without to reach the expected standard, which they assert is because of several factors including, ethnic background and socio-economic status. The study also mentions that the data used shows that the key ethnic minority

groups in this study, Black Caribbean and Black African are still more likely to be categorised as having some type of SEN, which links with disproportionality literature discussed in the earlier chapters. Now, it is not known specifically from the paper if any, and what proportion of those pupils are from maintained special schools, which would be beneficial in understanding pupil and student performance from minority ethnic backgrounds in these specialist education institutions. It would appear that the study is concerned with mainstream provisions only. However, more studies like this are urgently required because they only begin to partially uncover some of the issues in this field and there needs to be a greater acknowledgment and understanding of racial, cultural and social differences and systems that perpetuate inequity and defunct tropes of inferiority but within special schools in England.

My personal account above regarding the hurtful comments from colleagues depicts one of my most difficult yet poignant encounters within a special school in multicultural London, in which my racial and ethnic identity have played the starring role. Whether it was staff members refusal to acknowledge and fully integrate diversity into the Eurocentric curricula, their general disdain for social equity or occasional effort celebrating racial and cultural events, there are real complexities involved when unpacking the intersections of race, ethnicity and special education in special schools. Imagine constantly questioning if your colleagues or peers understand your thoughts of feeling excluded and undervalued in the workforce and how that has affected your mental health (Arday, 2022b), concerns that your ethnicity and culture (and that of the minority learners) is not represented in the curriculum and staffing (Cochran-Smith, 1995a; Maylor, 2010a; Gorard *et al.*, 2023); or that a few events for Black History Month, occasionally, screams tokenism (Holyoak, 2021) at you as loudly as Halloween does in the same month of October.

I have experienced blatant racism and some less obvious forms of microaggressions, for example comments about my natural hair and the way that I incorporate culture into my lessons as a member of staff in English special schools, prior to the above incidents, which I have quickly challenged. There are also experiences that have not involved me at all, situations that I have witnessed, against Black and minority ethnic children with SEND that I have always challenged. These incidents have stayed with me, reminiscent of a scar that



although healed, bears the hallmark of a former wound, a constant reminder, like Kunte Kinte and *Roots* did many years before. However, these were my experiences in English special schools and literature provides very little other accounts in this space, although staff and student accounts of racism, exclusion, microaggressions and discrimination in mainstream, higher education are well-informed by several home and international studies (Codjoe, 2001; Maylor, 2009a; Allen, 2010; Lander and Santoro, 2017; Arday, 2018a; Joseph-Salisbury, 2020; Page, 2020).

A report on race and racism in mainstream English secondary schools carried out by Joseph-Salisbury (2020) for Runnymede revealed four main areas in Greater Manchester high schools that require immediate attention: teaching personnel, curricula, policing in schools and school policies. Twenty-four teachers shared their unique perspectives of schooling in secondary schools in the north-west of England, although I agree with the author that the likelihood of findings being largely relevant across England is high. The first two issues and the rationale behind them have been identified in this thesis through my own experiences as well as by the participants in the study as a persistent issue in special schools in England.

The Runnymede report calls on immediate action to diversify the profoundly White teaching population with more BAME staff with the additional instruction that it is more than simply increasing the headcount of minority staff but also the racial knowledge and competence of all staff, whose responsibility it is to promote anti-racism. Moreover, they contend that the National Curriculum is not diverse enough and intentionally avoids compulsory engagement with the country's colonial and racist history and foundations. The curricula must be decolonised and diversified and brought up to recognise contemporary England. Though police in schools (problematic for BAME students) and school policies (clarity on anti-racist policies and reconsideration of policies that disadvantage BAME students) have not been much of a feature of my research study, the Runnymede report's findings suggest that these two areas are just as critical in recognising the role of race and racism in education along with the other two factors.

In 'Young and Black: the young Black experience of Institutional Racism in the UK' (YMCA, 2020) the critical thoughts and feelings of Black young people provided meaningful insight

of institutional racism through their eyes. The mixed-methods study utilised data from a survey (n=557), focus groups and workshops conducted with 16–30-year-old participants that identified as Black and Black-Mixed ethnicity (e.g. Mixed Black and White Caribbean). The study focused on education, employment, health services and the police as the primary, secondary institutions that enact socialisation practices (Lahire, 2019) and systems that construct relationships and roles in cultures and society. A few of the report's findings reveal that young Black people have experienced racism in school, with 95% of them having witnessed or heard racist language being used, they feel the need to adapt who they are to fit into society, 49% feel that racism is the main obstacle towards academic success, and they have a distrust for the Police and health services. This report is a comprehensive, illuminating look at systemic racism through the experiences of young Black people in the UK, who not only share how they feel about education, crime and health but they also make recommendations for change. Some of those suggestions are akin to the Runnymede work above, including reviewing school policies through the lens of race and ethnicity, embedding an anti-racist curriculum in schools and unconscious bias, cultural competence training.

It cannot be determined from neither the Runnymede or YMCA reports whether dis/ability factored into the discussions and to what extent. However, it is clear from the results of this thesis that parents and school personnel have quite similar thoughts, feelings and experiences related to race and racism in the English special school of their Black British children/ young people with autism. The content of these reports above can provide a springboard for more research to be carried out with individuals with autism in special schools to garner their views and for special schools to conduct their own investigations into their systems, policies, and practices. Although, I stress that in the first instance there needs to be an acknowledgement by these specialist institutions of the importance and relevance of the work to be done, followed by a genuine commitment to long-lasting and meaningful change, which I will expand upon, along with other recommendations in the concluding chapter of this thesis. In my experience, race and racism in special schools in England hides behind the veil of children's ability as the dominant characteristic, however, the discrimination and racism that many have experienced needs further investigation as

if the institution of education is racist (which a substantial amount of empirical evidence has validated), then what of special education and special schools- they must not be made exempt.

### **The lasting impact and influence of racism: “You can’t be the teacher, you’re Black!”**

The underrepresentation of Black teachers was initially the main reason I returned to higher education, to pursue a career in teaching. The special schools that I have worked at or visited typically had a high Black and minority ethnic pupil population, which supports research discussed in chapters throughout this thesis, but little (one or less) to no Black or minority ethnic teacher or senior leader. On one occasion when I provided cover for an absent teacher in a ‘high functioning’ class (as the school called it) for children on the autistic spectrum, one of the Black pupils loudly proclaimed, *“You can’t be the teacher, you’re Black”* [sic] and that *“Black people could not be teachers”* because she had never seen one at the school or on TV. She told me she always looked for someone like her in the media, whether on television shows, YouTube, or even commercials with *“dark skin”*, *“tight curly hair”* who was *“a little bit different”* (in reference to her autism) and could not understand why they were not there.

Because this young Black girl had never seen a Black teacher, she firmly believed that they did not occupy those spaces and positions within education. When I relayed this experience back to the senior leadership team and questioned them, as I had done in the past on the lack of Black teaching staff, the headteacher at the time replied that *“we can’t recruit them”*. ‘Them’ being Black people, as if we were some specialist types that did not belong in the field. Over the years I have reflected on my encounter with this young girl many times. I recognise the deeper impact that this unassuming, sincere conversation with one of my pupils had on my racial identity then and now but equally the perceived influences seeing me regularly as her teacher, a Black Caribbean female teacher, had on her identity, when upon seeing me around school after the above incident, she would remind me that she would become a teacher just like me.

## **Representation has always mattered**

The absence of BAME teachers, academics, and senior leaders in English schools and higher education has been a persistent issue for decades (Bush, Glover and Sood, 2006; Maylor, 2007; Boyle and Charles, 2011; Johnson and Campbell-Stephens, 2013; Arday, 2018b). Research carried out by Tereshchenko, Mills and Bradbury (2020) for University College London's Institute of Education found that 46% of all schools in England do not have any BAME teachers. Additionally, teachers from ethnic minority backgrounds are concentrated in the capital, as well as working in disadvantaged schools in the area. Equally, government data reporting on the school teacher workforce (Department for Education, 2023a) shows that 92.5% of headteachers in English schools are White British. The marked lack of BAME teachers and senior leaders in special schools was something that I noticed immediately when my son began to attend one, and when I started to work in one, and it remains an issue across schools in England. The teacher workforce data also indicates that 85.3% of teachers in special schools or Pupil Referral Units (PRUs) are White British, with Black Caribbean and Black African teachers making up 1.4% and 1.0% of the workforce respectively (Department for Education, 2023a).

I was deeply dismayed that the minority pupil population, predominately Black Caribbean, African and Asian Pakistani and Indian was not reflective in the academic staff profile or across other facets of the school, such as the curriculum, or the resources that were used to support the pupils. An example of this lack of cultural appropriate resources included the symbols used to communicate with the pupils. All the symbols used across the school that denoted a person, feeling, or other information had white faces, regardless of the diverse races and ethnicities of the pupils. Although it only took a few clicks of the specialist programme used to create or adapt them, most staff simply did not bother. I recollect the numerous times that I raised this with the teachers and staff and was told "*why does it matter*" or "*I don't have time for all of that*" [sic].

Research continues to examine Black and minority ethnic representation across different structures, including *media* (Sobande, 2020); *politics* (Krook and Nugent, 2016); and *education* (Vieler-Porter, 2021). Nancy Fraser's (2000, 2008) distinct yet interconnected theories of redistribution, recognition and representation can perhaps provide a basic

framework with which to change and address such underrepresentation. She argues that the politics of representation in particular serves to disrupt the economic, cultural, and political power barriers partially through increasing marginalised group representation. However, the education system itself is built upon these same entrenched barriers thus making the shift to an equal power balance an ongoing, long-standing battle.

Both the comments I mentioned earlier from a previous headteacher and the young Black girl who was shocked that I was her teacher drove my passion to challenge the racial imbalances that I experienced in special education. However, they left me with more unanswered questions about politics of belonging, gender, identity and space that were entangled with racial, ethnic and cultural attitudes (Lan, 2017; Yuval-Davis, 2019; LaFleur, 2020). Additionally, children and young people from ethnic minority backgrounds do not often see themselves reflected in the curriculum, resources and school workforce, including senior positions, which impacts not only those students but the whole school community who miss out on experiencing the richness from culture-infused teaching and learning and diverse understanding from BAME teachers. Evidence suggests that the shortage of these teachers, senior leaders and academics is linked to racial discrimination and the prevalence of racism (Lander and Zaheerali, 2016; Arday, 2018a; Bradbury, Tereshchenko and Mills, 2023) which then leads to students being subjected to racism by non-BAME staff (Duncan, 2019) and a void of culturally enriched and meaningful learning (Demie and Huat See, 2022).

### **“They don’t know who they are, they have special needs!”**

I vividly remember a heated discussion myself and several members of the team were having one lunch time a few years ago in the school’s staff room where I was working which left the room divided. I was planning an art lesson for my ASD class for our topic, all about me and decided we were going to make self-portraits. They were certainly a bunch of Picassos’ in the making, in my humble opinion. All the standard lesson details were in place, from the learning objective to differentiated learning and all that remained was gathering a few more resources. Someone asked what I was doing, and I enthusiastically shared the activity that I had spent the last couple of days planning. She looked over at another colleague before dryly proclaiming to me, but really the entire room, *“oh that’s gonna go*

*down well... they don't know who they are they have special needs! Do you really think they know if they are a brown boy or a blue one?"*.

The staff room started to buzz with clique-grouped conversations and whispers about what the children at school knew and did not know. I was intrigued by her comment more than anything else because in my mind her rationale did not have any real substance. I thought to myself if this is what she truly felt, why was she here? Did everyone feel the same way about children with additional learning needs? I understood that we had learners of varying needs at the school, but surely, she was doing them a disservice by categorising them as incapable of understanding, recognising or engaging with a part of who they are- their racial identity. Children and young people with autism are often pigeon-holed and typecast as inadequate learners rather than capable and smart individuals who learn and understand in unique ways (Williams, 1996; Howlin, Baron-Cohen, and Hadwin, 2006; Hatton and Boughton, 2011) discussed further in chapter three.

I thought carefully about how I was going to respond because this did not only feel like a slight against my wonderful ASD learners but also a personal attack on my son, who some of the staff knew. Frankly, any and everything related to autism made me think of my son, and so I could not just let this go. I knew this would turn into a debate and it seemed that everyone was ready to stand their ground. My line of questioning was straight to the point and quick, I wanted her honest thoughts without hesitation, although I had not thought about what I would do with the answers. *"Do you think the children know this is school and not home?"*, I started. The resounding answer was yes, although the woman who made the initial comment said no along with about 2 others. *"Why?"* I continued. Comments ranged from the simplistic, *"they just do..."* to *"we tell them"*, and *"it looks different"*. There were other comments besides the shocked faces who wanted no part of this conversation. I then hit them with my closing question, like prosecution/ defence attorneys do in court to seal their respective arguments. *"Do you think [name of my son] knows that I am his mom?"*. Quite a few people started to clap, I guess to show they agreed with me. And the person who started this whole thing? Silence. Not silence with a hum of murmurs but complete utter silence.

It took the dishwasher beeping signalling the end of its cycle for the room to return to the bustling space it was before. I was still waiting for a response but accepted that her silence was the only comeback I would acknowledge other than a resounding “yes” to the question. As I gathered my things and prepared to leave the room to teach my exciting art lesson, she finally found her voice, courage to speak. She quietly said, *“I am sorry if I offended you”*. To which I replied with a louder voice, *“save that apology for the children who you think don’t know who they are”*. My art session was fun and messy but mostly fun. The whole class was engaged in the learning activity, and I am confident that their portraits are worthy of premium gallery space in the heart of London someday. I was especially pleased that when I gave the children a choice between brown and blue paint for their skin tones, they all chose brown, all the children in the class were Brown, Black children. Although if anyone chose blue, I would not have been offended because it is their identity after all.

### **The danger of bias versus the power of meaningful learning**

Teacher assumptions and perceptions, as well as the whole school experience more widely can significantly affect Black pupils and students in a number of ways including academic attainment, self-belief, confidence and identity (Demie and Mclean, 2007; Gillborn *et al.*, 2012; Andrews and Gutwein, 2017; Leath *et al.*, 2019; Redding, 2019; YMCA, 2020; Demie, 2021). Teacher attitudes towards pupils with autism were assessed as part of a larger Spanish qualitative study conducted by Rodríguez, Saldaña and Moreno (2012). There were 69 participants (over 80% were female) who taught pupils with autism in mainstream and special schools. Race or ethnicity were not mentioned. They were interviewed using two different questionnaires that measured their attitudes and their requirements to support teaching pupils with autism. Findings presented teachers as having positive expectations of pupils with autism, which included their role as being instrumental to pupil development as well as their connections with the families were a contributing factor to their attitudes. This study sits within an increasing body of research that explores perceptions of mainstream teachers of pupils with autism (Helps, 1999; Al-Shammari, 2006; Humphrey and Symes, 2013).

However, the perspectives of teachers and staff in special schools are rare and their

perceptions and assumptions as highlighted through my own experience above are necessary to better understand the inner workings of special education in England. Moreover, as has been highlighted earlier and in extensive educational research, dynamics change when race, ethnicity and culture are variables, and so more research that explore such intersections is vital to better understand and support children and young people educated with autism in specialist provisions. Finally, with the number of special schools in England due to increase to meet the demand for pupils with SEND and the SEND ‘crisis’ (Adams, 2024; Department for Education, 2024b; ITVX, 2024) as well as the large numbers of Black children and young people being educated in these spaces, the lived experiences of learners, families, and school personnel affords a closer, authentic understanding that can challenge the bias, negative assumptions and inequity that persists for Black children and young people in education.

I have replayed the above comment made by a colleague *“they don’t know who they are, they have special needs”* repeatedly like an old record stuck on the needle. I have used it to question myself and my own reasoning for wanting my son and students to embrace their multiple identities in ways that are suitable and accessible. I truly believe that all children have a right to explore their identities and should be empowered to celebrate who they are. That it is important and necessary to acknowledge what makes us different and be aware of the ways that we can learn from each other through this difference, as we learn to navigate the multicultural world around us. I do not agree that our differences should be used to limit us but instead inspire us. I felt this way before I became a parent of a child with additional needs, but I feel even stronger about it now because of him.

If I, as a neurotypical adult can engage with my distinct identities, then why should he, or anyone else that has differing abilities not be able to do the same. By restricting the ability to learn about one’s identities, I feel that it is like denying someone access to all that makes a person whole. Therefore, because I wholeheartedly believe in, and subscribe to, the United Nations (1989) Convention on the Rights of the Child, then I must do what I can to represent all 54 articles, particularly Articles 8 (protection and preservation of identity), 23 (children with a disability), 29 (goals of education), and 30 (children from minority and indigenous groups) both as a parent, and a SEND professional. A few of the ways in which



I have done this have been explored in this chapter, including the exposure to race, ethnicity and culture for my son and the pupils that I teach and through meaningful teaching and learning experiences that connects them to different parts of who they are in ways that are appropriate to their needs.

I maintain that children and young people with autism do understand who they are, and this understanding is constructed in a variety of ways. Individuals with autism have often been known to learn through singular or multiple approaches that include rote learning (Williams, 1996) and more active learning (Carnahan, Rao, and Bailey, 2009). The profile of a learner with autism is extensive, so too are their learning styles because of their dis/ability and other associated needs (e.g., medical) and factors (e.g., environmental) that may impact their abilities and often require specialist strategies, teaching styles and creativity (Rao and Gagie, 2006; Pitman, 2007; Perepa, 2013; Pritchard, 2014; MacDonald and Ahearn, 2015; Wood, 2019; Roberts and Webster, 2022) the comprehensive scope of which sits outside of this thesis. However, it has been necessary to briefly touch on some aspects of the teaching and learning of children and young people with ASD to evaluate the findings in later chapters, especially as several participants have continually highlighted appropriate meaningful learning as an example for the children/ young people in special schools to be able to recognise their racial, ethnic, and cultural selves in the school environment, and not separate to it, which too has been my own experience. Learning styles are only one part of the puzzle; however, they go hand in hand with teaching, environment, knowledge, frequency and more to duly support the learner to make deeper connections to who they are.

At present, extremely limited literature exists that explores meaningful learning through culture, ethnicity and race among autistic populations and in special schools. Marshall and Goodall (2015) deliberated appropriate and meaningful education for children on the autistic spectrum based on human rights beliefs and international laws and legislation, which included the International Convention on the Rights of the Child (United Nations, 1989) and Convention of the Rights with Persons with Disabilities (United Nations, 2006). The authors presented and assessed different global legal and human right's perspectives that defended an autistic child's right to experience meaningful education through the

correct provision (i.e., mainstream or special school), inclusive education, choice, best interests, and access to appropriate resources. The authors argue that despite human rights principles and international law children with ASD may not be subject to a meaningful education because of the lack of clarity within the laws and suitable resources.

Based on my study, I would also argue that the intersectionality of multiple identities that meet at the axes of race, ethnicity, culture, and gender further complicate the effectiveness of these laws and rights for children and young people with autism. If such laws, rights and policies are left open for schools' interpretation, without the consideration of multiple identities then children with ASD are at risk of not being able to access meaningful education that acknowledges their diverse positionalities, which in turn can affect their identity formations by not providing education that is suitable for purpose, inclusive or best for their interests.

My experiences in special education provisions have reinforced the importance of the institution of education as both a place and space that has an essential role in the development of identity for Black children and young people with autism. Thus, it is necessary that special schools in England look beyond the singular strand of dis/ability as the only or primary identity of their pupils and students and begin to recognise their intersected identities that include, race, ethnicity and culture as prominent and important facets that inspire self-awareness, belonging and pride.

## **Chapter Summary**

In this chapter I have briefly explored some of my personal auto/biographical accounts that connect to the broad themes of this research, critically examined alongside literature. It was imperative that I engaged with my lived experiences as a mom to a Black son with autism and SEND professional within this thesis to not only justify my positionality but also to connect and situate the relevance of our story (my son's and I), to those of others and the significance of this study, discussed in chapters five and six.

It has been through these unique spaces that I occupy that I am able to make-meaning of these auto/biographical narratives and reflect on being an 'insider'/ 'outsider' and 'in-between' in this study. Within this chapter the notion of identity has been discussed in

part through the lens of my own upbringing as a Black Caribbean child, pupil, mother and educator. In addition, I have looked at the institution of education and school sharing experiences of discrimination and ableism, challenging and disrupting institutional racism in education. Autism and SEN have been the subject of copious studies, however the educational experiences and treatment of Black-British children and young people with autism and parental perspectives thereof in special schools remain scarce, particularly in England. In the next chapter, I will continue to engage with literature on autism, identity, race, ethnicity and culture in the pursuit of deeper knowledge of this thesis' themes.

## **Chapter Three: Autism, Identity and Socialisation**

### **Introduction**

In the preceding chapter I shared some of my personal experiences as the mom to a young Black man with autism and a SEND professional. I began to use literature to reinforce and make meaning of these experiences and in this chapter, I continue to explore what is known about the central themes of this study. Although empirical literature has neglected investigating the intersectionality of race, ethnicity and culture in autism identity-formation there is sufficient scholarly evidence to begin to critically examine wider connections between the study's themes to establish why it is important to empower racial, ethnic and cultural pride among Black British children and young people with autism in special education.

### **Autism/ Autistic spectrum disorder**

Autism or autistic spectrum disorder is typically defined as a lifelong cognitive, neurological developmental delay that impacts social communication, understanding, interaction, and behaviour (Baron-Cohen, 2009; Hyman, Levy and Myers, 2021; NHS, no-date; Joon, Kumar and Parle, 2021). Its prevalence in England alone over several decades has increased significantly with the British Medical Association (2024) reporting that 1 in every 100 children as well as an estimated over 700,000 people have an autism diagnosis. The word spectrum in the name refers to the vast scale of symptoms and severity thereof that people with autism experience, no two people with a diagnosis present in the same way (National Autistic Society, no-date).

Kenny *et al.*,(2016) surveyed over 3000 people from the United Kingdom (UK) with a connection to autism in some way, such as individuals with autism, their families and wider supporting members, about the ways that autism should be referred to and described. The demographic of participants included those from different genders, ethnic backgrounds (although mostly White) and with an age range from 19 to over 66 years. The results found that there was not a collective agreement on the term(s) that should be used in relation to autism. The main dispute was whether autism should be described with a focus on the individual (e.g. person with autism), the preferred language used by many professionals, or the disability (e.g. autistic person), which persons with autism and a small number of parents

favoured.

I have chosen to lead with person-centred language in this thesis, as I do not believe autism defines my son or others, however as explained in chapter one, if the disability-first description is used in literature or by participants, I have respectfully kept the terminology used. In the upcoming methodology chapter, I will explain how children and young people with autism have taken part and their experiences utilised in this study including a brief explanation of how their ability was categorised, although it must be noted that this differentiation had no bearing on them being able to be included in the study.

Through the years, there have been debates that categorise autism, along with disability more generally, as situated within either a medical or social model. The distinction between the two models, can be simplistically determined within their titles, as the medical model focuses on autism as being an inherent deficiency or inability, whereas the social model considers that people with autism are impacted by societal structures and their environment, and therefore treated differently because their neurodiversity is seen as the minority in a neurotypical world (Kapp, *et al.*, 2013; Woods, 2017; Anderson-Chavarria, 2022; Sense, 2024). Autism is typically classified based on the medical model through the use of diagnostic tools and criteria that identifies and subsequently diagnoses what the individual is unable to, has significant difficulty with etc., thus requiring medical and other treatment and intervention. I have refrained from an in-depth discussion of the medical versus social model debate in this thesis because I believe that there is a need for more of a combined model that firstly emphasises the structural barriers that see autism as a deficient ability but also still recognises the medical needs of individuals with autism. However, throughout the different chapters you will note that I lean predominately on the side of the social model of autism based on both my personal experiences and knowledge, as I fight to disrupt the notion that individuals with autism should be viewed as sub-standard but rather active members of society whose multiple identities and abilities have much to offer.

For a long time, abilities that fall outside of neurotypical behaviours and expectations have been painted in a negative light. These powerful and often harmful generalisations of disabilities are reinforced through adverse language and dehumanising stereotypes thus

often creating an unfair, uncomfortable, marginalised hierarchy that positions neurodivergent individuals as lesser than others (Zola, 1993; Byron, 2005; Ripamonti, 2016; Lister, Coughlan and Owen, 2019). Equally, there has been a disability movement in recent years in which some individuals and groups have chosen to proudly embrace and reclaim their disabled identity, positively rewriting outdated narratives, empowering difference, and ensuring they do not lose access to necessary services and support (Haller, Dorries and Rahn, 2006; Andrews, *et al.*, 2019). These discourses around disability can help or hinder the ways in which identity is constructed by self and others particularly for those with quite varied needs, such as autism because of the belief that they exist in their own social world. There are very few studies that explore how children, young people, and adults with a diagnosis of autism spectrum disorder develop their identity/identities. And with the commonality of autism among Black groups particularly, it is becoming critical to delve further into the juncture of diverse, multiple identities alongside autism.

### **Whose Identity is it anyway?**

Do we choose an identity to lead with daily or is it based on interactions with others? Is there always one dominant, prominent characteristic that we wear proudly, or do we shy away from who we really are so that those we encounter do not feel intimidated by our individuality? How do we deal with our conflicting identities or grapple with new ones that seemingly go against all we have ever been taught or know? While *racial* (Swanson *et al.*, 2009; Patacchini and Zenou, 2016), *ethnic* (Phinney, 1989), *gendered* (Steensma *et al.*, 2013; Foroutan, 2019) and/or *social* (Stets and Burkem 2000; Postmes, Haslam and Swaab, 2005) identities may seem the more obvious constructions of who we are, the notion of identity runs much deeper and obscure.

Understanding identity is tricky, as it is referred to as a phenomenon due to its multi-faceted nature. Identity means different things, in different ways to different people, contextualised by circumstances, time, experience and other elements that shape individuals (Tajfel, 1978; Foucault 1982; Hall, 1995, 1996; Carr, 2021; Tatum, 2021). Discourses around identity, particularly those that include race, ethnicity, and culture will often refer to seminal works by Stuart Hall, as discussed in chapter two. Hall (1996) contends that identity is developed through acknowledging difference and not the similarities that bond us together. They evolve

in part through social structures, power and history. Lewis and Phoenix (2004) agree with Hall for the most part contending that racialised and ethnic identities are founded on both similarity and difference, contextualised within disparity that has been built upon ideologies of power.

Both earlier and more contemporary studies on identity seek to compartmentalise and label the subject to define characteristics and simplify the complexity of distinct and overlapping identity types. For example, according to Phinney and Rosenthal (1992) and Mandara *et al.*, (2009) the development of positive ethnic and racial identity promotes strong psychological health, wellbeing, and self-esteem. The addition of tight knit familial networks is also consistent with building cultural pride and supporting social awareness and inclusion (Umaña-Taylor, Bhanot and Shin, 2006). Disability identity often emphasises identity as a binary concept. Here, a person navigates dual identities according to ability. On the one hand their identity shares a neurodiverse space with others and on the other they inhabit a more familiar environment due to their disability, such as autism (Myers, Ladner and Koger, 2011). The salience of identity is that it need not be fixed and limiting but instead always evolving. However, what can make identity development problematic is that a person's identity becomes like a piece of armour, protection from the judgement of others. But the realisation is that this judgement and critique is often strong enough to penetrate even the strongest of layers of who we are, whether for a fleeting moment or even longer still.

Scholars have argued that identity is a fundamental yet multi-dimensional facet that makes us who we are. Identity shifts across space and time, through subject and culture prompting intimate reflections of self and making meaning of others, although these ideas are constructed in much broader concepts and theoretical positions. For example, psychological origins argue that identity formation is a developmental process (Erikson, 1994; Adams and Marshall, 1996), while other disciplines, such as sociology explore identity as a fluid part of life significantly influenced by others and the world around us (Tajfel, 1978; Leitch and Harrison 2016). The shared commonality uniting these diverse perspectives of identity and others, is that it is extremely complex. How then is the complex nature of identity formed for individuals who have intricate learning, social, and educational needs, such as autism?

## **Autism, Race, and Identity**

A fascinating ethnographic study conducted by Bagatell (2007) over a 9-month period explored the process of identity formation in a young man with autism. The author explains how Ben was very much in control of his participation in the research story, much like a co-collaborator. From deciding what they would do and what he would share during their time together, she was able to use his narratives to begin to understand how he shaped his identity. While it has long been suggested that communication is one of the primary and main obstacles that people with autism are faced with, limiting their interactions with others (Biklen and Schubert, 1991; Donnellan, Hill and Leary, 2013) the author expresses that Ben's storytelling was a pleasure. Through a variety of methods such as interviews and observations, the finished account details some of the challenges that this young autistic man faced in making sense of his identity/ identities. Ben's honest admission of depression, contemplation of suicide, trying to fit in, acting 'normal', therapy, social interactions, love, and so much more is an in-depth look at the uncertainty and ever-changing world of identity intersected with autism. His story is told with due care and attention to his needs with the author suggesting that people with autism construct identities through their uniqueness and creativity and exchanges with people around them. Ben is described as a young man with 'high-functioning autism' (HFA). HFA is often confused with Aspergers Syndrome (Gillberg, 1998) but is distinguished with others on the spectrum as it is said to be without the intellectual deficiency (Alvares *et al*, 2020).

There are no current statistics on the number of individuals with high-functioning autism in England and although this categorisation has been frequently used and continues to be used in research studies, it is becoming more defunct in favour of simply recognising that functionality is not an accurate marker of intellect or ability (Alvares *et al.*, 2020). I would argue this individual study of Ben's identity highlights that across the broad autism spectrum, children and young people with ASD require alternative and appropriate ways of understanding identity formation suitable for their differing level of needs. The study makes no mention of Ben's racial/ ethnic or cultural origins, which presents some limitations in exploring how his identity develops in relation to these components. Ben had parental support, attended specialist therapy, groups, and services, which research has shown has



been difficult for families from minority ethnic backgrounds with autistic children to access or engage with (Corbett and Perepa, 2007; Zeleke, Hughes and Drozda, 2019; Morgan and Stahmer, 2021).

There are also additional hurdles that include: cultural beliefs, stigma, and judgement that many BAME families affected by autism are dealing with or have experienced, which require understanding, sensitivity, and respect (Slade, 2014; National Autistic Society, no-date b). Suzy Rowland (2023) wrote an encouraging blog about intersectionality and autism, as the mother of a young Black autistic male. She animatedly lets the reader into a part of their world of 'autism intersectionality' as she calls it, where being autistic and Black necessitate the rules of play to be adapted to the uniqueness of these intersected identities. She explains that although her son has faced racial and ableist discrimination, bullying, and academic challenges, he (they) have been able to tackle these hurdles through recognition of intersectionality and his will to develop self-awareness of his racial, gendered identities as an autistic individual. The purposeful recognition of intersectionality in Suzy's blog post is a personal, inspiring way of thinking about the multiple strands of identity and what that means for identity formation within the wider context of race and autism.

Roman-Urrestarazu *et al.*, (2021) original quantitative study exploring the link between race, ethnicity, and social disadvantage in autism pervasiveness among pupils in England indicated that Black and Chinese groups were the highest ethnic groups. The research consisted of more than seven million pupils in England, of which just under 120,000 were pupils with autism. Data was gathered from the Department for Education's National Pupil Database that comprised of the 2017 Spring Census and Pupil Level Annual Schools Census data (where ethnic information was provided) where findings highlight that Black children/ young people (between the ages of 5-19) in state-funded education were found to be the most prevalent of ASD and face significantly more social disadvantage than other ethnic groups.

The results also ascertain that geographical location, local authorities or councils, and other factors alongside race/ ethnicity influence the commonness of autism in England, subsequently leading to disparities in identification and referrals. Additionally, Black pupils also had the highest amount of EHC plans among the different racial/ ethnic groups and males

overall, were more than likely to have an ASD diagnosis than females. In the first chapter I reported on the statistics of pupils with SEND, whereas this study by Roman-Urrestarazu *et al.*, provides more comprehensive information on autism specifically. Therefore, with such a prevalence of autism in Black children in England, it is imperative, as the authors in the above study argue, to dissect the association between race, ethnicity and autism in much greater detail, which I will continue to do as this chapter develops.

Similarly, the global Coronavirus pandemic provides a further example of the complexity and challenges of autism and race. Significant to themes in this thesis, some COVID-19 studies have suggested that Black and South Asian groups are at more risk of being impacted by the virus due to housing status, occupation, geographical location, mental health, and medical inequalities (Henning- Smith, Tuttle and Kozhimannil, 2021; Office for National Statistics, 2020; Public Health England, 2020). According to current government reports the ongoing COVID-19 pandemic has greatly compounded mental health referrals and requests for support, including autism (Department for Education, 2020). Autism research has found that the change and loss of structured routine, lockdown restrictions, school and service closures, lack of understanding of the severity of COVID-19, general uncertainty related to coronavirus just to name a few has had detrimental physical, emotional and psychological effects on not only those diagnosed with autism spectrum disorder but their families and carers also (Mutluer, Doeniyas and Genc, 2020; Latzer, Leitner and Karnieli-Miller, 2021; Manning *et al.*, 2021). The present threat of Coronavirus is not as rampant as it was a few years ago and research into the enduring impact of the virus continues, particularly on vulnerable groups such as people with autism. Such disastrous events like the pandemic arguably influence different parts of an autistic person's identity as they contend with uncertainty, vulnerability and the unknown, which studies show they already struggle with as part of their lifelong condition (Boulter *et al.*, 2014; Hodgson *et al.*, 2017; O'Nions *et al.*, 2018).

Studies by Gepner, Gelder and Schonen, 1996 and Klin *et al.*, (1999) have investigated race in autistic populations through facial recognition in autistic children and groups. Yi *et al.*, (2015) conducted a more recent quantitative study with autistic participants to investigate if they process their own-race or the faces of other races differently. The study was conducted with 78 Chinese male and female teenagers and young people with a diagnosis of autism spectrum

disorder and intellectual disabilities, as well as typically developed individuals. The participants were shown images of Chinese and White faces and test results infer that the participants with autism recognised the same/ own race face more than the faces of the other race group. The study also found that the participants spent more time looking at the eyes of the White faces, and the nose and mouth of the same-race, Chinese faces. Although the rationale, methods, and other elements of the race-recognition study are not comparable to this study, inferences can be made that suggest that individuals with autism are able to recognise faces of the same and different races. I make this statement with caution because consideration must be given to the well-documented intense education practices and expectations of Chinese children/ young people (Li *et al.*, 2017; Gan and Bilige, 2019), which although considered as a minority ethnic group, further emphasises the fact that not all minority ethnic groups are the same or are impacted the same based on racialised, ethicized societal connotations.

When searching the literature on forming either a racial, ethnic, or cultural identity as a person with autism, the offerings become noticeably slim and yields little results. A meta-analysis by Simpson (2021) investigated the development of cultural identities among Canadian, American, Australian, and New Zealander autistic indigenous groups and found that positive cultural identity formation is possible through strategies that are created by or in collaboration with the community it is designed to support. The author goes on to state that that the most effective initiatives are culturally appropriate and educationally-focused, which is important because they allow indigenous, autistics to see themselves as part of a bigger group, and *“including their presence, perspective, and lived experience is as valid and meaningful, as it is necessary, in shaping individual and collective cultural identity”* (p.423). By interviewing the children and young people with autism personally in my study, I can share their interactions, experiences, and amplify their voices in their own unique ways. Likewise, these direct and unfiltered exchanges allowed me to observe first-hand the ways in which they recognised and interacted with their multiple identities.

Stewart (2008) conducted a study with five (5) self-identified neurotypical Black/ African-American students, three (3) women and two (2) men at a predominately White college in the US investigating how they navigated and incorporated their multiple identities into their

opinions of self. Participants took part in a number of semi-structured interviews about their social and cultural identities including exploring their backgrounds, their understanding of how their various identities take shape, and how their intersected race, gender, and class influenced their life as students. A few themes transpired from the data that align with the themes of this thesis. Some of the key findings suggest that race was a leading factor in the construction of identity, and that education (the institution and processes) impacts how an individual's identity is shaped, reflected upon and negotiated in that space. The participants' critical self-awareness and reflection of the importance of their intersected multiple identities on not only their identity formation but also lived experiences in a predominately White institution demonstrate the immeasurable value and need for Black and ethnic minority students to be exposed to race and culture in education and for institutions to recognise the significance of multiple identities in framing identity. This recognition of diverse identities is particularly important for learners contending with intersecting identities that are still often positioned as a deficit or marginal, such as minority groups with SEND (Richards, 2015).

Literature continues to develop in the examination of how persons with autism develop and understand their diverse identities, including their *autistic* (Botha, Dibb and Frost, 2022; Cohen *et.al.*, 2022), *gendered* (Cooper, Smith, and Russell, 2018; Kourti and MacLeod, 2018), *religious* (Jegatheesan, Miller and Fowler, 2010; Lui *et al.*, 2014), *sexual* (Tissot, 2009; Barnett and Maticka-Tyndale, 2015) and *multiple* identities (Stewart, 2008). A reoccurring theme among many sources, however, was the intersection of multiple identities, (e.g., race and gender, race and autism, race, gender, and sexuality) and autism, which could be argued reinforces the outlook that diverse identities rarely operate independently of each other and can have a substantial impact not only on the ways in which people view themselves and how they are perceived by others but also their lived experiences, inequalities they face and more (Mandell *et al.*, 2009; Bobb, 2019; Davis, Solomon, and Belcher, 2022; Lovelace *et al.*, 2022; McQuaid, Lee and Wallace, 2022). At the time of writing this thesis, research that involved the intersections of the multiple identities of race, ethnicity, and culture among people with autism were harder to find.

## **Autism and Multiple Identities**

Although gender/ sex (herewith gender) was not one of the main themes of this study, it is difficult to ignore its impact on identity formation. The prevalence of autism in males over females is well documented (Baron-Cohen, *et al.*, 2011; Russell *et al.*, 2022; Beyond Autism, no-date a; National Autistic Society, no-date c) and resembles the higher number of boys/ young men with autism that I both saw and was told about in the special schools that took part in this study. My experience of raising a young Black male with autism and teaching the same (group) in special schools has given me varied learning experiences when it comes to understanding identity.

Gender is a distinct identity in its own right, however when combined with race, ethnicity, and ability there are different dimensions. In the previous auto/biographical chapter I shared some of my fears associated with my son's race and gender. These identities alone as a joint unit: Black male, immediately situate my son in a society that is beleaguered with negative stereotypes and discrimination. With the addition of his dis/ability identity, the oppression can also either expand further or lessen if one of these identities is overlooked, for example his racial or gendered identities are ignored in favour of solely his ability (autism) identity. I will explore what I call 'identity-exemption' in chapter six, when I discuss the findings of the participants in this study and their experiences with Black British children/ young people with autism.

Race, gender and autism intersect in a psychological study conducted by Hirschfeld *et al.*, (2007) that investigated racial stereotypes among children with and without autism. The study involved twenty-one autistic children between the ages of 5-11 whose responses to tasks tested their attitudes to race and gender. The results implied that children with autism knew and employed stereotypes based on race and gender in the same way that non-autistic children did, which the authors suggested can provide knowledge about the strength of the autistic mind and social ability, but it required further exploration. Although useful, the study does not provide current insight into the depth of intersectional attributes of race, ethnicity, culture in Black British children and young people with autism in special school settings, which has changed substantially in recent years, thus excluding a sociological perspective and

significant first-person experience of how minoritised children and young people with autism make sense of their racial, ethnic, and cultural identities.

As the mother of a Black British young man of Caribbean heritage it would be remiss of me to ignore the positioning of his racial, ethnic, and gendered identities at home, school and wider society. Each space dictates constant negotiation of self in the present and who he is becoming that can have consequential impact on identity formation (Younge, 2010). For Black British males, in particular those from African and Caribbean backgrounds, education in England has often been a process of discrimination and strife for the individuals and their families. Gilborn *et al.*, (2012) two-year study explored the experiences of Black middle-class parents at the axes of race-class-gender intersections and education in England. Over 60 parents self-identified as being of Black Caribbean heritage took part in interviews with an additional round of interviews taking place at a later stage involving a smaller group of the parents to delve deeper into some of the topics emerging from the data.

The parents disclosed that their Black sons were at greater risk of exclusion and harmful labelling. The participants shared examples of Black boys/ young men constantly being depicted by teachers and staff in a negative light such as being troublemakers and combative. Although there were examples that illustrated Black girls being subjected to stereotyping also, there seemed to be a concentrated effort towards males, which corresponds to much of empirical literature on the subject. Gillborn (2015) then utilised additional data from the study to focus on intersections of race-class-gender-disability in education and suggested here that parents flagged concerns for their Black boys/ young men who were often isolated from others in separate buildings to the general school and referred for SEN assessments when they were victims of racist behaviours by White pupils. Several key themes from the study emulate findings from the participant groups in this thesis and will be discussed in more detail in chapters five and six, however, when it comes to the intersection of disability, gender and race, as Gillborn asserts, these identities are more intricate than they are often portrayed.

Additionally, in a study conducted by Love *et al.*, (2019) four Black parents of Black girls some with disabilities, took part in focus groups and interviews to discuss their experiences of school disciplinary practices and more. One key result pertained to how a father used

socialisation to prepare his daughter with special needs to recognise racism and ableism, by conforming to the same narrow standards he was against. His rationale for teaching his disabled daughter to follow the rules that he considered discriminatory was for her protection as not only a Black girl but a Black girl with a disability. Yet he taught his neurotypical children to identify and fight against racism. The study does not specify the daughter's disability which may have had an influence on the father's decision to teach his daughter to follow the rules. I too, as a parent have also chosen to protect my child against the perils of racism in the past but now have exposed him to the reality of it, which he has been witness to so that he can also protect himself through knowing that racism is not his fault.

### **The role of home and school in racial, ethnic, and cultural socialisation**

In both the preceding chapters, I emphasised that the family and school are central agents of socialisation. By sharing some of the personal stories of my own upbringing, I have reflected on the ways these groups impacted my own diverse identities thus influencing the way that I am raising my son in order to help him develop a sense of his own racial, ethnic and cultural identities as a young person with autism. Racial, ethnic (also referred to as a joint entity, racial-ethnic or ethnic-racial) socialisation (socialization – American spelling) is described as the process of conveying information, customs, values and more about race and ethnicity (Coard and Sellers, 2005; Iqbal, 2014; Neblett Jr. *et al.*, 2016; Tang, McLoyd and Hallman, 2016; Osborne, Barnett and Blackwood, 2023). The sharing and imparting of this information can be intentional, unintentional, and delivered in different ways (i.e., through behaviour or speaking) but seeks to impart profound knowledge that operates within different categories of racial-ethnic socialisation. Different studies either interchange, separate, or combine the terminology of racial-ethnic socialisation, and in this thesis, I make the distinction between racial and ethnic socialisation, in the same way that I separate race and ethnicity as defined and explained in the first chapter, except when referring to existing literature that combines them. It is necessary to recognise the variation between the terms to identify problems and barriers associated with these identity strands, meanwhile also understanding the contextual purpose behind them (Grills, *et al.*, 2016).

Existing literature on racial-ethnic socialisation commonly refers to these four (4) areas, although more exist, including: *cultural socialisation*- empowering racial pride and identity

through cultural history and tradition (Juang and Syed, 2010; Daga and Raval, 2018), *preparation for bias*- sharing the realities of racism, discrimination, and social inequity due to race and ethnicity to better prepare individuals to deal with these issues (Doucet, Banerjee and Parade, 2018; Scott, Pinderhughes and Johnson, 2020), *promotion of mistrust*- applying caution to interactions with people from different races, cultures, and backgrounds based on experiences of discrimination (Hughes and Johnson, 2001; Lane and Kuhn, 2021), and *egalitarianism*- promoting the ideology that everyone is equal thus it is more important to recognise similarities rather than difference because of race, ethnicity, and culture (French and Coleman, 2013; Iqbal, 2013). Arguably such a notion as egalitarianism ignores equity as a significant concept that vehemently endorses justice and fairness, identifying and acknowledging the differences between racial, ethnic, and cultural groups and the hurdles that they must continuously overcome due to the systemic racism and bias.

Racial-ethnic (and the different variations of the term) socialisation is dominated by American studies in Black (African-American) communities and research that explores the UK context is thin. However, Iqbal's (2014) paper focused on one strand of ethnic-racial socialisation, preparation for bias, among families in the UK. The findings here were part of a larger mixed-methods study exploring multicultural parenting and utilised the qualitative experiences of thirty-six (36) British-born mothers of Indian, Pakistani, and White (non-immigrant) heritage, their ages average in the mid-thirties, with their children between the ages of five (5) to seven (7). Iqbal was interested in the ways in which the mothers of each group engaged with their children on the topic of ethnic socialisation, particularly, preparation for bias, and whether there were comparisons and differences between them. The interview data provided five (5) main themes (further sorted into subthemes) including '*culture and identity*', '*ethnic-racialisation*', and '*experiences with racism*' and there were three (3) findings highlighted in their results. They were setting, proactive and reactive parenting. It was suggested through these findings that race and ethnicity were influential in both the lives of the children and the mothers in numerous and different ways across the groups. The authors describe the geographical setting for this study as urban and multicultural, therefore the interactions within these diverse spaces were important to the nature of socialisation. Incidents of discrimination based on ethnicity, race, and religion were shared predominantly by the



Pakistani mothers in comparison to the other groups, and equally they deployed ethnic-racial socialisation through preparation for bias parenting with their children.

Interestingly, the White mothers were the next group behind the Pakistani mothers who recounted feelings of discrimination, ahead of the Indian group, sharing stories of being branded racist and their children being isolated, as they became the minority in ethnically diverse schools. The approach to preparation for bias as part of ethnic-racial socialisation among the groups was categorised into reactive and proactive parenting. The Pakistani group of mothers navigated discussions of race and ethnicity in both a cautious and responsive manner. They expected that their children would be subjected to discrimination and therefore prepared their children for such, a direct contrast to having to adopt an immediate, automatic reaction to racial, ethnic incidents. Reactive parenting was also commonly used by White mothers where either them or their child encountered race-related problems, thus applying proactive measures where necessary in cases such as being the minority in the environment, as explained earlier. The results indicate that despite the historic groundings of discrimination and racism among ethnic minority groups, in this study, British-born, non-immigrant White mothers shared their experiences of discrimination connected mostly to setting, and no longer being the majority in certain settings subsequently leading to feelings of bias.

Some of the findings from Iqbal's study matches with results from both the auto (my personal stories) and biographical (experiences of the participants) parts of this thesis, such as experiences of discrimination in different settings and the rationale and importance of ethnic-racial socialisation for ethnic minority groups particularly. As will be discussed in chapter five most of the racial, ethnic and cultural socialisation that took place for Black-British children and young people with autism in this study was at home. Parents were instrumental in ensuring their children/ young people were exposed to their race, ethnicity and culture in accessible ways for multiple reasons including pride, their own childhood and experiences of discrimination, marginalisation, and racism. Their accounts along with my son's and my own, provide first-hand, practical examples of racial, ethnic and cultural socialisation in England with a group of individuals who face dual or multiple marginalisation because of race and ability, or further still because of gender, religion, or other characteristics, previously

mentioned.

Overall, this pioneering study by Iqbal (2014) of ethnic-racial socialisation in the UK serves as a crucial reminder that differences exist between groups that are often classed together because of similarities, such as ethnicity or race. However, the sentiment shared in this thesis, and highlighted in Iqbal's work is that they are not one homogeneous group, thus any commonalities and differences must be considered at intra (same) and intergroup (different) level and intersectionally. Studies and meta-analysis reviews have begun to explore racial-ethnic socialisation among White families and groups that feature messages of colour-blindness, unity, and silence (Loyd and Gaither, 2018; Pahlke, Patterson and Hughes, 2021; Umaña-Taylor and Hill, 2020; Abaied *et al.*, 2022; Nieri, Montoya and Carlos, 2023). White British groups remain the majority across the UK (Office for National Statistics, 2022) however, the ethnic landscape continues to diversify and in some regions across the nations, White groups are the minority. While it is important to explore this engagement with racial-ethnic or ethnic-racial socialisation on a whole or through the specific areas mentioned earlier (e.g., preparation for bias or egalitarianism) in White groups, it is equally necessary to do so through a critical lens, acknowledging that such socialisation manifests differently in White communities because of systemic racism and power imbalances at the core.

Bowman and Howard (1985) investigated race-related socialisation by interviewing nearly 370 male and female Black adolescents and young adults, aged between 14 and 24 years regarding the messages that the family conveyed about race. The participants took part in over an hour-long interview that delved into areas such as social background, school experience, and motivational temperament. Some of the outcomes relevant to the findings in this study purported that familial socialisation helps children/ young people make meaning of their racial, ethnic self through ethnic pride, racial barriers and personal empowerment. In this thesis, racial, ethnic and cultural socialisation has been identified as operating in a binary space, at a personal (McHale *et al.*, 2006) and public (Hughes and Johnson, 2001) level. The development of identity as it intersects with race, ethnicity, and culture among Black-British children and young people with autism and the influences of these themes on them and their families shape the individual perspective, while on the opposite end are societal views, which in recent times have been significantly intensified by persistent and strained racial tensions

around the world. One such structure that has been under scrutiny is education.

With parents and families playing prime position in sharing messages about racial, ethnic and cultural socialisation of children and young people, how exactly does school, another socialising agent factor into this process? Children and young people, including those with SEND continue to develop their identity, sense of self and others as they go through the different stages of school (and via other structures), and who they are and become is under regular construction. Like the family, schools (which includes the curriculum, staff, space, and all that encompasses education) will communicate information, messages about race, ethnicity, and culture to their pupils and students that may align, oppose, or confuse what they have been taught at home. The structure of education in England has been called out for being institutionally racist, discriminatory, and biased against minority ethnic groups, mainly Black groups, which has been extensively documented for years, as explained in the previous chapters (Graham and Robinson, 2004; Schulz, 2021; Swiszczowski, 2022).

There has been a recent push across education in England, from schools to universities, largely as a direct response to the outcry of racial inequality following the murder of George Floyd to demonstrate a commitment to racial equality. Examples of which can be found in the Race Equality Charter (Advance HE, no-date) and the Anti-Racist School Award initiative created by the Centre for Race, Education and Decoloniality (CRED) (Leeds Beckett University, no-date). The award is made up of a five-point framework that includes governance, leadership and management, school environment and parents and community partnerships that schools embed as part of an anti-racist culture to be awarded bronze, silver, or gold status. Such strategies bring to light the institutionalised racial disparity throughout English education, whether through the underrepresentation of Black, Asian and minority ethnic (BAME) teachers, senior leaders, and academics (Bhopal and Pitkin, 2018), minority ethnic student attainment/ awarding gap (Universities UK, 2019, 2022) or the White colonial curriculum (Peters, 2018) and challenge schools and institutions to make a pledge for real and sustainable change. Utilising the body of research on racism and disadvantage in English schools, briefly done in the previous chapter, can serve to benefit the broad discussion on racial and ethnic socialisation in schools but once again, American research is at the forefront of this topic.

Saleem and Byrd (2021) offer “The School Ethnic-Racial Transmission Model” as a framework that includes three (3) main elements, “transmitters, content and methods, and outcomes” (pg. 1107) to make sense of this type of socialisation in schools. The components have specific responsibilities: messenger(s), the message(s) and how they are delivered, and the result, respectively. Although the model may appear simplistic in nature, the underlying premise serves to unpack the complexities of ethnic-racial socialisation in schools, taking advantage of the empirical literature on familial ethnic-racial socialisation. First, the scholars recognise the multiple transmitters of school ethnic-racial socialisation, which as outlined in earlier sections of this thesis, work at individual and group levels. They include, school personnel, staff, external professionals, peers, families, as well as historical settings, policies, and systems. Next, the messengers relay different messages about race-ethnicity and culture that have been categorised into five (5) areas. I have listed all of them here as they can all be used to better understand the work in this thesis. *Cultural Socialization*- the value and significance of culture and taking pride in one’s cultural history and background; *Promotion of Cultural Competence*- cross-cultural learning and developing cultural knowledge of other groups; *Critical Consciousness Socialization*- exposure to racial inequality as a tool to develop awareness of such and more, an extension of the preparation of bias function in parental ethnic-socialization; *Mainstream Socialization*- messages about the standards and customs of the US, which may be different, ignore and/or conflict with personal and familial customs and traditions; and *Colorblind Socialization*- promoting the idea that race and colour does not matter as everyone is equal.

These messages are transmitted in a variety of ways such as, verbal, or non-verbal, intentional or unintentional, regularly or sporadically, which also feeds into the value of the message and how it is embedded into the practices and life of the school. The third and last element in the school ethnic-racial socialisation model is outcomes, which fall into either academic outcome, psychosocial (e.g., school relationships, self-worth) or ethnic-racial attitudes (i.e., identity-formation, recognition of other ethnicities, races, cultures). The authors have built upon some of the general ideas of parental ethnic-racial socialisation, but equally developed elements specific and relevant in a school context. They have not tried to further complicate the already complex process of racial-ethnic socialisation but instead have constructed a model that can

be adapted across education according to different learners, abilities, education levels and global contexts. It can also be used in a more intersectional way that includes gender and class for example. Although the concept of ethnic-racial socialisation is more established in the US, which as a country differs on significant levels to the UK, culturally, politically, and socially, this school model is a valuable resource for unpacking the delicate construction of race and ethnicity in education in England. Furthermore, the comprehensive description of each component in the model can not only help facilitate more positive and honest discussions about race, ethnicity, and culture in schools but also foster equitable and practical long-term solutions.

Other studies and literature on ethnic-racial and cultural socialisation in schools or education more generally present similar conclusions about the influence on identity (Byrd and Legette, 2022), academic attainment (Kuchirko and Nayfeld, 2021), or the impact of experiences of discrimination and racism (Dotterer, Hale and Crouter, 2009). In Iqbal's (2014) study about ethnic-racial socialisation among Pakistani, Indian, and White mothers in the UK, which was discussed earlier, the findings also indicate that schools have a responsibility to manage race-related issues that play out in their settings. The author argues that choosing to ignore or skim over race or ethnicity, creates future issues between groups. I would also state that the individual is also significantly impacted in the first instance before the group by such any approach that ignores their diverse identities.

In a recent study, Cohen *et al.*, (2022) probed how schools contribute to shaping autistic identity and other identities such as race and gender. The participants were a mix of teenagers and adults ranging in age from 15-35 years old who through qualitative interviews were asked to reflect on how their primary through high school experiences affected their identities. The results are particularly significant to this study, as they alluded to participants feeling that their autism was viewed with negative connotations and they were treated different to others because of their other identities such as race, gender, and sexuality were overlooked, while for others these other identities were viewed alongside their autistic identity impacting teacher bias. The first-hand account of individuals with autism in this research delivers a powerful message about the negative impact school can have on the multiple strands of identity for autistic young people and adults, and what can be done to reframe these

experiences into more positive, affirmative ones.

### **Belonging and sense of self**

Childhood and the subsequent adolescent years are a critical time for identity development and learning about self and others, which often takes place at home and school. McNamee (2016) and Wyness (2012), both utilise the sociology of childhood to argue the discourse that children and young people are active, able participants within school and society, shaped by experiences that connect to their race, ethnicity, culture and more. McNamee also contends that the different constructions of disability, for example through the medical or social model of disability, as briefly defined in chapter three, can also impact how children understand themselves in relation others, although they do not delve any deeper into the thread of this discussion. As children and young people are socialised through different stages of life, they begin to develop a greater sense of self and belonging that connects to their diverse identities.

Maslow's original theory of motivation (1943) developed into a hierarchy of needs (1987), positions belonging as a psychological need that requires other needs to be met at a basic level in order to satisfy the greater reward of self-attainment and personal gratification. This simplistic overview is often adopted as a foundation for understanding belonging, however, belonging is as diverse as the subject areas that it covers, across a number of disciplines (Yuval-Davis, 2006; Bennett, 2015; Halse, 2018; Allen, 2021). Belonging has been linked to personal and academic outcomes (Haim-Litevsky, Komemi and Lipskaya-Velikovsky 2023) and relative to this study, identity (Gaither, 2018). Earlier in this chapter, we discussed identity development and autism, but how does this link to belonging and sense of self.

Cullinane (2020) carried out a study that explored the idea of belonging in children with SEND. Thirty-seven students in total took part in the two-part study which involved both a self-assessment tool to measure school belonging (phase one) as well as semi-structured interviews (phase two). The results of both phases propose that students with SEN experience belonging at a lower level than non-SEN students. Suggestions were made that interventions to increase sense of belonging for SEN students must focus on the needs of the students, which concur with a core principle of this study, that consideration must always been given to the appropriateness of the needs and abilities of the individual.

Research conducted by Haegele and Maher (2022) examined feelings of belonging through peer relationships and connections in young autistic males in inclusive, mixed physical education (PE) classes. The qualitative study involved the views of eight autistic males aged between 13-18 years old who were verbal communicators. Their race/ ethnicity was identified as White for all participants. Some of the results showed that the participants experienced bullying by neurotypical peers that forced them into solitude and self-harming behaviours and relationships were nurtured through similar interests over time and through the interactions away from adults and lessons, such as in the locker room. So, despite the PE classes being inclusive with autistic and non-autistic young men, positions of belonging and feelings of being truly included among the autistic group felt unfeasible and missing. And although neither of these two research studies above incorporate intersectionality of race, ethnicity, or culture among their autistic participants they provide some insight into some of the common themes of identity formation that came out of the results in this study, as will be explored in later findings chapters.

A qualitative study conducted by Hodge, Rice and Reidy (2019) investigated the role of educators understanding of how autistic pupils developed a sense of self. Four schools (special and mainstream) were involved in the study with twenty-five school staff between them taking part in focus-groups. The researchers were interested in the participants own understanding of 'sense of self' and how they understood this concept as it related to the autistic pupils, their perceptions of barriers that influence sense of self among autistic pupils and how they supported these pupils in developing a sense of self. Of the findings that are relative to this study was that school was thought to play an influential role in autistic children developing a sense of self, however, this influence was disempowering and negative primarily for the autistic pupils who were expected to be the ones to regulate their behaviours and feelings and conform in this space, and in order to develop a positive autistic identity the pupils needed access to a shared group they could connect with.

### **It is a part of our identity: religion, music and food**

In the previous chapter, I shared some of the ways that my family kept my siblings, and I connected to our ethnicity and culture, which included religion, music, food, clothing and more. It was an intentioned way of life that was reminiscent of my parents Caribbean roots

and upbringing and their desire to ensure we followed in the same traditions here in England (Bauer, 2018). Whether it was attending church regularly, listening to music from the homeland, and enjoying home-cooked traditional food on a daily basis, these customs and values were weaved into the intricate fabric of our racial, ethnic and cultural identities. Walters (2012) suggests that people categorise their ethnic identity based on different characteristics that are meaningful to them and who they are such as religion and language. Oppong (2013) asserts that children of parents who are devout in their faith are likely to become dedicated to their faith because of their parents influence. While Hemming and Madge (2011) discuss religion as its own identity strand, not only connected to ethnicity, culture, or race but an identity that like these characteristics is fluid and multi-layered.

Eaude (2019) speaks about the relevance of practical, real-life examples and opportunities for young children's construction of identity, which they regard as an ever-changing part of life influenced by important factors that includes religion, race, gender and dis/ability. When children are able to actively engage with their religion and/or race for example their identities become more inherent recognising the appropriate ways of navigating different settings and spaces. Additionally, identity in children is gradually formed through regular interaction and routine with culture and traditions, such as going to church or prayer before bed, passed down through the generations, which was mentioned by participants in this study.

Equally, food and music are tangible, sensory ways that can create a long-lasting association to cultural and ethnic identities. Across different cultures and ethnicities food has been studied for many reasons including its health and healing properties as in a Singaporean study (Reddy and van Dam, 2020) and gender such as a study of Ghanaians living in London, where the woman is primarily responsible for cooking traditional meals as they would have been back 'home' (Tuomainen, 2009). Much has been written about the power of music and Wanjala and Kebaya (2016) explored how pop music influenced identity formation among Kenyan adolescents. They suggest that music extends beyond its obvious purpose of entertainment but rather is instrumental in the construction and reconstruction of different identities that are either imposed on them or innately reflexive through the music. I would suggest that religion, food, and music provide simple, yet special ways for the parents and families in this study to not only bond with their child/ young person, which includes ensuring



that they are included in family and cultural social events but also share and hopefully sustain a deeper connection to their ancestral heritage through these means, that provide joy and happiness as a basic necessity also. Literature has neglected to adequately investigate the intersected racial, ethnic, and cultural influences and socialisation of religion, music and food among children/ young people with autism however, which I believe would prescribe even more depth to the discourses of socialisation and identity.

### **Britishness, Englishness, Otherness**

The shortage of English studies investigating racial, ethnic (which includes cultural) socialisation in schools, specifically special schools greatly restricts our knowledge in this area, for example if, and how race and cultural values is taught in English special needs schools and any perceived impact that it may have on pupils, families, and the entire school community. As this thesis was completed there was no literature available on racial, ethnic socialisation in special schools in England, although there are articles, government reports, papers, and information pointing towards cultural education (in the UK and abroad) for pupils with SEND, yet sparse or outdated (Gay, 2002; Lamorey, 2002; Department for Culture, Media and Sport, 2012; Lindon, 2012; Amatea, 2013; Boddison, 2021). However, cultural education is not cultural (or racial, ethnic) socialisation, although they have sometimes been used to mean the same thing. It has a broad definition that covers exposure to culturally enriching subjects, such as art or dance (Department for Education, 2013; Arts Council England, 2021). These subjects can be used as the basis of racial, ethnic socialisation in all schools by incorporating and celebrating diverse cultural backgrounds as a starting point of inclusion.

Wearmouth (2019) states that teaching in special education should be responsive to the ever-changing cultural diversity of its students, which has been a developing political discourse through the years though primarily in mainstream education. It feels as though England often teases equality and inclusion, particularly within the structure of education, as a response to criticisms of institutional racism and socioeconomic disparity, but the follow through is slow. Moreover, this performative charade uses culture as a soft launch, rather than race, which makes people uncomfortable, and I affirm is likely a more palatable approach for those who support neoliberalism or believe that we are in a post-racial society (Bhopal, 2018).

In 2014, many schools, including special schools in England subscribed to guidance, which seemed more like a directive, from the Department for Education to promote Fundamental British Values (FBV) of democracy to ensure pupils were best equipped for life after school in ever-changing Britain. By doing so they subsequently met their duty of care and commitment to the Education Act's (2002) Spiritual, Moral, Social, and Cultural education. The values listed within FBV include rule of law, individual liberty and mutual respect and tolerance for those of different faiths and beliefs. The latter stands out in direct contrast to the rest of the list, feeling more like an add-on, to appease those who fall into the category of others, not British and can be problematic as it can be considered exclusionary rather than inclusive of different identities (Tomlinson, 2015; Crawford, 2017; Lockley-Scott, 2019; Vincent, 2019), especially as FBV was part of the Prevent strategy (Home Office, 2011) response to terrorism and radicalisation. If schools have the autonomy through the National Curriculum and policies such as FBV to adapt their teaching in a more culturally responsive way as a preparatory tool, it can be argued that they can do the same to include race and ethnicity in their curricula, teaching practices and school culture. It can be done through socialisation methods that acknowledges and respects, informs and educates, and includes and protects the diverse cultures, races, and ethnicities that populate the UK, instead of imposing Britishness or Englishness as identities located in white identity supremacy or misguided nationalism (Hall, 1999; Kumar, 2010; Leddy-Owen, 2014).

Davidson and Alexis (2012) contend that for some Britishness is masqueraded as multiculturalism, which they claim is problematic and discordant, lacking unanimity in definition. They continue that there is an important place for culture in education but argue that Black children cannot develop their cultural identity when it is constantly deemed lesser than other cultures within the British school system, which significantly impacts them through outcomes, teacher expectations and equal access to opportunity. I include special schools in this debate and reiterate that they must not be excluded from adopting racial, ethnic and cultural socialisation practices but ensure it is suitable, consistent and meaningful for its learners for not only their immediate but also future development.

## **Chapter Summary**

In this chapter, I have continued from the discussions in chapter two utilising additional

empirical literature to explore what is known about the intersections of race, ethnicity, culture and identity with autism. Literature that investigates these combined themes is narrow, especially across England and special school settings. However, some significant research was found around identity formation and autism and ethnic-racial socialisation, as well as highlighting the need for further study into special schools in England. Some of the findings from the studies mentioned in this chapter provide more general information towards this thesis' research questions, meanwhile reinforcing the rationale behind investigating the relationship between race, identity, and autism. As this thesis maintains and empirical studies have shown developing cultural, racial and ethnic identities are essential to individual and group membership, a sense of identity and belonging, which I stress should include Black-British children and young people with autism.

## Chapter Four: Methodology

### Introduction

This chapter discusses the various processes used in creating, preparing and conducting this research study, including the aims of the research, the methodological paradigm, tools of data collection utilised, positionality and ethical considerations. It provides a clear rationale and justification of a research model that involves vulnerable participants, and how the diverse data was analysed. In addition, this chapter describes the methodological and practical challenges encountered while carrying out this research and the ways they were resolved.

### Research Questions and Aims

A reminder of the primary research questions for this study:

- *In what ways have my own lived experiences of raising a young Black British man with autism helped construct his identities?*
- *To what extent do Black British children and young people with autism ‘understand’ (are aware of, engage/ interact with and recognise) their racial, ethnic, and cultural identities through exposure at a) home and b) school?*
- *How do English special schools incorporate race, ethnicity, and culture into all aspects of their pedagogy, and wider school community.*

The aims of this research are first from an auto/biographical perspective, discussed in the previous chapters, as I sought to explore how my son is supported in developing his distinct identities, as a young Black male with autism. Second, whether Black British children and young people with autism understand (i.e., are aware of, engage/ interact with and recognise) their racial, ethnic, and cultural identities (and the perceived influence of this engagement on their identity formation), in an accessible way across their home and school environments. The third aim was to explore more broadly how English special schools and families expose and teach them about themes of race, ethnicity and culture to empower these identities, tackling racial inequalities, bias, and discrimination. Due to the auto/biographical element of this research, which focuses on some of my personal narratives and experiences, which also includes parts of my son’s story, akin to the themes

of race/ ethnicity/ culture, identity and autism, the decision was made from the beginning to conduct this study within similar parallels of these themes, as much as possible, for example with Black British children/ young people of Caribbean and African heritage that have a diagnosis of autism that attend (or have) attended a special school, college or specialist autism unit in England. The full criteria for the research will further be expanded on later in this chapter.

**Research Setting: English Special Schools**

There are currently over 1000 special schools in the England, with 31.7% of all pupils of school age with a place in these settings (i.e., nursery, primary, and secondary) classified as ethnic minority or non-white British (Department for Education, 2024c). The number of special schools includes state-funded and non-maintained private special schools not independent schools or colleges. The Association of Colleges (no-date) reports that there are approximately 99 specialist college provisions across England and Wales that provide education to post-16 individuals with learning disabilities and/ or difficulties. The 2023/2024 school census as reported by the Department for Education (2024a) further indicates that there are just over 9000 pupils of Black Caribbean and African backgrounds in special schools (state-funded and non-maintained) in London (Table 4). This data, however, does not include special colleges who do not provide data for the school census or independent schools, which are usually privately run, fee-paying provisions without input from the local authority (Department for Education, 2024c; Twinkl, no-date) and so the figure is likely to be higher.

**Table 4: Pupil Characteristics, Ethnicity and Language 2023/2024**

		Headcount	Percent
Black - Black African	Non-maintained special school	122	3.0
	State-funded special school	7,400	4.7
Black - Black Caribbean	Non-maintained special school	24	0.6
	State-funded special school	1,794	1.1

**Source:** Department for Education, 2024c

It was initially decided that any special school setting, from primary schools to colleges, across Britain would serve as eligible for this research study, this was then changed to

England more specifically to maximise the potential number of participants with first-hand experience and knowledge of the themes. Moreover, data collected from participants across the UK would also provide some comparative information from areas less ethnically dense. However, this choice was later re-evaluated, as it transpired that most interest in the study was coming from within London primarily, with a few outliers in less diverse regions, possibly because of the reach of the recruitment. Therefore, special schools, colleges, and specialist autism units in England, within and closely bordering the geographical area of London (Image 4.1), as seen below, became the primary source for the pupil component of this study, for a few reasons.

**Figure 4.1: Map of Greater London boroughs and surrounding areas**

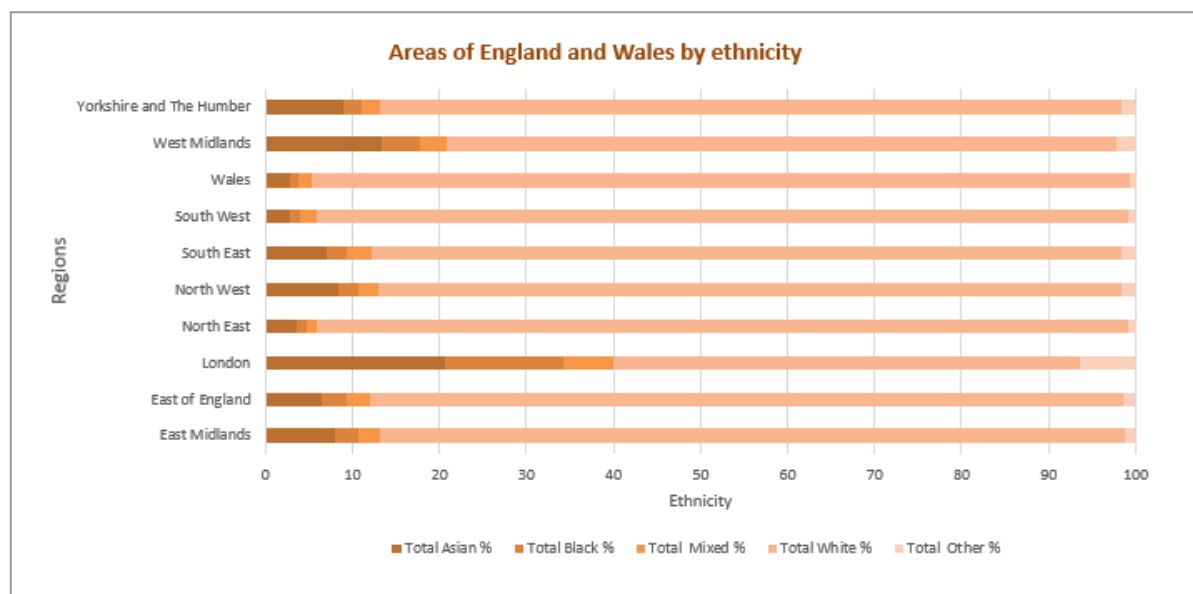


(Source: Manorial Counsel, no-date)

First, ethnicity and ethnic identity is one of the core themes underpinning this study and its research aims. According to the 2021 Census data for England and Wales (Office for National Statistics, 2022b), London is listed as the most ethnically diverse region. The

census data for the capital city revealed that 46.2% households that responded identified as being from/ of Asian, Black, Mixed, or 'other' heritage, with 13.5% identified as Black, seen below in figure 4.2 that I created from the data.

**Figure 4.2: Regions of England and Wales by ethnicity**



**Source:** Office for National Statistics, 2022b

There were 3 different 'high-level' Black ethnic groups within the breakdown of the London census data (2021), which were, *Black* (49.3%), *Black African* (46.8%) and *Black Caribbean* (55.4%). The largest Black group within the above data spotlights a well-established and deep-rooted Black Caribbean (55.4%) connection within London that includes me, as the daughter of first-generation migrants who came to the United Kingdom from the Caribbean in the 1960's, a part of the 'Windrush generation' to help rebuild the country after the WWII (Taylor, 2020; BBC, 2024). As discussed in the previous chapter my strong, resilient racial and ethnic identity and cultural pride is inspired by the rich stories of my Caribbean parents and others from the bountiful shores of the islands also known as the West Indies (Matthews, 2018; Grant, 2020). Equally, there has been a substantial increase in Black African populations that have migrated to England, from predominately East and West African countries over the last 40 years fleeing war and political unrest, seeking better job prospects and quality of life (Ochieng, 2012; Babatunde-Sowole, *et al.*, 2016; Flahaux and De Haas, 2016).

I therefore decided to focus on Black British children with autism descended from Black Caribbean and Black African backgrounds as they are the largest self-identified Black ethnic groups within England, and most representative of this ethnic community in English special schools, initially brought to light by Coard's (1971) work and others, on the over population of Black West Indian children in specialist schools, as discussed in the previous chapters. I also choose this demographic because of the similarities to the auto/ biographical strands in this study, my son, as a Black-British young person with autism, with Black parents whose heritage originated from migration. While our migration ties are from the Caribbean (via Africa), there are parallels with the migration history of Black African people to the UK, as well as a shared racial Black identity. Moreover, by utilising these two subject groups I was able to further analyse the data for any comparisons and contrasts within the larger racialised Black in-group against the research aims. As a large body of literature suggests dual, mixed, and multiple racial people often navigate between/ across more than one heritage (Wallace, 2001; Lusk *et al.*, 2010; Johnston-Guerrero and Pecero, 2016; Törnngren, Irastorza, and Rodríguez-García, 2021) which has different implications on their identity and sense of belonging, which did not align with the purpose of this research.

Based on the current census figures above, it was therefore anticipated and expected that participants from across the London region would be representative of Black African and Caribbean ethnic groups and could be easily reached. Secondly, as a SEND professional who lives in and works at a special school in London, I have a strong knowledge and network of special schools and colleges across the various boroughs of London and neighbouring ones, which I felt was beneficial in allowing me some research access as an insider. Equally, I hoped that not only would this insider perspective as a SEND practitioner be helpful, but also my positionality as the mother of a Black-British son with autism be advantageous in gaining the trust of the different participant groups for the study.

In all London boroughs, the number of special schools and colleges is markedly fewer in quantity (e.g.,  $\leq 1$ ) compared to mainstream provisions. In addition, there was a small percentage of Black British children and young people with autism of Caribbean or African heritage, in a few of the special schools, colleges, and autism units that took part in this study, which could potentially risk making the vulnerable participants and others in this



study identifiable, I therefore decided not to list the specific borough areas that the provisions were in. Consequently, one of the definitive factors of mainly concentrating this research within a racially, ethnically, and culturally diverse demographic area, such as London, was my belief that participants would have actively and regularly engaged in the development of their cultural and ethnic identities, on both a micro level, through familial ties but also at a macro level, such as through different structural groups, like schools and community links. However, it is important to note that the few participants who took part in this study that live in less diverse areas surrounding London were extremely passionate and connected to their racial, ethnic and cultural identities.

### **Auto/Biography as a methodology**

Crotty (1998), Mukherjee (2020), and Creswell and Guetterman (2021) all emphasise the importance of understanding methodology as an all-encompassing design of gaining knowledge, which then aids researchers in choosing the most appropriate one for their research. In chapter two, I discussed my rationale for using an auto/biographical approach in this study. As a parent, I began exploring the ways in which my son engages with his racial, ethnic and cultural identities as a young Black male with autism. I pondered whether he felt any sense of belonging to the Caribbean connection we descended from. The connection, which I felt and lived so deeply from childhood that I had consistently tried to expose him to at home through music, food, and a way of life, and whether those interactions were contributing to the socialisation and shaping of his identity. As a researcher, I then thought about whether other Black children and young people with autism and their families navigated similar questions about their intersecting identities within their home and school environments.

I believe that there is an element of personal storytelling within all research, which I recognise as a powerful vessel. There is a uniqueness in our stories and lived experiences that allows the audience to interpret and make their own meanings that can differ or relate from one person to the next. Stories can connect, inform, share, reconcile, build, transform, question, and help our very existence and that of the world we live in, in a variety of profound ways. They are universal and not simply bound between hard covers of books, the television, or scripted reality dramas. From our interactions to triumphs, experiences

to struggles and everything in between, stories are everywhere and everything we are. Thus, the importance of the auto/biographical approach that frames this research study.

Roth (2005) suggests that auto/biography should embody not only personal knowledge, and experience but also collective constructions of that knowledge. They argue that inner subjectivity becomes grounded through intersubjectivity, as one makes meaning of the 'self' to also make meaning of the other. Similarly, work by Letherby, Scott and Williams, (2013); Morgan (2020); and Rogers (2011) all employ auto/biography to share narratives as a means to develop the ways we understand our lives and those of others, unpacking the dichotomy of objectivity and subjectivity in research. In chapter two I have explained that engaging with an auto/biographical methodology in this research was necessary to the relationship between my own lived experiences and that of the other participants lives. I have acknowledged the importance of this positionality particularly wherein my role as the researcher intertwined with that of those being researched, discussed later in this chapter.

Methodologically, I also drew auto/biographical inspiration from Coard's (1971) book, 'How the West Indian Child is made Educationally subnormal in the British School System: The Scandal of the Black Child in Schools in Britain' and his personal rationale for writing it (Coard, 2005). Coard not only ran activities and groups for children labelled as "educationally subnormal" but he also taught these children, which afforded him intimate, first-hand access to an education system that used specialist institutions, which he describes in his own words as *"a convenient dumping ground for Black children"*. He describes his anger at what he was witnessing that the Black West Indian children being sent to special schools at that time was unjustified, permeated in racism. His personal desire to investigate the educational, social injustices he witnessed resonated with some of my own experiences of teaching in a special school and the discrimination faced by Black children, including my own son, families and staff members discussed in chapter two and in the later results chapters. His work and the legacy of his findings that called out institutional racism motivated me to explore and engage with my lived experiences and that of other parents and SEND professionals to challenge the racialised, ableist inequity in English special schools giving rise to the voices of the ignored or excluded and the injustice that hides in plain sight.

However, this research goes beyond wanting to give a voice to my son and others like him from marginalised and vulnerable groups, as they have already have a voice, although different from traditional, medical and ableist definitions of the word. But rather to amplify their stories and lived experiences that might have been excluded from research because of their multi-layered identities that include their race, ethnicity and ability. As active members of society they have the right to be heard and should be encouraged to share their experiences in their own way, which will provide a better understanding of any challenges and experiences they navigate and opportunities for all to learn from and support one another. By including vulnerable groups in a variety of research, the opportunity exists for better awareness, tolerance, acceptance and acknowledgement of our differences, as well as affording significant contributions to wider research. Additionally, by utilising the shared stories of this vulnerable group and their families and educators in this research, the benefits outweigh the risks, as if they were excluded, this information could not be accurately obtained on their behalf without potential assumptions of someone speaking on their behalf. Moreover, the above reasons for carrying out this research as well as those previously discussed in the earlier chapters helped to create a more robust framework to reflect and build upon in search of the most appropriate paradigm.

### **Research Paradigm**

Educational research is often situated within a particular paradigm that helps researchers to structure and process how people understand phenomena, the world they live in and how they create meaning of reality (Waring, 2017; Walsh, Böhme and Wamsler, 2021; Matta, 2022). Therefore, it is necessary to understand the critical role that paradigms play in the design, methodology, and analysis of empirical research. Kuhn (1996), a philosopher of science is typically regarded as the influential figure who forged the idea of the paradigm, which he argued to be a series of connected expectations, ideas, values, and knowledge about the social world that are used to construct rational and literal meanings of that world. Kuhn's paradigm characterisation was developed through a scientific perspective. Over time the paradigm has since evolved into different disciplines such as the social sciences, however, the notions that Kuhn founded are still instrumental (Sparkes, 1992; Guba and

Lincoln, 1994; Hammersley 2012). An auto/biographical, qualitative study was deemed to be the most suitable approach as it best allows for the subjective experiences and views of those involved to be collected and analysed.

Individuals with disabilities and learning difficulties are an underrepresented group in literature. Research is often conducted ‘about’ them and not ‘with’ them included as the narrators of their own story (Coons and Watson 2013). The intersections of race, ethnicity, culture, and identity alongside disability, add a deeper dynamic in discourses around each of these areas (Stuart; 1992; Kramer-Roy, 2015). While I understand that there are limitations on the cognitive abilities of pupils with learning difficulties and disabilities, I argue that this should not prevent them from having the opportunity of being involved in research. Despite the common characteristics of some children with autism, such as *communication difficulties* (Baron-Cohen *et al.*, 2009; Gillberg, 2006; National Autistic Society, no-date d), *multiple sensory* processing needs (Kern *et al.*, 2007; Russo, *et al.*, 2010; Jones, Handley and Riby, 2020) and *social differences* in understanding and interacting with the world around them (Müller, Shuler and Yates, 2008; Bottema-Beutel, 2017; Scheeren, Koot and Begeer, 2020), I was committed to demonstrating that their inclusion in research was indeed possible. As this study has shown by ensuring that their involvement was safe and appropriate to their capacity and needs throughout.

The use of diverse Augmentative and Adaptive Communication (AAC) (e.g., objects, pictures, symbols, gestures etc.) has allowed participants with disabilities to fully participate in this study and encouraged them to play an active role in research about them. Therefore, a qualitative method, especially in this study will provide meaningful data to be thoroughly analysed that quantitative data cannot. I acknowledge that this study does not fall within the realm of participatory action research because the participants have not been involved as collaborators in the creation and other aspects of the study as members of the community under research (Canosa, Graham and Wilson, 2018; Cornish *et al.*, 2023), however their involvement, particularly the children and young people with autism has provided invaluable input that both historical and contemporary research has overlooked.

If research is founded on philosophical enquiry and the desire to explore what we know of

the world we live in, or epistemology, and what is presumed to be real and true; ontology (Krauss, 2005; Scott and Usher, 2011; Rehman and Alharthi, 2016; Kivunja and Kuyini, 2017), then the mode(s) we utilise to unpack and understand that knowledge is imperative. Some of these modes include positivism, critical theory, and interpretivism. Qualitative studies are mostly associated within the scope of the interpretivism paradigm, although not exclusively, because they delve into the reality of people's feelings, thoughts and experiences as they live and make them. Interpretivists argue that people construct meanings from the social world that they interact with and are influenced by such as people, culture, identities, and more (Alexander *et al.*, 2016).

The counterargument of positivism is that knowledge is factual based on scientific underpinnings that are measurable and observable, through tests and objective deduction (Cohen, Manion and Morrison, 2018). These brief contrasting definitions of positivism and interpretivism, which pit objectivity against subjectivity are just some of the ideologies that create a basis for research. However, I assert that not everything fits neatly within one paradigm, as was the case in this study. I applied both interpretivism and critical theory as research paradigms to investigate the intersected themes of race, ethnicity, identity, culture, and autism for a few reasons.

First, as previously outlined, interpretivism allowed the experiences of each participant to be shared in their own words, connected to their own meanings and understanding. Guba and Lincoln (2018) contest that the notion of interpretivism is that reality is fluid, not fixed and exists in various interpretations people hold. Within this paradigm, I was able to investigate the why's and the ways in which the themes of the study influenced not only the participants but also my own connection to the themes. Second, Grix (2019) states that researchers are interconnected to their research, which I agree with, not only through the auto/ biographical element of this study but also recognised through the dual positionality of 'insider/ outsider', discussed in chapter two and discussed later in this chapter. However important the relationship between the researcher and study was, the focus was equally on the experiences, views, and events through the lens of the participant groups.

I regularly made a conscientious effort to be reflexive throughout this research process,

acknowledging my own personal thoughts, attitudes, and power. Finally, the inclusion of critical theory as a paradigm probed the dynamics of power and structure specifically in relation to the intersections of race, gender, and dis/ability themes. Critical theory contends that parts of our reality and knowledge are social constructed (e.g., race, gender, class) because of the hierarchical status of power that privileges certain groups above others (Thompson, 2017; Esposito and Evans-Winters, 2022). Critical theory seeks to challenge and disrupt the dominant forces of power that marginalise and subjugate groups. So, within this study, I explored how the topic of race and ethnicity was taught in English special schools, which traditionally subscribe to the National, Eurocentric curriculum. In addition, whether Black British children and young people with autism had experienced racial or ableist discrimination and the perceived influences that it had on them and their families.

Scott and Usher (2010) and Müller-Doohm (2017) argue that a fundamental aim that sets critical theory apart from other paradigms, must be to elicit and fight to change the injustices and inequalities that exist within our practices, values, and indeed everyday society. The intention of utilising a critical theory paradigm within this study was to confront the racialised biases and discrimination that exist in the structure of English special education and navigate towards tangible, accessible change for Black children and young people with autism, their families, schools, and indeed the wider community, which have been underexplored in research contexts. Whether this change was at a micro and individual (e.g., empowering racial, culture identity in children/ young people with autism) or macro, structural level (e.g., raising awareness of the importance of the intersections of race, ethnicity within special education, policy reform) or somewhere in between, the purpose was to do more than produce knowledge. The use of more than one paradigm as a toolkit, across this research has examined how reality has been interpreted by those with first-hand knowledge and experience of the study's themes in their own ways, as well as advocating for critical change for the vulnerable and marginalised groups that have been oppressed by those in power. All of which were necessary steppingstones towards selecting the most suitable methodology, methods, and theoretical approach to attain this knowledge and information.

## **Theoretical Toolkit: Intersectionality and DisCrit**

The foundation of this research investigates the relationship or intersection between more than one central theme (i.e. race, ethnicity, culture and ability) on the identity formation of Black British children and young people with autism. Therefore, this study was intentionally developed through two distinct theoretical approaches, Intersectionality and Disability Critical Race Theory (DisCrit). The multiple themes discussed in this study necessitated a robust framework to examine their complex nature, and any connections/ differences between them. Intersectionality has become widely embraced within educational research and other disciplines, such as law and health, in understanding the interplay between a person or group's diverse identities (e.g., race, class, and gender) and systems, processes, and structures of inequality (McCall, 2005; Collins and Bilge, 2020; Crenshaw, 2022). Thus, intersectionality allows the cyclical processes at play in the production and reproduction of racism and other inequalities to be challenged in significant ways.

Utilising an intersectional approach within this study of marginalised and vulnerable individuals and groups gives rise to their own stories, ways of being and the construction of lived experiences and their meanings, connected to their race and culture that are not conflated by Western interpretations and ideologies founded on injustice and supremacy. The impact of not only recognising but disrupting these barriers begins to make way for change that can help Black children/ young people develop pride in their multiple identities for the present and future.

The other theoretical perspective applied in this study was Disability Critical Race Theory (DisCrit). DisCrit suggests that ability and race are socially constructed, interconnected means used to both racialise and disable people of colour against notions of normality, intelligence, and other categories (Annamma, Connor and Ferri, 2013; Lewis, 2021). However, such notions are inherently problematic due to their own constructions embedded in ideologies including racism, colonialism, and eugenics. While DisCrit is still a relatively new theory, its underpinning in the more established Critical Race Theory and other critical models seeks to expand knowledge and develop greater understanding that can only be derived from investigating the intersections of race and disability, which is why

I have chosen to engage with it in this study. Neither Disability Studies nor Critical Race theory independently provide the most suitable framework to critically analyse the deeper intersections of race, and special educational needs.

Employing DisCrit in this research study allowed me to delve further into the ways that both race and disability influence identity, curriculum, pedagogy, policy, and social interactions among Black British children, young people, and their families, as well as school personnel in English special schools and at home. Like Intersectionality's ways of exploring the effect of systemic modes of power and oppression across more than one identity strand/ area, DisCrit seeks to address the imbalance that restricts or denies opportunity, access, and more from people of colour because of ability and race.

## **Sample**

Although I have a diverse professional and personal network of colleagues, peers, and families who have a connection to autism and SEND in some capacity, I was still concerned that the sensitive topics and focus of this research may present challenges with sampling and access (Cohen, Manion, and Morrison, 2018) and reliability and validity (Brooks, Te Riele, and Maguire, 2014), the latter of the two will be discussed as the chapter continues. Moreover, I was determined to ensure that the population groups for this study were not exclusively made up of my work and personal contacts, which I explain in greater detail in the recruitment section of this chapter. I was also slightly concerned because one of the participant groups involved children and young people with autism, which presented several ethical concerns.

The population for this study was a highly selective groups of adults and children or young people, as it was central to the research. The sample therefore for this small-scale study focused on 3 specific groups:

1. **Black-British children and young people** with a diagnosis of autism that are enrolled in (or have recently finished) an English primary, secondary special school or college, or specialist autism unit.
2. **Parent(s)** of a child/ young person with a diagnosis of autism that is enrolled in (or has recently finished) an English primary, secondary special school or college, or



specialist autism unit. Parents in this study refers to people who identity as Black African or Caribbean and not those of dual/ mixed heritage.

3. ***School personnel*** who have previously, or currently work within an English special school, college or specialist autism unit with children who have autism, SEND. School personnel were further defined as anyone who has an active role in the day to day teaching and learning of SEN pupils (e.g. Teachers, Teaching Assistants, Learning Support Assistants, Care Assistants), senior leaders responsible for overall management and decision making within special schools (Headteacher, Deputy Headteachers), other professionals such as Educational Psychologists, Therapists, Special Educational Needs Coordinator (SENCO) who are involved in supporting SEND pupils, families and schools with specialist provisions. As titles vary across settings, this list was not exhaustive.

There were clear exclusions to the above sampling. Within the school personnel group, any staff whose roles were more administrative based (e.g., school business managers, office staff, cleaners, catering team etc.) who have limited interaction and teaching and learning remits with pupils on the autistic spectrum were excluded. Black-British children and young people from dual, mixed, or multiple ethnic backgrounds (e.g., Black- White mixed etc.,) were also excluded from taking part, for the reasons outlined earlier in this chapter. Parents who did not self-identify as being from one of the following groups: Black British (Caribbean or African), Black African, or Black Caribbean were also unable to take part, as previously discussed.

I initially decided on a sample size of 10 participants for each of the above groups. Due to the vulnerable nature of the children and young people required for this study, it was unknown precisely how many participants from this specific demographic would be recruited. This number allowed for a small number of potential dropouts and withdrawal while still having a significant number to reach saturation (Gill, 2020) and make a valuable contribution to the research. Additionally, as the research involves semi-structured interviews, this method was likely to produce a large amount of raw data and so this number was also manageable for me as the researcher and a study of this size. The initial

response I received from the recruitment drive for this research was extremely positive, which meant that some of the groups, specifically the school personnel and parents were oversubscribed, with more than 10 willing participants who met the criteria and wanted to take part. However, upon further investigation, some of the participants were unable to take part because their child attended a mainstream school or was under the age threshold for the study for example.

Originally, the lowest age set for the study was 8 years old, however, this age as a starting point was lowered. The age range of the participants was from age 6 to 65+, which I felt was suitable for a few reasons. Firstly, for children and young people with learning disabilities and difficulties, such as those with autism, differences are more likely to exist when age is a variable. In short, their mental age may not match their chronological age (Gersten, 1983; Staples and Reid, 2010; Caplan, Neece and Baker, 2015; Russo *et al.*, 2021). Therefore, while chronological age was not a determining factor for this study, it was understood that children and young people with autism may be functioning with a lower mental age and capacity. Children younger than a chronological age of 6 were not permitted to take part as it was felt that they were likely to have fewer practical years of school experience (e.g., working with teaching staff, attending lessons etc.,) which was beneficial in supporting this participant group with completing the interview, which was delivered like a school activity/ task.

In the UK, the diagnostic tool used to assess a person for autism varies and can include Autism Diagnostic Observation Schedule [ADOS], Diagnostic Interview for Social and Communication Disorders [DISCO], and Autism Diagnostic Interview- Revised [ADI-R] (Evans, Golla and Morris, 2015; Carrington, *et al.*, 2015; Mc Ewen *et al.*, 2016). The International Classification of Diseases, eleventh edition [ICD-11] and the Diagnostic and Statistical Manual, fifth edition [DSM-5] define criteria for an autism diagnosis, which practitioners then use in conjunction with one of the above diagnostic methods. I detail the three functioning levels of autism shortly that was used to categorise ability levels of the participants with autism in this study. I decided to refer to information from the DSM-5 (American Psychiatric Association, 2013) as it continues to be widely used as a global standard for autism diagnosis, and I felt that it provided a more simplified categorisation

than the ICD-11 of those on the autistic spectrum. The functioning level of autism was not a defining factor for participation in this study because it was understood that the spectrum of autism meant that the participants abilities and levels of need were varied and may not easily fit into one of the 3 categorisations. Therefore, the functioning level of autism was used in the following ways: a) to assess the participant's understanding and interaction with the interview task and b) to provide the appropriate and tailored support to each participant. For reference purposes the functioning levels are:

- **ASD Level 1-** Requiring Support: difficulty initiating social interactions,
- **ASD Level 2-** Requiring Substantial Support: social interactions limited to narrow special interests,
- **ASD Level 3-** Requiring Very Substantial Support: severe deficits in verbal and non-verbal communication skills.

There were 42 participants across all the groups in total, 15 Black-British children and young people- Group A (Table 4.3) from 7 special schools and colleges, 14 parents- Group B (Table 4.4), and 12 school personnel-Group C (Table 4.5).

**Table 4.3: Group A- Participants by gender, school and communication level (child/ young person)**

<b>Participant</b> <i>(pseudonyms used)</i>	<b>Gender</b> <b>Female/</b> <b>Male</b>	<b>School</b> <b>level</b>	<b>Functioning</b> <b>levels of</b> <b>autism</b>	<b>Communication</b> <b>level</b>	<b>AAC tools</b>
Miles	M	Primary	ASD Level 1	S	CC
Hakeem	M	Primary	ASD Level 3	NS	PECS
Chidi	M	Primary	ASD Level 3	NS	PECS, G
Malik	M	Primary	ASD Level 3	NS	Sy, M
Hassan	M	Primary	ASD Level 3	NS	Sy
Riley	M	College	ASD Level 3	NS	Sy, CC
Chadwick	M	Secondary	ASD Level 1	S	CC
Hani	F	Primary	ASD Level 3	NS	PECS, G
Harper	M	College	ASD Level 3	NS	Symbols, G
Ashar	M	Primary	ASD Level 2	S	PECS
Moshin	M	Primary	ASD Level 1	NS	PECS
Zuma	M	Primary	ASD Level 3	NS	PECS
Carlton	M	Primary	ASD Level 3	NS	O, Sy
Shahida	F	College	ASD Level 1	S	CC
Denzel	M	Secondary	ASD Level 1	S	CC

**Table 4.3 AAC Key**

**CC-** Communication Charts, **PECS-** Picture Exchange Communication System, **G-**Gestures, **SAL-** Sign-A-Long, **M-** Makaton, **O-** Objects, **Sy-**Symbols, **I-** Images

There are 2 main communication levels that I use within this study- *speaking* and *non-speaking*. Speaking denotes that the individual uses speech and verbal language as their main source of communication, therefore, non-speaking communication refers to communication without speech, these communication levels are also known as verbal and non-verbal (Stone and Yoder, 2001; Mandal, 2014; National Autistic Society, no-date d). I used both speaking/ verbal or non-speaking/non-verbal, depending on what was used by

the participant/ family. The parameters of what constitutes speaking and non-speaking communication are not definitive and vary across subject discipline, registered bodies, and others. For ease of reference in this study, speaking participants with autism were able to communicate using consistent verbal, spoken language or written language. Participants were considered non-speaking if they predominately used any other means to communicate, including but not limited to, sign language, and symbols. It should also be noted that some participants used multiple AAC tools, and their most common method has been listed in the table above.

As discussed in the introduction chapter, males are more likely to be diagnosed with autism than females (Baron-Cohen, *et al.*, 2011; Werling and Geschwind, 2013; Ratto *et al.*, 2018). The above information aligned with the data for participant group A (i.e., Black British children and young people) in a few ways. First, the special schools, colleges, and specialist autistic units that took part confirmed that they had more males (boys) on roll than girls with an autism diagnosis. Next, of the parents that contacted me directly for their child to take part in the study, almost all were boys. Finally, when I went to visit the schools to conduct the interviews with participants from group A, I observed more males than females in classes and around the provision, although I do not know of their diagnosis. The male/ female imbalance was also confirmed by the school staff. This observation of more males in special schools has also been my personal experience working in and with English special schools. In the following chapter, I analyse the results against some of the data demographics (i.e., male/ female or African/Caribbean) of the participant groups in greater detail.

**Table 4.4: Group B Participants by gender and ethnicity (parents)**

<b>Participant</b> <i>(pseudonyms used)</i>	<b>Gender</b> <b>Female/ Male</b>	<b>Ethnicity</b>
Ava	F	Black Caribbean
Sanaa	F	Black Caribbean
Regina	F	Black Caribbean
Viola	F	Black African

Kerry	F	Black Caribbean
Sterling	M	Black African
Phylcia	F	Black African
Taye	M	Black African
Marsai	F	Black African
Lupita	F	Black Caribbean
Yara	F	Black African
Angela	F	Black African
Morris	M	Black Caribbean
Halle	F	Black Caribbean

All but three of the parents who took part in this study were mothers, which tallies with information that suggests that mothers are primary caregivers of children and young people with autism (Boyd, 2002; Pandya, 2018; Fewster, Govender and Uys, 2019; Samadi and Samadi, 2020).

**Table 4.5: Group C Participants by gender, ethnicity and job role (school personnel)**

<b>Participant</b> <i>(pseudonyms used)</i>	<b>Gender</b> Female/ Male	<b>Ethnicity</b>	<b>Role</b>
Lisa	F	Black Caribbean	Speech and Language Therapist
Brenda	F	White British	Teacher and KS Lead
Andrea	F	White British	Teacher
Valarie	F	White British	Deputy headteacher
Indira	F	Asian British	Deputy headteacher
Brandon	M	White British	Teacher
Denise	F	Black African	Teacher
Cassandra	F	Black Caribbean	Teaching Assistant

Maya	F	Black Caribbean	Teaching Assistant
Dylan	M	White British	Teacher
Claudette	F	Black Caribbean	Educational Psychologist/ Teacher
Zuri	F	Black African	Teacher

This issue of underrepresentation has been discussed in chapters one and two and touched on again in the following analysis chapters. Although the sample size of school personnel is relatively small it highlights the well-documented national issue of underrepresented Black, Asian, Minority Ethnic (BAME) staff in education, particularly as teachers and within leadership roles (Elonga Mboyo, 2019; Tereshchenko, Mills and Bradbury, 2020).

My foremost thoughts when considering sampling for this study were once again connected to the overall purpose and aims of this research (Robinson, 2014; Punch, 2016), as well as recognising the likelihood that some of the potential results could and should not be generalised (Van Hoeven *et al.*, 2015; Andrade, 2021). I came to this latter conclusion because the results from the Black British children/ young people with autism sample group were (1) not likely to be representative of the wider population of autistic children/ young people because autism presents differently in everyone (2) understanding (awareness, engagement, interaction and recognition) is subjective, as such there is no way to make causal links between what one child with autism does, knows, or understands about their identity and that of another one, even with similar needs. It would require a more longitudinal study to assess understanding of this complexity. However, the above limitations provided little justification to deter gaining a deeper understanding of the research questions and their contribution to the important themes discussed in this study.

Purposive sampling was the most applicable strategy to lead with because I had a clear and explicit population of interest driving this study and their direct knowledge and intimate experiences with the themes would provide rich data and information (Kelly, 2010; Palinkas *et al.*, 2015). As the recruitment process began to take shape, sampling began to snowball (Cohen, Manion and Morrison, 2018), as I started to receive multiple requests from parents

who either wanted to take part in the research themselves and/or have their child/ young person involved also. Through discussions with some parents, it emerged that they shared and recommended my study to others because they felt the research was *“very important and needed to be done”* and *“just because our children have autism it doesn’t mean they do not understand their heritage or know about their ethnicity”* [sic] and similar comments. I also felt that I was able to break through any initial barriers of distrust primarily because of my ethnicity and gender and personal connection to the research as a mother of a Black son with autism, as well as my extensive experience with autism and SEND.

### **Recruitment: Parents and School Personnel**

Recruitment for the adult participant groups was conducted through my academic social media (Twitter and LinkedIn), parent forums and groups, direct contact with special schools and colleges through my university email account. A recruitment poster that outlined the title of the study and criteria (*appendix a*) was created and shared through the above online channels seeking participants. Interested parties were instructed to contact me via email for further information and enquiries. I also welcomed anyone who I encountered through the recruitment to share the poster within their own networks if they wanted to. Participants were recruited from both within and outside of my networks, although I was determined to ensure that those who took part in this research were not exclusively made up of work and personal contacts. I was able to do this in a variety of ways: *i*) interacting online (via Twitter, LinkedIn and email) with individuals and groups not known to me in a personal or professional capacity, with some connection to the research themes of race, autism, and SEND, *ii*) disseminating my work in progress at related conferences, workshops, and seminars in the same research fields, *iii*) through referrals and signposted contacts from others, and *iv*) directly emailing special schools in London and the surrounding geographical areas previously described in the research setting.

### **Recruitment: Black British children and young people with autism**

I relied on either parents or school personnel to recommend any children/ young people that met the study’s criteria to me. Once a parent or legal guardian put their child/ young person forward for the study and gave informed consent for their participation, the child/ young person’s assent was still sought if selected to take part. If the referral came from a



member of a school's personnel, then I contacted the child/ young person's parents directly telling them about the study, and as above, sought their consent and the child/ young person's assent. It was not a given that if a parent took part in the study that their child/ young person would also or vice versa, the choice was theirs. I understood through a few enquiries from the recruitment appeal from some parents that they were worried about their English language skills, and other factors such as their child/ young person's ability (e.g., non-speaking) levels. I addressed each of these concerns as a matter of priority by letting parents know that I would be utilising the online translation services on ZOOM (online communication platform used for the adult interviews) and GOOGLE if necessary. However, no translation service was required.

With regards to the query related to the child/ young person's ability, I reassured the parent/ guardian of my past and present experience of working with individuals on the autistic spectrum and role of a mother to a young son with autism. I also reminded them that I would work closely with the child/ young person's teacher to ensure that I was working within the parameters of their capabilities. If selected, participants were reminded at several stages that they had the right to withdraw. For the child/ young person, their parent or legal guardian could withdraw their data from the study, as it would be difficult for some of the vulnerable participants to do so but not impossible, I will discuss consent and other ethical concerns later in the chapter. It should be noted here, although also mentioned later in this section that if any child/ young person did not give assent on the day of the interview then the interview did not take place. I intended to have Black British children/ young people with autism from at least 10 special schools, units and colleges take part, as one of the research aims is interested in how special schools expose and teach their children and young people to themes of race, ethnicity, and culture, however, due to the lack of responses to my recruitment requests from the schools directly, I was only able to recruit participants from 7 educational institutions. This school target was more of a guide and not a strict requirement, although I felt that it would further reinforce some of the research validity, which I discuss later.

## **Recruitment process**

I began recruitment for the study immediately once ethical approval (appendix b) was granted in April 2022. The overall recruitment process took approximately 11 months, which affected data collection due mainly to access issues because of COVID-19 restrictions, school closures and holidays, and other contributing factors like sickness, vacations, and other personal reasons. Participants were confirmed as meeting the inclusion criteria previously outlined. Once the inclusion criteria for the study was met, they were selected on a first come, first serve basis until the project sample size was met. However, due to increased demand from parents requesting to take part and/ or also have their children/ young parent included in the study, I made the decision, after seeking advice from my supervisory team to allow additional participants. My primary rationale for this decision was wanting to allow these groups the opportunity to contribute to this important research of which their voices were underrepresented. I was also aware that recruitment for studies of this nature that involve vulnerable groups, in this instance children that have an additional layer of concern because of their disabilities can be challenging to recruit for due to ethical and practical reasons and others already discussed in this and previous chapters (Alderson and Goodley, 1996; Norozi and Moen, 2016; Adams, 2017; Corsaro, 2018). Everyone who expressed an interest in taking part in the study and that met the criteria was able to do so.

Upon reflection, the biggest challenge that I experienced with the recruitment process was making contact with some of the special schools, specifically receiving an acknowledgement or response from them. I can only speculate as to why that was, as I did not receive any outright refusals or communication from schools to state that they did not want to take part. I do believe that some schools may not have been ready or did not want to engage in discussions about race, as the subject can be seen as contentious. I also recognise that my thesis may not align with the priorities of many schools or be considered important enough on their current agenda. Another reason may have been that schools were reluctant to have their pedagogical practices and policies related to diversity, race and culture scrutinised (Williams, 2020) despite the purpose and intention of the research being detailed in the participant information sheet for adults (appendix c) which was sent

in the recruitment email (appendix d). I would also suggest that the recruitment email and subsequent messages may have been missed, did not get redirected by the school office accordingly or considered spam. Finally, of the schools that did contact me and were willing to share the recruitment poster and details of the study in staff rooms and meetings, there was only one with no uptake. Overall, the response and feedback from the recruitment process was both positive and encouraging. Being able to exceed the initial recruitment targets was promising, which in turn provided greater opportunity for rich raw data collection and analysis.

### **Methods of Data Collection: Semi-Structured Interviews**

As previously mentioned, this study was concerned with whether Black British children and young people with autism, including my son, understand their racial, ethnic and cultural identities when exposed to them in a suitable way for their needs and abilities at home and school. It seemed most reasonable and appropriate to garner the lived experiences of the different adult participant groups through qualitative means as previously explained, using semi-structured interviews. Like any method of data collection, semi-structured interviews have their limitations. They can be time-consuming, laborious and require experience to conduct (Harvey-Jordan and Long, 2001; Adams, 2015), so it was vital that this method was congruent with the entire methodological process. I chose this method for data collection as it remains one of the most common and accessible modes whereby the participant can express and share their thoughts, feelings, and experiences in ways that they feel and understand them (Scott and Usher, 2011; Al Balushi, 2016; Adeoye-Olatunde and Olenik, 2021). Mears (2017) and Bearman (2019) propose that the technique involved in interviewing is more insightful than posing a question and receiving a response, but instead requires resolute, determined interactions that allow a researcher to uncover what a person knows, thinks, feels, and has experienced and furthermore what is meaningful about it.

Semi-structured interviews require careful planning and skill for the researcher and participant to build a reciprocal space of trust that will allow the most out of the interview. In this study, semi-structured interviews were a helpful tool that gave the researcher charge of the interview schedule but more so as a guide, allowing the participants the

liberty to be as open and candid as they wanted. It also allowed me the opportunity to probe deeper where necessary, based on some of their responses. The initial preparation prior to conducting the interviews including using my previous interviewing experience and specialist knowledge of the subject area was especially important when working with the vulnerable groups.

I conducted 26 adult (i.e., parent and school personnel groups) interviews in total, online via ZOOM. I used this online video communication platform due to benefits such as accessibility, translation services, cost efficiency, and recording functions to name a few (Oliffe *et al.*, 2021; De Villiers, Farooq and Molinari, 2022). In recent years, particularly because of the global COVID-19 pandemic, use of video conferencing technology like ZOOM has significantly increased, thus allowing the world to continue to function, albeit in a less traditional face-to-face fashion. However, while use of this online platform does have its disadvantages, such as network issues or an impersonal feel, neither I nor the participants experienced any challenges. I used an interview schedule of 10 questions for the parent group (appendix e), and 15 for the school personnel group (appendix f) to guide the interview around the research objectives. The interviews for these participant groups were audio-recorded and transcribed. Due to the acute needs of the vulnerable participant group, the children and young people with autism, their interviews required more work and preparation.

### **Methods of Data Collection: Using Aided and Augmentative and Alternative Communication (AAC) and Visual Research Methods (VRM) to conduct Semi-structured interviews with vulnerable participants**

A fundamental part of this study required the interaction of vulnerable children and young people with autism as active participants. It was extremely important to me that this research would be accessible to any child or young person that met the criteria, especially those who were non-speaking communicators, like my son, as their experiences seemed to be greatly underrepresented when I conducted a review of literature into research using non-speaking or non-verbal children as active participants. Throughout this chapter, I explain the rationale and justification for working with this vulnerable group, whose voices are at the core of this research. Traditional research and their methods can often be ableist,

and so certain groups are excluded from participating. So, while I again decided that semi-structured interviews would be best, it was with the premise that they would be adapted to meet the diverse communicative and ability needs of the participants. I chose to employ aided and augmentative and alternative communication (AAC) tools in the interviews that the children/ young people typically used so that they would be fully participate on their terms (Biggs, 2003; Spencer, 2010). AAC strategies are commonly used alongside other interventions in supporting the communication needs of children with autism or individuals, who have no to minimal language or speech or other communicative difficulties (Branson and Demchak, 2009; Baxter *et al.*, 2012; Iacono, Trembath and Erickson, 2016; Royal College SLT, 2024). AAC can comprise of items and tools such as symbols, objects, speech-generated devices but also include gestures, pointing and more.

Due to the acute complexities of SEND and learning difficulties, I knew that I would have to heavily rely on my skills and expertise of autism and SEND when preparing and conducting the interviews with the children and young people participant group. Additionally, as all the participants, apart from two had not met, interacted, or worked with me before, I understood that I would have to work closely with their teachers, support staff, and parents for a successful outcome. Each participant interview in this study with the children and young people with autism was unique to them and had to be carefully designed according to their communication needs, as well as their cognitive abilities, and physical, social, emotional and behaviour needs. Although this approach was labour-intensive, it was a very necessary step to ensure every one of the participants was given an equal, inclusive, and equitable opportunity to take part. The process will be fully explained later in this chapter.

My primary source of communication in these interviews involved using AAC methods. I used a mix of visual and SEND accessible, appropriate materials, including dolls, symbols, speech-generated devices, pictures, communication boards, autism specific communication aids and more (figure 4.2) that were familiar to the children and young people. All the interviews were conducted in an appropriate manner to meet their unique abilities and needs, adapted for each participant



**Top Left:** Communication board, **Right:** Voice Output Communication Aid



**Above:** Some of the dolls – various races



**Above:** Some of the images of children- various races (left) and subject, verb, object communication board

**Figure 4.2: AAC materials used in interviews with child/ young person**

Visual and creative research methods allow studies to be more inclusive of differences such as ability and culture, which is key to expanding what we know and understand of different groups, people, phenomena and the ever-changing diverse world in which we all live. In extracts from different qualitative studies conducted by Musicka-Williams and Cook (2022) participants that had a range of disabilities, including autism, were able to share their stories and experiences. The authors highlight the imaginative and inspiring ways of adopting innovative research tools that make research more accessible and inclusive. Warwick and Chaplain (2017) contend that when conducting interviews with younger children there are various issues to consider, which include using non-verbal cues, the vocabulary used, and pitching the question(s) correctly. The importance of navigating and overcoming various challenges when interviewing children, young people and vulnerable groups for research is generally shared across literature because of *children's rights* (O'Reilly and Dogra, 2018), *sensitive subject matter* (Poole, 2016; Eneman, 2022), *power relations* (Nishiyama, 2018), *ability* (Gibson, 2012) and more. Hence why I heavily relied on my vast experience and knowledge of working with children and young people with autism. However, as no two children/ young person is the same, this uniqueness meant that I had to tailor each interview to the child, young person taking part.

I was deeply impressed with each of the children and young people who took part, as they interacted with me and the interview task extremely well, particularly having never met or worked with me before (apart from 2 participants). For many children and young people with autism, building trust and a rapport, and keeping to routines are essential to their overall wellbeing, behaviour management and more (Taylor and Fisher, 2010; Glazzard and Overall, 2012; Gilmore, 2016; O'Nions *et al*, 2018; Musa, Dergaa and Mansy, 2021).

I conducted 15 interviews with children and young people with autism all of which involved the use of AAC in some capacity. I decided to conduct the interviews with the child/ young person participant group at their school or educational institution unless there was a valid reason not to, because this was a familiar and controlled learning environment for them, similar to what the interview would mimic in ways. There were a couple of other reasons why I felt that schools were the most suitable research setting. At school, the participants had the security of teaching staff in the interviews that they recognised and were

comfortable with. Another reason was that children can behave differently at school and home (Mayall, 1994; National Autistic Society, 2017; Arky, 2023) as the demands are different (Hedegaard, 2014). I was concerned that if the interviews were conducted in the family home, that the children/ young people may not want to take part and be distracted. I also wanted to control the research environment and conditions as much as possible, and felt that if conducted at home, the children/ young people might be influenced consciously or unconsciously by family members. Finally, conducting the interviews at their respective schools gave me the chance to observe their learning spaces, which helped me to better connect with the children and young people and partially understand the school ethos as it related to the themes of the study.

With the interviews being conducted during the school day, the participants were not taken out of school, nor did they have their routines disrupted for this study. I either asked the staff present to record the interviews to manage the environment and ensure that teachers nor support staff also did not influence the results or I used a tripod. All but one of the interviews took place at the participant's school setting and the other was conducted over ZOOM, as requested by the parent. The young person speaks and has a functioning level of autism 1, their family/ school refer to them as having 'high-functioning autism' and strong cognitive abilities. They have advanced IT skills and were able to independently interact and fully engage with the interview online. I used the same resources including different ethnic dolls, google stock images of random objects and children/ young people of different genders and ethnicities, and AAC aids repurposed and adapted for each interview.

### **Procedure: Data Collection (Child/ Young Person)**

Collecting data from the child/ young person participant group was more intensive and complex, due to their vulnerability, needs, and abilities. The process involved different stages that had to be completed before moving forward to the next and included the child/ young person's parent or legal guardian, teacher, and most importantly, the child/ young person themselves as an active participant. If both the parent and child/ young person were selected to take part in the study, I interviewed the parents first so that they had the opportunity to meet me, ask any questions and so that I could explain what their child/ young person's involvement entailed beyond what they read in the participant information



sheet.

As previously discussed in the recruitment section, once a child/ young person that met the criteria had been identified and selected, the first requirement was gaining informed consent from their parent or legal guardian. Without fulfilment of this prerequisite, they were unable to take part in the study. The consent form was returned to me in one of two ways, via email, direct from the parent to myself, or by hand, returned with the child/ young person in their home-school link/ communication books and then collected by me. Once informed consent was given by the parent or legal guardian the next step was to liaise with the school to arrange the interview. School here refers to the teacher, senior leader, or another gatekeeper with authority. Most often, communication was between me, the parent and the participant's teacher. If the school did not already know about the study, which was the case when they did not make the initial referral about the child/ young person being suitable for the study, then I would send them the participant information sheet and arrange to discuss any queries or concerns they may have about the study beforehand. My contact with all school staff was welcoming and supportive of including the child/ young person in the study, which made the process easier.

During my contact with the parent and child's teacher, I also gathered as much information about the child/ young person as possible to help with planning and facilitating the interview. These questions included '*how the child/ young person communicated*' (i.e., speaking or non-speaking), '*did they have any stresses or support needs to manage*', '*how they might respond to an unfamiliar person and task*', '*what they liked and disliked*', and '*any known positive or adverse behaviour triggers?*'. Schools were provided with proof of my enhanced DBS status if required, although a member of school staff or parent was always present with the child/ young person and myself. As an additional measure, I sent a picture of myself to the staff team that could be used to help the child/ young person become familiarised with me before the interview. This step was optional and only if the school and I felt it was appropriate and would help support the needs of the participant prior to the interview. Most teachers did not feel that this measure was necessary either because the participant was able to cope well with change or that it may have the opposite effect of helping if something changed, and the interview did not take place for example.

My aim throughout the process, as supported by parents and school staff was to minimise any disruption to the participant through taking part. Some examples included conducting the interview on a 'quieter' school day, first thing in the morning, after lunch or when the participant was likely to be most responsive. Once the school and I had agreed a mutually convenient time for the participant interview I proceeded to prepare the appropriate resources for the interview that were tailored to the unique communication needs of the participant, as outlined in the methods of data collection section of this chapter.

I reconfirmed the details of the interview with my school contact, 1-3 days in advance and again on the day of, to ensure the participant was present. There was still no guarantee that the child/ young person would take part, and I had to seek their assent or dissent, independently witnessed by the teaching staff before the interview could begin. I further discuss the complex nature of assent, dissent, and consent later in the ethical considerations section of this chapter. When I arrived at the school site, I showed my university photographic student card at reception and signed in. I made sure to allow myself enough time to travel to the school and still have time for any additional preparation, like familiarising myself with safeguarding policies and more.

Additional preparation was also involved in a small number of interviews (3) where the AAC symbols used by the child/ young person were created with specialist IT software that I did not have access to. Some of the symbols were easily accessible, as they were already being used at the school and others had to be created, which took a few minutes. I then had between 10-15 minutes to set up the space before the interview (e.g., arranging tables and chairs, setting out the resources, and setting up the camera tripod for recording). Before I met with the participant, I briefly explained the format of the interview to the teaching staff. I chose not to give any detailed information like the questions that would be asked, as that could potentially skew the outcome. Once they confirmed that they were ready to begin the participant was escorted into the interview space where I was waiting.

Before starting the interview, I allowed the participants as much time as they needed to get familiar with the space, and me. I wanted them to feel as much at ease as was possible, which meant respecting their moods, need for space, and time to process who I was and

what I wanted. For most children they seemed to get comfortable within the first 5-10 minutes of us interacting with each other. These interactions were different for each participant and progressed from me signing and saying “hello” to giving each other “hi-5s” and even singing a made-up song with the participant’s name. I used my experience and knowledge of autism, as well as that of the participant, provided by the school and parent, to build up to the interview in ways that I felt were calming and appropriate.

Once the teacher and I felt that the participant was ready to proceed, the next important step was gaining the participant’s assent or dissent, which was not the same for everyone because of their diverse needs, abilities, and understanding as children/ young people with autism. It was crucial that I tailored my communication approach accordingly. Participants that had a functioning level of autism Level 1, such as those who required minimal support, were able to read, and could communicate verbally were given choice of accessible formatted participant information sheets (appendix g). I wanted to acknowledge their agency at this early stage by giving them a choice. If they were a speaker, we read the participant information sheet together out loud and if they were non-speaking then I read a more accessible version of the participant information sheet to them. For ASD Level 1 participants, I asked them if they understood what they were being asked to do (e.g., “*do I want you to answer questions or eat a sandwich*”) this question was tailored appropriately, so that I could check their understanding. Once it was agreed by myself and the teacher that their understanding was acceptable, I then proceeded to obtain assent by asking if they would help me to answer some questions.

I asked the teacher to start recording at this stage to capture the participant’s assent or otherwise. If they dissented to taking part, the recording would have been immediately stopped, and the interview would not begin. They could choose to verbally express their choice, write it down, or circle it on the adapted assent form (appendix h). For ASD Level 2 and 3 participants, who were mostly non-speaking and required substantial or very substantial support, the question of taking part and obtaining assent was significantly simplified, according to their ability. For these participants assent or dissent was explained using symbols or Makaton for example to ask if they wanted to take part and my approach was tailored to how they worked in their classes to complete a task. An example of this was

with the language that I used. It was simple and minimal, like *“help, yes, no?”* or *“[participant’s name] work with [researchers name] yes, no?”*, reinforced with the symbols or another AAC tool. Each participant was given different lengths of processing time. If appropriate, I verbally asked again or used AAC tools because they did not respond or were distracted.

Assent in each case, was given by the participant as confirmed with the participant’s supporting teacher or assistant, to further safeguard the participant’s rights. There were two participants who took a while to respond, more than 5 minutes, because they were distracted by the setting and possibly because of my unfamiliarity to them. Both the teacher and I felt it was best to give them more time to adjust to the space and ask again. When I then tried again after a few more minutes, they provided assent, although one participant only responded to the first 4 questions before requesting to finish.

The interview schedule consisted of the same 5 questions for all participants. There were 2 additional questions, bringing the total to 7 (appendix i) for the participants who required minimal to no support, mainly ASD Levels 1 and 2 but also level 3 for one participant. I would offer additional questions if I noticed participant’s particularly engaged by a picture or object. Some of the questions from the schedule included *“Can you show me [participant’s name] picture?”*, the participant was asked to select their own picture from random images of children/ young people of different ethnicities but the same gender *and* *“Can you show me the same as you?”* [sic], here, the participant was asked to match an image of a child/ young person with the same race to as theirs. I also included items that were culturally significant, such as images or actual examples of traditional dress, instruments (e.g., drums, steel pans), images of food (e.g., plantain, jollof rice, canjero, injera), religious objects (e.g., prayer mat) etc., as in figure 4.3 below, on the table to see what the participant would engage with, with or without being asked. I am unable to show some of the personalised resources that I created due to anonymity.



**Figure 4.3: Selection of the ethnic and cultural references used in interviews with child/ young person**

The questions were designed to explore the child/ young person's understanding of their ethnic, and cultural identity. Participants had the choice to pause and take a break or stop the interview, whenever they wanted to, which they indicated in different ways like verbally saying "stop" or "finished", giving me a stop or break symbol, walking away, not responding, or signing. The most common request was for a break (although only

requested by 5 participants), which often was a chance for the participant to self-stimulate (e.g., flapping, stimming), which helps with managing anxiety, sensory overload, and other needs (Masiran, 2018; Kapp, 2019). After any breaks or pauses, I would check if the participant wanted to continue with the interview, needed more time, or stop completely. Even with the proactive measures and contingencies that I had put in place ahead of the interviews, such as allowing movement breaks, providing sensory tools to help participant's focus, I still had to on occasion, as previously mentioned, be reactive to the needs of the participants and utilise innovative measures where necessary to keep the interview engaging, for example, changing my voice and moving around the room with the participant.

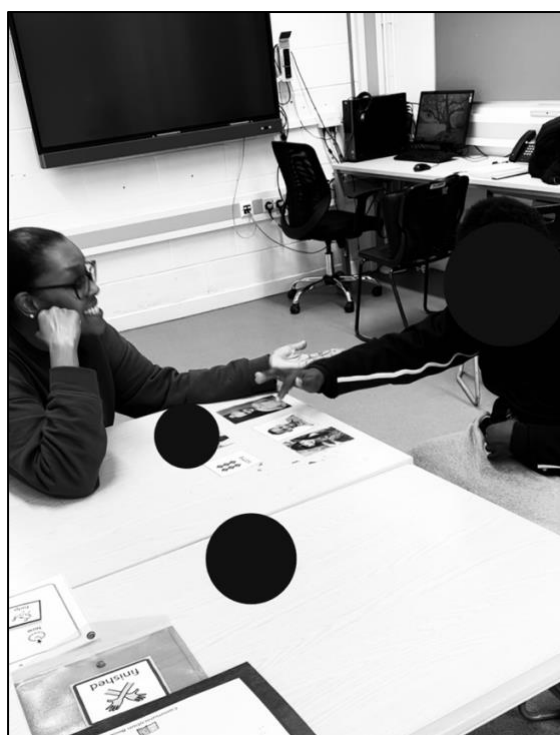
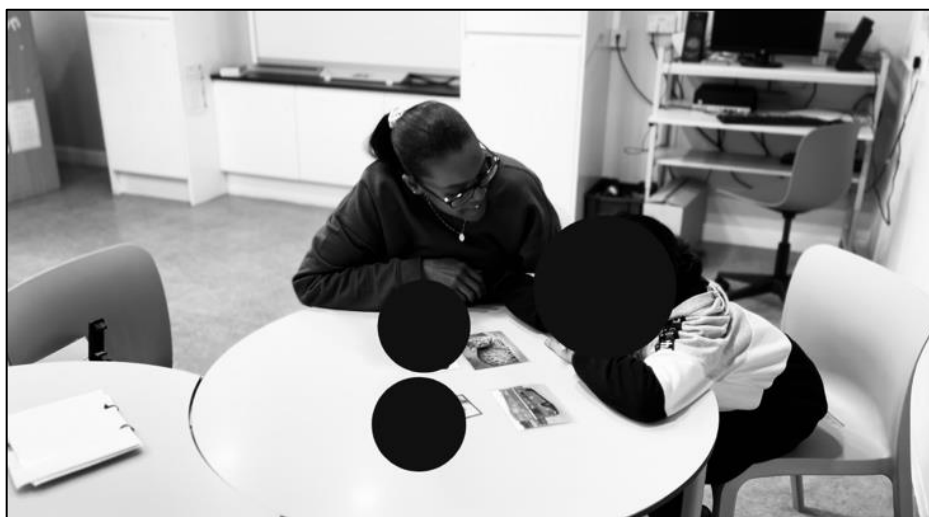
The participant's first answer was taken as their response so as not to cause distress by asking the same question several times, allowing adequate time for processing, unless they seemed unsure, in which case I asked them the question again to be sure of their response. I made sure to move images around so that they were not in the same location or switch the objects around in my hand to further check understanding in some cases, like if the participant was only selecting items in my right hand. After the participant answered either all the questions or requested to stop, then the interview ended. I wanted to make sure this was clearly communicated to each participant, so I cleared away all the resources, thanked the participant and ended the interview in the same way their teaching sessions ended, for example, *"counting to 5 and work will be finished"* or *"[participant's name] has finished helping [researcher's name]"* or using a symbol to indicate that work had finished. I thanked the participant and staff for their help and patience and the participant went back to class. Below (figure 4.4) are some images from the interviews with a few of the participants. They are intentionally in black and white with faces obscured to ensure anonymity and protect their identity.











**Figure 4.4: Images of some of the interviews conducted with Black British children and young people with autism**

The times for each interview varied, with the quickest being approximately 5 minutes and the longest being just under 30 mins, allowing the participant movement breaks and time in between each question as needed. The interviews were video recorded on my DSLR camera, or smartphone by the teacher or support staff or using a tripod. I manually transcribed each interview within 48 hours of it taking place. The interviews were uploaded to my Brunel University London (BUL) One Drive where the data was safely and securely

stored and managed. The data initially included only their unedited video recording until it was anonymised and transcribed and assigned to a named (pseudonym). To protect the identity of the participant the video recording was safely disposed of in line with BUL data management policies. To ensure that I worked within the guidance provided by BUL regarding data management and conducting research, I completed a compulsory research integrity programme and familiarised myself with the Code of Research Ethics (Brunel University London, no-date) before commencing data collection. I contacted each participant's parent after the interviews had taken place to thank them and their child/ young person again for taking part and to provide them with the child/ young person's pseudonym name.

I would argue that for almost all of this participant group, withdrawal of data is a complex notion to understand, therefore I reminded the parents that they had the responsibility and right to withdraw their child's data up to a month after the interview had taken place, as was detailed on the signed consent form. I also explained that they would be notified about the outcomes of the study in due course once my thesis was submitted. Of the 15 children and young people that took part, only one of them did not respond to all the questions. Some of the participants even offered additional context related to the themes outside of the interview schedule (e.g., *"you have dark brown skin, [teacher's name] has white skin, I have light brown skin"*) which developed into a lovely interaction between the participant, myself, and their teacher about different skin tones and colours.

While I did not encounter any major issues with the interviews conducted with this participant group, I recognise that this self-assessment was likely to have been influenced by my extensive autism and SEND experience and knowledge. Even in the earlier mentioned cases where one of the participant's did not want to respond to all the questions, I did not see this as a negative outcome but those participants exercising their rights. The one obstacle in the process of interviewing this participant group was related to the interview spaces. The interviews were conducted in a variety of different school rooms and spaces, which was outside of my control. Some of them were plain learning rooms with only furniture and windows, others were more visually distracting spaces like classrooms or learning spaces with large furniture, computers, colourful displays on the walls and

more. I was placed in whatever rooms were available at the schools, which was slightly challenging, as they proved distracting for some participants. Again, relying on my experience, I had to be creative and quickly adapt to the needs of the participants, like incorporating the distractions into the interview. In one interview, I used a table as a drum to engage and motivate the participant, which proved to be very successful. I also took care to consider the clothes, jewellery, and perfume that I was wearing to the interviews in case it was a distraction or trigger.

### **Data Collection (Parents and School Personnel)**

The procedure involved in collecting data from the two adult participant groups (i.e., parents and school personnel) was the same. The following is a thorough description of the process involved in each participant interview except where stated. Once the participants were selected, as previously explained, formal arrangements were made via email to discuss completion of the adult consent form (appendix j) and arrange a mutually convenient date and time for the online interview to take place. Once informed consent was attained through a duly completed consent form and the interview scheduled, each participant was sent a ZOOM link, with specific joining instructions and guidance. Participants were sent a reminder email 1-3 days before the scheduled interview, and on the day of.

Before the interview began and the recording started, I thanked the participants for their willingness to take part in the study, and their time. I explained that I had a few important points to mention prior to beginning the interview. Firstly, I outlined the format of the interview by explaining that I would ask the participant a series of questions (approximately 10 for the parent participant group and 15 for the school personnel one and that they should respond as openly and honestly as possible. I used this opportunity to also explain that I would be taking some notes throughout the interview to help me gain a better understanding of their experiences, which meant that I would not be steadily looking at the screen. Secondly, I reminded the participant that the interview was both recorded and transcribed, so that their responses could be accurately captured and later analysed. I further clarified that only the audio-recording would be used to manually cross-check against the transcript within 48 hours of the interview.

Once the transcription was checked, then the video and audio recording were safely disposed of, as described in the participant information sheet. Thirdly, the participant was reminded of their right to withdraw before or during the interview, without giving a reason, as well as their data being withdrawn up to one month after the interview, as per their signed consent form. In addition to this point participants were also reminded that the interview was subject to data protection and confidentiality and that all data would be anonymised. I confirmed that each participant understood the above points before continuing. Next, participants were reminded that if they wanted to take pause or stop the interview that they could do so by stating this at any stage of the interview. If the interview was paused, the researcher would check that the participant was willing to continue before proceeding. The researcher then asked participants if they had any questions that they wanted to ask either about what was just explained or the research itself. The participants confirmed their understanding and any questions were answered. Finally, the researcher checked whether the participant was ready to proceed, and the interview commenced.

The interviews lasted approximately 40-90 minutes across both participant groups, dependent on how much the participant wanted to share and whether the researcher probed any of their responses deeper. I spoke clearly and slowly, requesting that participant's ask me to slow down or repeat myself at any time. I made sure to clarify certain points to check my understanding of the participant's experience and summarise their thoughts and feelings through active listening. I looked for nuances in their tone of voice and body language, interviewing skills that I have developed over time. While participants from the school personnel group had more questions on the interview guide than the parents this difference did not equate to their interviews being longer. The participants in each group answered all the questions without anyone requesting to pause or stop. After the interview was completed (i.e., when the last question was answered) the recording was stopped. At that point, I asked the participant again if they had any questions, which were answered accordingly. Before ending the ZOOM meeting, I again thanked the participant for their time and sharing their experiences with me. It was at this time that I gave them their pseudonym for the study, or it was emailed to them after the interview. Lastly, I told them that I would let them know the outcomes of the study once

my thesis was fully completed but that they could contact me if they wanted any further information. The ZOOM meeting was then ended.

Almost immediately after the interview or very soon after, I would always spend some time with the notes that I had written. I would also jot down any immediate reflections or highlight anything that I may need to cross-reference against the recording. This journaling process is one that I found beneficial in previous research. After each interview I received an automated email notification from ZOOM that both the ZOOM recording and audio transcript were available. I spent approximately 2 hours or more checking the interview transcription against the audio recording for accuracy, which was done within 48 hours of the interview taking place. Three examples of transcribed interviews (one from each participant group) can be found in appendix k. Although this task was arduous, it was necessary, as the transcription was initially completed by a third party, ZOOM and I needed to ensure the interview was recorded correctly, free from any errors and prepared for analysis, this process is also known as data cleansing (Azeroural, Saake and Abuosba, 2019).

All data files related to the interviews (i.e., video and audio recording and audio transcription) were uploaded to the named participant pseudonym file in my Brunel University London (BUL) One Drive, as it was for the children/ young person participant group for safe and secure storage and management. Once the transcription was checked and anonymised, the audio and video recordings were once again safely disposed of for identity protection. There were a few teething issues with the technology in some interviews, such as frozen screens, and brief loss of connection but this problem was only in around 2-3 interviews and did not cause any major disruption to the interviews.

## **Data Analysis**

It was clear from the outset, at the research design phase that this was a qualitative study, whereby the participants made meaning of their own experiences as they lived them, as explained earlier. It was then necessary to determine how these experiences would be interpreted in line with the research study. I chose thematic analysis when working with the data as I wanted to uphold the authenticity and construction of the participants' stories and experiences as they shared them. It was important for me to explore the production

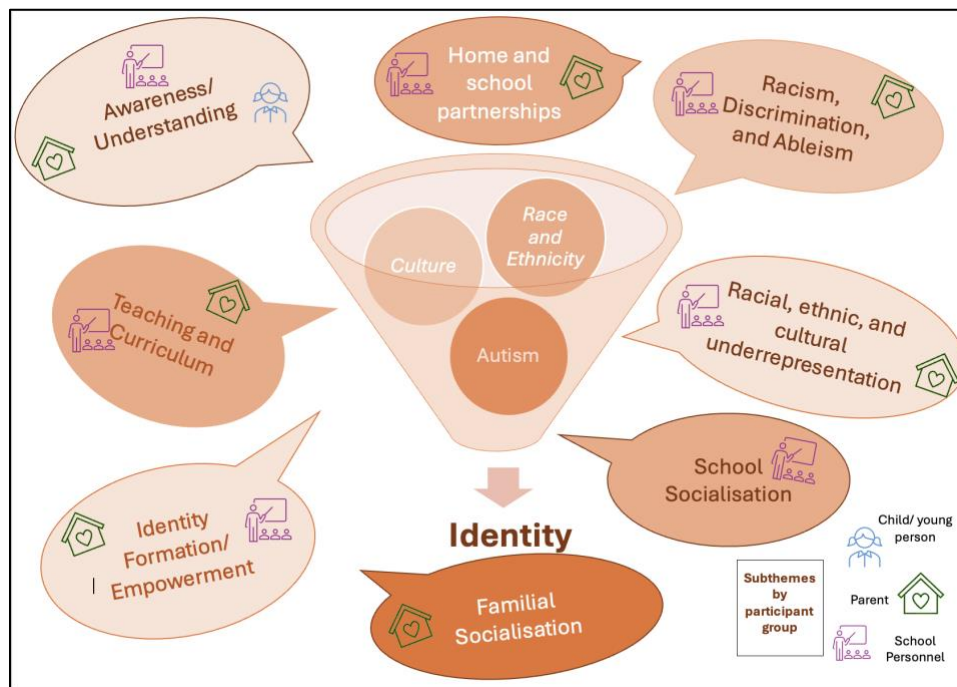
of their narratives in much the same way that I did my own stories, as in doing so I was able to examine any connections between the two and the research themes, like identity (Rosenwald and Ochberg, 1992).

Braun and Clarke (2006) argue that thematic analysis is a flexible, robust tool with which to make sense of data. While it can be used across various disciplines and paradigms, they assert that within qualitative research thematic analysis, specifically the approach they created, relies on themes from the data being developed naturally, with the researcher deeply connected to the process. They continue that thematic analysis's strengths lie beyond simply placing information into themes or categories and when applied correctly, allow data to be interrogated more intensely. At each stage of this research process, and especially while analysing the data, I have had to constantly reflect on my own philosophical assumptions and knowledge, which allowed me to be instinctively more careful and comprehensive. Braun and Clarke (2006) originally created a six-step approach to thematic analysis; however, they have since revised their work, which has now evolved into Reflexive Thematic Analysis (RTA) (Braun and Clarke, 2022).

This new RTA is a process that is heavily reliant on the researcher's flexibility and subjectivity and still subscribes to some of the original arguments like inductive versus deductive analysis and semantic versus latent ideas from the data for example, but now compromises of ten core ideas. They include researcher subjectivity/ bias, constant data interrogation, coding data to reveal patterns, themes that develop through the researcher's active and regular engagement with the data, and reflexivity as a crucial step throughout. Following the outlined reflexive thematic analysis above was an iterative process whereby I had to continuously engage with the data and my own subjectivity, my thoughts, experiences, and more. I collaborated with others when coding, which felt like a more natural organic event that developed a greater understanding of the data through the eyes of few other people. Finally, through RTA, themes came to fruition because of my reflexive and deeper engagement with the data. Because of my closeness to this research through my different positionalities as the mother to a young Black man with autism and SEND professional, adopting a RTA approach meant that I could own my subjectivity, acknowledging the unique perspectives that these roles bring to this study.

Because of the large volume of data, thematic analysis not only afforded a methodical way of interpreting all the data, but also an opportunity to go through each interview in a detailed and subjective way. The data was first collated into general codes identifying reoccurring or isolated areas for further interpretation, in accordance with the data type, semi-structured interviews. I used a variety of different techniques like brainstorming and mind-maps to aid coding the interviews by hand, which I have used in the past as a preferred way of staying fully connected to the data, as opposed to software like NVivo or AtlasTi. A coding frame (appendix I) was created that detailed the arranged semantic main and then sub-themes as I continued to scrutinise and review the data through inductive means where these themes emerged organically from the data (Peel, 2020). With the lack of literature exploring race, identity, and autism through intersectionality, I was naturally being led by the data, coding inductively, rather than through pre-decided, deductive codes (Proudfoot, 2023). Finally, I settled on the study's findings, themes and subthemes (illustrated in figure 4.5 that I created below), names, descriptions, and interview extracts, as seen the coding frame for the next step of exploration alongside existing literature, my research questions, and my personal experiences.

This is a succinct outline of how the data was analysed, however, the actual RTA process was extensive and continuous. For example, when analysing the data thematically, my various positionalities played an important role in seeking to understand whether I had influenced what they shared due to my experience as a SEND professional and mom of a young person with autism.



**Figure 4.5: Illustration of the study's main themes and subthemes by participant group**

The joint data collection and analysis process utilised in this study afforded specific information to be collected about the intersecting themes of race, ethnicity, identity and autism from the unique lens of Black British children and young people with autism, their families, and teachers. Consequently, a deeper understanding of the subject can be constructed, which subsequently provides more scope for solutions that are sustainable long-term. I was able to honour the experiences and stories of racially marginalised and vulnerable individuals and groups that have been traditionally absent and overlooked in educational research spaces by using thematic analysis. Each story is made up of pauses, filler words, dialect, cultural nuances, and emotion that represent their thoughts and feelings, which shifted their stories from ignored to noticed, from void to valid. Plummer (1995) and Riessman (2008) both explored the idea of representation being a central element of storytelling, in which narratives become representative of the not only the person sharing the story but the researcher interpreting their narrative, as well as the reader of the interpreted narrative. Thus, the story's epistemological meaning and significance is reliant on the production and co-production of the story by the represented parties, the researcher, and the social context with which it is constructed in.



Rather than treating data analysis as a systematic process that should only begin after the completion of data collection, I found it more valuable for them to work in conjunction with each other, allowing me to capture some of the anecdotal nuances and observations that I witnessed in real time for later analysis and reflection (Moon, 2004; Oliver, 2014; Cresswell and Guetterman, 2021). These field notes served as an additional way to help me contextualise my understanding of the stories and experiences shared by the participants. I found it easier to handwrite my notes, in some ways it felt more personal. I made sure that no identifiable information was in the notebook but to add an extra layer of protection, I took photos of the entries and uploaded them to the respective participant account saved on my One Drive and then disposed of them safely once the analysis was completed.

Delamont (2016) describes an almost intimate relationship between researcher and field notes that advances from the private observations (field notes) to the public viewing gallery (research). My fieldnotes/ diary were beneficial when going through the related data, such as the interviews and connecting moments together. In this moment the data started to become alive, instantly creating patterns and meaning that when further examined alongside the interviews created a much clearer picture of how the participants experiences provide rich insight into the research questions.

### **Reliability, Validity and Trustworthiness**

If data analysis is to be a process that is robust and conducted with integrity, then it must be reliable and credible. However, as Cohen, Manion and Morrison (2018) and Bazeley (2013) suggests validity and reliability in qualitative research is not as straightforward as it seems. The latter used an example of two people coding a sample of data and coming up with different codes to each other because they assessed the information with different knowledge, influences, and personal views. This example does not mean that the codes they came up with are not reliable but rather as the author suggests that reliability and validity in research is founded upon diverse factors such as the transparency and depth of the evidence and justification of actions.

Thematic analysis is not without its challenges. Issues such as trustworthiness and researcher bias are critiques associated with using this tool when analysing data. While

writing about some of the challenges of thematic analysis, Nowell *et al.*, (2107) shared their qualitative, mixed-methods study as an example of how to use this method in a practical, rigorous way. They used the Braun and Clarke (2006) original six-step thematic analysis process to explore large amounts of data from interviews, field notes and other information, produce codes, look for themes and then review them, before defining them and then creating a report. Each of the steps detailed specific ways that they mitigated problems with trustworthiness including data and researcher triangulation, member checking and debriefing. They also listed their experience of each phase along with concrete examples. The outcome is a tangible, best practice tool that illustrates how thematic analysis can be used effectively and authentically.

I took the time to carefully plan and organise every aspect my research from the questions and aims to the methods used, right from the initial stage of considering the study making sure to pay close attention throughout. In this thesis, I heeded reliability and validity through several different ways including keeping detailed notes and records, strict data storage and management (Leung, 2015), and through triangulation (Noble and Heale, 2019). Patton (1999) describes 4 types of triangulation: methods, sources, analyst, and theoretical. They assert that triangulation helps to eliminate any uncertainty in research that involves a single method, researcher, or theory for example. I deployed all four types of triangulation in for this thesis, from the sources of data, which includes my own data (e.g. diary, blog, field notes, interviews) to theory triangulation and the use of intersectionality and DisCrit.

I also utilised data triangulation through three different participant groups: Black-British children/ young people with autism; parents; and school personnel. In addition, because of my personal connection to the study I enlisted the help of a few peers, colleagues, and individuals with different levels of knowledge to work with me to code collaboratively and analyse the data for patterns, however, as previously mentioned this collaboration still kept my reflexivity at the centre of the analysis. While triangulation provided ways to build a greater picture of the research phenomena being explored and offered a source of trustworthiness (Oliver-Hoyo and Allen, 2006; Bazeley, 2013; Bans-Akutey and Tiimub, 2021), it was not used as a means to create objectivity that did not embrace my research

subjectivity and positionality, which was a key component of analysing the data thematically.

### **Ethical Considerations: Conducting research with vulnerable groups**

One of the leading ethical concerns in this study was the intention to conduct research with a highly vulnerable group: children and young people. This matter was further compounded by additional or intersecting characteristics including race, ethnicity, and disability (Nadan and Korbin, 2019; Bešić, 2020; Misra, Curington and Green, 2021). Research suggests that it can be a challenge to access (Anderson and Hatton, 2000) and recruit (Smith, 2008) vulnerable groups for studies because of the danger of exploitation, competency, culture, agency and consent, and respecting their rights (Morrow and Richards, 1996; Moore and Miller, 1999; Rabiee, Sloper and Beresford, 2005; Kendrick, Steckley, and Lerpiniere, 2008; Graham *et al.*, 2014).

Pillay (2014) conducted a study investigating ethical issues in educational research with children in South Africa. The qualitative study involved 8 professionals with vast knowledge and expertise in ethics. The findings suggested that child participation in research was crucial to understanding child issues, as well as the safeguarding role of ethics committees, cultural contexts and protecting children from harm. Ethical regulatory bodies provide clear policies and guidance designed to acknowledge and protect children's rights (Brooks, Te Riele and Maguire, 2014) and consent (Warwick and Chaplain, 2017) to name but a few when conducting research with this group, although there have been calls for greater scrutiny into some ethical policies (Parsons *et al.*, 2015). British Educational Research Association's (BERA) Ethical Guidelines for Educational Research (2018) expects researchers to operate within parameters that include transparency, trustworthiness, due care, and attention, and more to ensure the protection of all parties.

The United Nations Convention on the Rights of Persons with Disabilities (2006) provides 50 articles that outline the rights of people with disabilities. Many of these articles such as Article **3**: General principles, Article **7**: Children with disabilities and Article **30**: Participation in cultural life, recreation, leisure, and sport contextualise the ethical responsibilities and rights, as well as importance of working with vulnerable groups. There were a few reasons

why it was necessary to conduct research with this group. One of the main aims of the study was to explore if, and how Black British children and young people with autism engage and interact with and understand their racial, ethnic and cultural identities, of which there is little to no research. Although there are differences in the cognitive ability as well as developmental and learning disabilities and other associated difficulties of children/ young people with autism (Ozonoff, 1995; Happé, 1999; Arabameri and Sotoodeh, 2015; Livingstone and Happé, 2017) these limitations should not prevent them from having the chance to be actively involved in research about them, if conducted in inclusive ways, appropriate to their needs and abilities. By doing so, we develop a better understanding of any challenges and experiences that they navigate through and can work on resolutions to these issues.

## **Safeguarding**

Another ethical concern was related to safeguarding. Safeguarding is the responsibility of all involved in keeping people safe, not just physically but also mentally and emotionally as well (Chambers, Cantrell and Booth, 2021; NHS England, no-date b). There are additional concerns that relate to safeguarding vulnerable groups (i.e., children and young people) that are governed by law. Some of this legislation in the UK includes *Safeguarding Vulnerable Groups Act* (2006) *Keeping Children Safe in Education* (Department for Education 2023b) and *Working Together to Safeguard Children* (Department for Education 2023c). The NSPCC Learning (2024) also emphasises the need to recognise intersectionality within the safeguarding of disabled children and young people, whereby their diverse identities including ethnicity and gender, can also create further barriers and discrimination alongside their disability. Moreover, they provide various guidance for safeguarding children and young people with disabilities and their multiple identities.

I ensured that any safeguarding concerns in this study were mitigated as a matter of priority in various ways. I disclosed to the parents and schools that I held a current enhanced DBS certificate as a SEND educational professional and provided evidence of this when required. To minimise any distress caused to the vulnerable participant that may arise due to the unfamiliarity of the researcher and further aid in keeping the participant safe, the interview with the vulnerable participant was conducted in the presence of a familiar adult (e.g.,

parent/ carer/ teacher) who remained for the duration of the interview. I made sure to respect their personal space and time. Additionally, I designed the interview to be an interactive task that explored the research question in a structured but fun way without placing any emotional or academic demands on the participant. Finally, the participants were able to stop and finish at any time during the interview, to further safeguard their rights and emotional wellbeing. However, I must acknowledge that my positionality, specifically my power as an adult, working with vulnerable children and young people in a school setting could have been a significant contributing factor to their participation.

Equally, it was important to recognise my duty of care to the adult (and younger, as previously explained) participants within this study as the subject of race can be considered sensitive to discuss (Bolgatz, 2005; Tolsma *et al*, 2009; O'Hara and Shue, 2014). I managed any potential sensitivities by reminding participants of their right to stop or withdraw at the beginning of the study, I closely monitored obvious and subtle changes in body language and voice and signposted participants to provisions that offered support as part of the debrief at the end of the interview (e.g., Mind, no-date; Black Minds Matter, no-date) and encouraged them to contact their health care professional if they felt necessary.

### **Gatekeeping**

An extension of safeguarding included gatekeeping. It was also necessary to liaise with relevant gatekeepers at the schools with the authority to provide access and clearance to the school and pupils for research purposes (Cresswell and Guetterman, 2021). Emails or letters of permission were provided by the headteacher or teacher at the schools that the children/ young people who took part attended, in accordance with ethical approval of this study (appendix m).

### **Assent, Consent and Dissent: Working with vulnerable participants**

Hammersley (2017) suggests that while in most cases a person's autonomy should be respected there will also be times that their freedoms are challenged because of their capacity and even cultural identities. He further explains that in such cases the individual's consent is still necessary, along with that of a parent for example in the case of children, as an added layer of protection. I made no assumptions about the participant's ability, and

informed consent or assent by the participant was dependent on the ability and understanding of the participant through a discussion with the participant's parent, teacher, and researcher collectively. In this study there were 3 different permission outcomes identified by the researcher. The first was assent. I recognised that in most cases, the participant's dis/ability would affect their understanding of what it meant to give informed consent and their willingness to take part may be more of indifference and submission (Alderson and Marrow, 2011; Dockett and Perry, 2011). As a result, a multi-layered authentication procedure was implemented to ensure the participant was able to provide assent this involved:

- informed consent for a child/ young person to take part being obtained from a parent/ legal guardian for all participants prior to the interview being scheduled,
- discussion with the parent and teacher regarding the child/ young person's functioning level of autism, abilities, and needs,
- confirmation of their communication level (e.g., speaking / verbal, non-speaking/non-verbal) and their AAC tools of communication,
- design of participant needs-appropriate consent/ assent form and AAC resources based on child/ young person's ability,
- participant being asked for consent/ assent at the start of the interview, as detailed in previous sections of this chapter using accessible and needs ability formats.

Each level offered additional protection for the participant in being able to access the research process on their terms, without compromising their autonomy, as they had the final say. If a child/ young person refused to take part by communicating their disdain, upset, or unhappiness vocally (e.g., making sounds), verbally (e.g. using speech/ language), through gestures or using an AAC method, like a 'no' symbol this would have been considered dissent (De Lourdes *et al.*, 2003; Kirby, 2020) and I would have accepted this assertion as permission being declined and no data collection involving that participant would have been collected at that time.

Due to the complexities of autism and SEND, it was noted that the participant may not consent/assent to taking part on the day due to their mood, understanding, illness, and

other underlying reasons. In this case, the researcher sought guidance from the parent (beforehand) and school staff of the participant that was present whether to try again at another time or withdraw them from the study, however, no such issues took place. To further protect the interests of the vulnerable participant, their consent/ assent was verified by the teacher or support staff that was present for the interview.

Finally informed consent. As it relates to ethics, there are specific directives and guidance about informed consent whereby if an individual is given full disclosure of information, whether positive or adverse, they should have the freedom to make the best decision for them or others to the best of their ability (Miller and Bell, 2014). However, it is this understanding of what constitutes 'ability' that can be problematic when seeking and obtaining informed consent, as consent should not be generalised (Neff, 2008; Millum and Bromwich, 2021; Resnik, 2021). Informed consent was sought from the following groups: children/ young people who were able to understand and explain the concept of consent, such as those with a functioning level of autism of level 1, as agreed by the parent, teacher, and researcher. Informed consent was also required of the parents, not only for their child/ young person taking part but also themselves, if they took part in the study as a parent participant. Lastly, informed consent was given by the school personnel participants who took part. Adult participants were required to fully complete, sign and return the relevant detailed consent form, of which there was one for adult and one for their child/ young person in advance of any data collection to protect the interests of the participants.

**Data protection and management** (including confidentiality, privacy, and data storage)

Researchers must ensure that participants personal information and data is always protected. In undertaking ethical research, researchers are expected to understand and abide by research integrity and policies that include keeping data safe, privacy, and confidentiality (Wiles *et al.*, 2008; Kaiser 2009; Morse and Coulehan, 2015). I was especially careful to manage these areas in this study because of the vulnerability of one of the participant groups and the small demographic information like special schools in London, which could have left participants at risk of exposure. All data collected as part of this research was managed in line with the Data Protection Act (2018) and no personal data has

been enclosed in the findings of this study. The names of participants were anonymised (pseudonym names were allocated to participants) to ensure they could not be identified.

All names and identifiable information were also removed from my field notes. The interviews were video and voice recorded, either via ZOOM (adult participants and one young person), my DSLR camera or smartphone (child and young person group). The adult participant video recordings were immediately deleted and safely disposed of, followed by the voice-recordings once the audio transcription had been checked and cleansed. The video recordings of the children and young people were also deleted and safely disposed of once they had been manually transcribed. As mentioned earlier in the data collection section, all data was safely and securely managed on BUL servers in line with BUL data management policies.

There were some other identified risks to the participants, others, and me as the researcher outside of the above ethical concerns like exposure to COVID-19, challenging behaviour, personal interest, and a few others, which were detailed on a risk assessment form (appendix n). This document not only described the risk but also the precautions that were taken to minimise and deal with them.

## **Positionality**

I began to discuss my positionalities in the auto/biographical second chapter. McGarry (2015), Thomas (2017), and Adu-Ampong and Adams (2020) all suggest that a researcher's positionality should embrace and accept the successes, challenges and lessons involved across the research process. In chapter two, I discussed the different roles that influence my positionality as researcher to greater extent but will briefly summarise the key messages again here. The detailed acknowledgement of my positionality in the auto/biographical chapter lent itself to my roles as a mother and SEND professional, but there is also my role as a researcher, treading both the 'inside' and 'outside' of this study. Dwyer and Buckle (2009) argue that recognising "the space between" (p.60) 'insider' and 'outsider' positionality deserves serious consideration, because of the unique intricacies and value this space holds for understanding the phenomena being explored. They suggest that the opposing position of being either an 'insider' or 'outsider' is an outdated



construction that not all qualitative researchers fit into. I both agree and resonate with the views of this argument.

I assert that as research evolves and becomes more complex so too should the various aspects of research including, design, methodology, and the researcher. And as a researcher it sometimes becomes necessary to challenge the hierarchical, patriarchal, dominant perspectives that underpins much of research practice, methodology, and positioning that can exclude the experiences of other individuals and groups through different concepts (Yancher, Gantt and Clay, 2005; Secules *et al.*, 2020; Kovach, 2021; Rizvi, 2022). In the context of this research, this stance is especially important because it explores marginalised and vulnerable groups inside the broader topics of race, culture, and dis/ability. Without embracing the unique 'space between', and my intersecting identities within this research I might not have been afforded the same access and insight shared by the participants or found the confidence to reflect upon my own experiences and positionality.

Conducting empirical research with the knowledge of an 'insider', while simultaneously maintaining an expected researcher objectivity as an 'outsider' required constant reflexivity, which was at times challenging, as I contended with the weight and implications of both roles on myself, those involved, particularly my son, and the outcome of such a personal project. However, I was unable to deny my connections to this research both 'inside' and 'outside' of the field, through my lived experiences as a mother to a young Black son with autism, and then as a SEND education professional with a passion for critical, social justice and I therefore welcomed the personal links to the research. These profound connections are predominately what led this research seed to take root and begin to grow. Researching personal and social life and narratives is fascinating, complex, yet necessary.

As a Black woman mothering a son with autism who has acute learning difficulties and needs, I empathised with the lived experiences of the parents and similarly understood some of the thoughts and feelings of the special school practitioners, because I am one. Moreover, I was greatly inspired by the children and young people, and my son because they possess a sense of resilience and independence despite the inferences that society

might make of their different abilities and identities. Finally, as a researcher, I felt privileged to be entrusted with their experiences, interwoven with mine and my son stories, examining them from the inside, outside, and in-between, each a powerful and important position in understanding race, ethnicity, identity and autism from those who embody it.

### **Power dynamics: Mother**

Through my own understanding and experiences as a Black woman I have been teaching my son about his racial, ethnic, and cultural identities to help him learn more about who he is, not only as I and society see him but also for his own construction of these identities. As his mother and primary caregiver, I acknowledge not only the parental power dynamic that exists but also that of a trusted and familiar adult. I have taken great care to safeguard his vulnerability, as a young person with autism and learning difficulties within this study in the following ways:

- Every part of this study that involved my son was explained to him in an accessible format, according to his ability and needs, including images, symbols, and other AAC tools,
- I sought and received informed consent from my son's father to allow my son to take part in this research study, including the sharing his of personal experiences,
- I sought and received assent (provided and received in an accessible format) from my son to take part in this research study and to share some of his personal experiences, as witnessed by his father and independent witness with no relation to my son, family, or study, including on the day of the interview to maintain research integrity,
- My son's right to withdraw from taking part was provided to both him and his father at several stages prior to him taking part and as was the same for all participants, one month after the interview date,
- His right to withdraw his personal voice from the auto/biographical stories was also exercised in the same way as the previous point,
- I have maintained the same ethical considerations detailed earlier in this chapter and ensured that they were adhered to when working with my son (e.g., declaring

my positionality, safeguarding, right to refuse to take part- dissent, use of risk assessment to mitigate harm).

Most of the auto/biographical experiences and stories that involve my son, and I shared in this thesis have been from my perspective. Although those that have included my son's voice or attributable interactions with him have been managed to ensure that he was not caused any harm or distress, such as using different sources (e.g., journal, blog) to retell historic events so that he did not have to relive them. His involvement in this study was to allow him the opportunity to share his experiences as a non-speaking young Black male with autism in response to the research question and aims and provide a greater understanding of the study's themes, of which there is a significant underrepresentation of research. However, my priority to protect his wellbeing and safety was recognising that I am his mother first and foremost before I am a researcher and if he or his father, as his representative refused at any point to take part then his autonomy would have been fully respected and I would have still been able to conduct this study without his interaction and input.

### **Power dynamics: SEND education professional**

It was necessary and vital to disclose and acknowledge my positionality from inception (i.e., research proposal) and continuously throughout this process, at every stage (e.g., data collection, analysis, and results) to preserve the research integrity of this important work because a few of the participants formed part of my professional and personal networks. I have worked as a SEND education professional for over 12 years. My experience includes but is not limited to teaching and supporting children and young people with autism, those with complex needs (including medical and physical disabilities) and profound multiple learning difficulties. I recognise the importance of ensuring that children and young people with SEND are afforded agency, appropriate to their needs and treated with respect. By providing full disclosure it was a way to mitigate any perceived or known risks associated with my positionality. However, I acknowledge that disclosure alone was not enough to negate power dynamics or account for trustworthiness and other practical challenges.

As outlined in the previous ethical considerations and data collection sections all

participants, regardless of how they were known to me as the researcher, were managed in accordance with strict ethical guidelines. In this study, I noted power dynamics between myself as the researcher and SEND practitioners, parents, and vulnerable children and young people who took part. Some of the challenges that these dynamics presented included conducting research within my field of practice, familiarity, and maintaining confidentiality (Bell and Nutt 2012). I took practical steps to manage some of these issues by ensuring that I made it explicit that my interactions with participants was in the capacity of the researcher seeking information related to the research questions to create a clear boundary and manage expectations. My positionality as a SEND practitioner and mother to a child with autism was made transparent in the participant information sheet, which all participants were provided with before consenting to taking part. This positionality as a SEND professional and mother meant that I understood certain language that was used during interviews, or could empathise with the participants experiences, however, I ensured that the participants remained the focus of the interviews with their stories and experiences and not my own. In addition, I made sure to follow any instructions and procedures presented, was respectful of space and time, wore/ showed my university student ID card and provided a copy of my study's ethical approval letter. Because this study was conducted within my service provision of special education there are implications on the practice that will be discussed in the conclusion chapter. My positionality as a researcher with inside knowledge and experience of the field of study my research is within required me to always be reflective, recognising the both the benefits and challenges that it presented while staying true to my commitment to conduct research that was ethical, honest, and robust.

## **Chapter Summary**

In this chapter, I have discussed and outlined the design of this research study. I have justified my rationale for working with a vulnerable participant group, committed to raising their underrepresented and marginalised profiles within empirical research. I have paid due care to mitigate and respond to multiple ethical considerations in line with regulatory guidance. I also discussed the driver behind the research, my son, and the purpose for adopting an auto/biographical methodology. In addition, this chapter has detailed the

processes involved in sampling, recruitment, and data collection. I have reasoned and argued my positionality as both an 'insider' and 'outsider' with a unique perspective on either side and 'in-between' the field. Finally, I have outlined the data analysis involved in this study, which will be evident in the next two results chapters.

## Chapter Five: You, Me, and Identity

### Introduction

In this chapter, I present the first set of results from my analysis of the data from the three participant groups that took part in this study: (i) *Black British children and young people with an autism diagnosis*, (ii) *parents of Black British children and young people with an autism diagnosis* and (iii) *school personnel in English special schools*. I have identified eight principal themes with fourteen subthemes in total, as illustrated in the previous chapter, which will be discussed across two chapters (five and six). The findings presented here in chapter five are relative to ideas of **identity** and span three themes and six subthemes, which have enabled me to address my research questions and the ways in which they relate to the complex intersectionality of developing and empowering racial, ethnic and cultural identities in Black British children and young people autism. Embedded within the discussions of the findings against existing literature and the theoretical approaches of Intersectionality and DisCrit (Disability Critical Race Theory) are my reflections as a mother to a young Black man with autism and SEND educator in a special school as a way to connect the dots of my auto/biographical accounts shared in chapter two.

Some of the key findings from the data that link to identity suggest that:

- *Black British children and young people with autism can ‘understand’ their racial, ethnic, and cultural identities when appropriate to their needs,*
- *parents and school personnel link belonging and sense of self to a diverse curricula*
- *music, food and religion- the most significant references to culture and ethnicity*
- *parental upbringing has a significant influence on their child’s identity formation*
- *implicit ethnic-racial socialisation takes place predominately in the home.*

### Research Questions and chapter themes/ subthemes: Identity

The primary research questions for this study are:

- In what ways have my own lived experiences of raising a young Black British man with autism helped construct his identities?
- To what extent do Black British children and young people with autism understand (are aware of, engage and interact with, recognise) their racial, ethnic and cultural

identities through exposure at a) home and b) school?

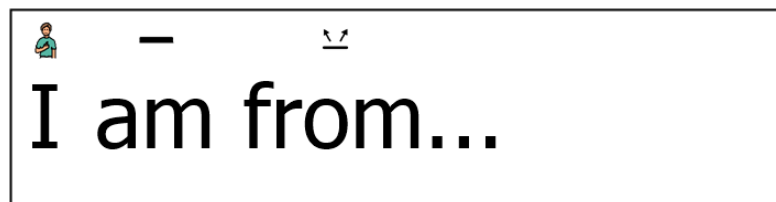
- How do British special schools incorporate race, ethnicity and culture into all aspects of their pedagogy, and wider school community.

There were three main themes and six subthemes that emerged from the analysis of the participant's experiences and interactions through the semi structured interview data that relate to identity. During the data analysis process, several patterns and commonalities allowed me to develop codes into themes and then sub themes together across the different participant groups. However, to both accurately represent, and acknowledge each group's results concisely, the participant group being discussed has been made explicit in each subtheme.

### **Awareness/ Understanding**

The first theme, '*Awareness/ Understanding*' refers to the ways in which Black British children with autism understand (are aware of, engage and interact with, and recognise) their racial, ethnic, and cultural identities.

### **Who am I? (Awareness of self: racial, ethnic, cultural identities) | [Child/ Young Person](#)**



(Miles, speaker, primary school)

In wanting to explore how the participants viewed and understood themselves and their identities, I sought to assess how they would perform in a selection task using pictures of themselves, images of other children/ young people, objects, and cultural references, examples of which were shown in the previous chapter.

All 15 participants were able to identify their picture out of a group of different items, which were either an image of / physical selection of random objects (e.g., toy bus, shoe, toy cat) or images of children from different races, ethnicities, and genders (e.g. White, Chinese,

South Asian) during the interviews. They confidently engaged and interacted with their own picture consistently throughout the session when they were asked to show me “[participant’s name]” or “where’s [participant’s name]?” for example. While most of the participants, ten in total, were predominately non-speaking (i.e. does not use speech as their main and regular communication source) they communicated their awareness of self in the interviews through gestures, such as pointing to or picking up their picture and giving it to me.

In addition, there were other body cues and mannerisms that I noted during the interview interactions including the way some of the participants smiled, vocalised sounds (e.g. “eh, eh” attempts to say their name, grunting, squealing, and other sounds), how long they looked at their picture, clapping, flapping, and other stimming types of autism sensory related behaviours (Masiran, 2018). When they were shown a picture of themselves and asked to tell me what they can see, the responses ranged from tapping their chest to indicate “me”, to using a subject, verb, object communication chart/ board (appendix o) and pointing out sentences such as, “I see [participant’s name]” to “I see black boy”. Fundamentally, it was their ability to consistently select their own picture when asked, no matter what other images or objects were present, or if I changed the order of images to check their understanding that demonstrated to me either a learned or intrinsic sense of the physical self, which mostly connected to their race and skin colour.

It did not come as a surprise to me that the participants were able to connect themselves to their racial identity by confidently and consistently selecting their images from a selection of other images and/ or objects. While it may be considered a simple task, it demonstrates the regular interactions that the participants are engaging in that relate to who they are and what they look like, which takes constant work. As both a parent and SEND professional with a long history of working with Black children and young people with autism, I felt a deep sense of pride that all the participants with autism in this study were able to connect with their racial identity in a way that was appropriate to their ability. The varied abilities and needs of each participant, as discussed in chapter four, meant that I had to recognise their needs, communication styles and abilities so that I could ensure they could access the task and what is being asked of them at an appropriate level for them.



## The Ethnic Pride and the Culture Club

The responses were similar when participants were asked questions that related to their ethnic or cultural identity, such as *“show me [name cultural/ traditional food]”* or *“where is [name of cultural/ traditional item]”*. The participants were exposed to a variety of ethnic and cultural references during the interviews, as shown in chapter four that connected with their parental heritage and backgrounds, such as images and objects of clothing, food, religion and music and once again all the participants showed levels of familiarity with them in different ways. When I played some Caribbean soca music, Carlton started to dance and laugh, compared to the pop music played, similarly, Riley got very excited by the beats of the African drums, nodding, and requesting *“more”* when I stopped the music. It was noted from the expressions and sounds that the participants made during the interviews and the ways that they engaged with their pictures that they could confidently recognise themselves in not only a biological/ physical form but also distinguish ethnic and cultural elements from random items that hold a personal connection to who they are.

In the methodology chapter I spoke about how I tailored each interview to accommodate the needs and ability of each participant to ensure the interview was fully accessible. By utilising a variety of techniques learned over time as a SEND professional and mother to a young person with autism, for example, simplifying my language, using Makaton (Syriopoulou-Delli and Eleni, 2022) or Sign-along (no-date) to sign the questions, and allowing each participant time to process the instruction) I noted a slight difference in a few of the interactions between myself and the participants with functioning ASD level 1 detailed in chapter 4. As all but one of the participants at this autism functioning level communicated through speaking, their interviews included more discussion beyond the selection of their pictures and other questions, all of which they all did with ease.

As the following example demonstrates, the participant provided more context about what they knew and felt about themselves and their culture without being prompted. When shown images of flags from around the world including the countries where his parents are from Chadwick confidently said, *“mum is from [name of country] and dad is from [name of country]”*. He also added more to the conversation telling me *“[name of town] in Africa is Grandma [name] is from”* [sic]. In another interview, Shahida expressed *“I like food, jerk*

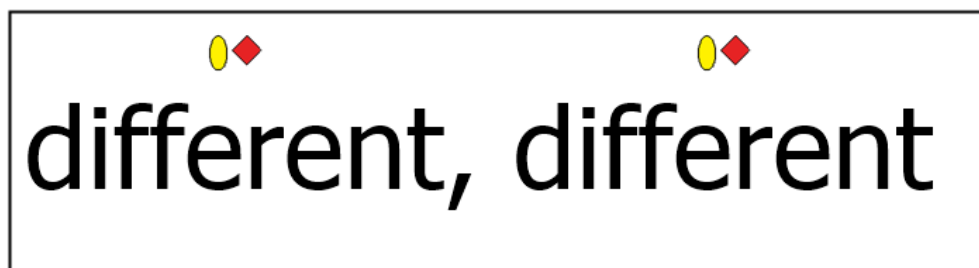
*chicken, which is from my family, spicy, spicy!*". When I asked her what music they play at home, she responded *"reggae music from [island mother is from] ... I can dance good to it, watch me"* [sic] as she proceeded to do a little dance. Moshin, non-speaking, pointed to an image of pounded yam when I asked what food he likes to eat at home, and when I asked to show me if he eats it with cutlery or his hands he pointed to his hands and pretended to eat some and laugh. There was a sense of both ethnic pride that Miles displayed in his interview when he declared with a huge smile *"I'm from [name of African country], my family is from [name of African country]"*.

I was inspired by the immediate correlations that the participants made to their ethnic and cultural identities during the interviews. The music, food, and religious references were similar between both groups (Caribbean and African heritage), however, when I showed traditional clothing images to the participants, those from African backgrounds related to them more, which tallies with comments made by the same group of parents, and knowledge that different communities, nationalities, and cultures in Africa dress in cultural, traditional attire, more so than that of Caribbean groups. In chapters two and three, I touched on the distinct ways that food, music, and religion in particular, held cultural and ethnic ties to identity among minority ethnic groups (Frith, 1996; Padolsky, 2005; Oppong, 2013).

While Flores (2003), Hall (2003), Lewis and Phoenix (2004) and other scholars all contest that identities, particularly, ethnic, racial and cultural ones are intertwined in historical and social meanings, which I have discussed in the preceding chapters, such meanings were not likely to have been the basis of the constructions for the Black British children/ young people with autism in this study. There was a simplicity and innocence that I noted from the participants when they made the links to the ethnic and cultural images and items, as well as the racial ones earlier that I took to mean that they were proud members of a special club and community that was important to them. A community, which will likely have deeper meanings for their parents, families and school personnel because of the structural implications of power, history and culture that have grown up around (Woodward, 2004; Younge, 2010) yet it will still hold meaning for the children/ young people, which I maintain is deep enough when appropriate to their abilities, which can impact the way they see and

understand their diverse selves in either a positive or negative light. Thus, as they grow through life and their abilities and awareness of the world around them changes, so too will their sense of self and others and the understanding of how their identities make them the same and/ or different. Additionally, it reinforced my belief that children and young people with autism are able to make meaning of things that connect to who they are, such as their ethnicity or culture, when it is provided consistently and in an appropriate way that takes into account their needs and abilities.

**‘Like me.../ Not like me...’ | CYP**



(Harper, non-speaking, college)

In much the same way that the child and young person participant group were able to demonstrate an awareness/ understanding of themselves, most were also able to indicate similarities and difference between themselves and others. Harper, non-speaking, tapped on the different symbol when shown an image of a white girl and himself and asked if they were the same or different. Although the processing time for each participant varied, they all were able to identify either images of children or families that were different to them because of race and ethnicity, or another factor such as religion, which can encompass race, ethnicity and culture for some (Ziegler and Rasul, 2014) . Hakeem, also non-speaking, is Muslim and pointed to the different symbol when shown a picture of an orthodox Jewish family in traditional clothing and asked if they are the same as him and his family. When he had to select the image of a family like his from a selection of five different families, including Chinese, South Indian, White, and Black, he chose the Black family in traditional Islamic clothing almost immediately.

During my interview with Denzil, he told me that his teacher (a White male), who was present during the interview was different because *“he has white skin”*. He initiated a

whole discussion about the skin colour of everyone in the room, which included his teacher, himself, and me, of his accord. He said, *“you have brown skin”* and *“[teacher’s name] has white skin”*. A similar discussion happened with Miles who when I asked him if we were the same or different, he said different *“because DM is brown and I am light brown”*. To further confirm their understanding and awareness of their racial identity, I challenged some participants to make selections (answer the question) by presenting more choice. For example, I asked Ashar to show me someone the same as him from images that included a picture of myself, a Black boy, Asian baby, and White boy, and he handed me the pictures of both me and the Black boy.

A few of the participants in my study found it difficult when a different identity strand was included in the question, such as when I asked them to distinguish between the same race and gender as themselves. This question was rephrased according to the ability level of the participant for example, *“same as [participant’s name]”* or *“who is the same as [participant’s name]”*. When Hani, non-speaking was shown an image of a Black girl and asked if she was the same or different, she pointed to different more than once. When I presented the same question with an image of a white girl she again pointed to different, I then showed her one more image of a black girl with curly hair, like hers, and she then chose and gave me the same symbol. While Zuma, a non-speaking male was able to correctly identify if the image of the child shown was the same as him, he took his time to look closely at each picture, longer than any other participant before he made his selection. In my interview with Shahida, when asked to identify an image of a young person that was the same race, ethnicity, and gender as herself, she responded by saying (when pointing at a picture of a Black girl), *“she is the same as me because she is Black like me, but I have braids in my hair”*. She was even more specific when looking at one picture remarking *“she is Black like me, but I am more Brown”*. For all participants, they found it easier to recognise and identify the same race but different gender when asked.

In much the same ways that I had witnessed with my son, (and other children that I have worked with in special schools) the children and young people could connect with racial, ethnic and cultural objects, language, images, and other references that held significant context for them, which they communicated to me through animated vocalisations,

gestures, and other visual tools, created specifically for the participants with autism (Hayes, Hirano and Marcu (2010). While the depth of their understanding could not be fully measured (and was not a determining factor in this study), their interaction and engagement with race, ethnicity, and culture through the interview task was enough to validate the importance of their comprehension, recognising that Black British children and young people with autism can understand their multiple identities but it requires a consistent, structured approach (Wearmouth, 2019) and as stated by one of the school personnel participants *“it needs to be meaningful to them so they can make the link back to themselves”*.

In addition, and what I would deem equally important is that any approach used must be accessible to the individual learner because of the broad continuum that autism spans. I discussed meaningful learning (Jonassen, Peck and Wilson, 1999; Medium, 2020) in chapter two, as a way for learners with autism to relate to who they are, which was a recurrent narrative from some of the adult participants, explored later in this chapter. It became apparent during the debrief with the school personnel after each interview (who were present for the interviews with the children and young people) that most of their racial, ethnic and cultural awareness of self, was heavily influenced by parents and families, and their home environment, and not through teaching and learning at school, as discussed in chapters two and three.

Younge (2010) shared that his cultural identity was initially formed through his upbringing, shaped by his immigrant mother and the family’s belief that they were not British because there was no way to construct what it meant to be Black and British at that time. Vaccarino and Walker (2011) assert that migrant families are often navigating between keeping their children connected to their culture and language, while also assimilating to the different practices and customs of the new ‘home’. Similarly, De Abreu and Hale (2011) suggest that children of migrant families are taught cultural practices to reinforce their own identity within the family culture, which then then use to provide support to their parents and families.

Most of the staff admitted that they did not do much cultural work or activities that were

tailored to the children/ young people's ethnic origin or identity at school, which I will explore as this chapter continues. Moreover, many were surprised at the ways in which the participants interacted and engaged with the cultural items and as a result spoke of wanting to include more of their ethnic and cultural identity into school, as it was being done at home.

As discussed in previous chapters it was fundamental that this study include the participation of children and young people across the autistic spectrum, regardless of their cognitive or communicative ability (e.g. speaking or non-speaking communicator) because dis/abled (differently-abled) voices are often missing or excluded from research about them, people with disabilities still remain an underrepresented group in many empirical studies, and wide-reaching disability research is necessary to impacting real change for dis/abled people and society at large (Barnes, 2003; Farmer and Macleod, 2011; Coons and Watson, 2013; Rios *et al.*, 2016).

Overall, the results of the interview task with the Black-British children and young people with autism indicated that all participants were able to interact and engage with, and recognise different strands of their identity, such as their race, ethnicity culture, and gender. Examples included, being able to recognise their picture among a selection of other children and young people's images and random object, categorising themselves among same- race/ gender or different- race/ gender images, and identifying objects associated with their culture. There was no difference in the results based on gender, although there were only two girls who took part in the study, which corresponds to the current data presented in chapter 1, that males still outnumber females in receiving an autism diagnosis (Ratto *et al.*, 2017; Cruz *et al.*, 2024), which makes it difficult to make comparisons/ contrasts between genders.

Due to the extensive spectrum of ASD and the varying levels of ability of the participants, it could not be determined from the limited time with each participant how much they understood the themes of race, ethnicity and culture beyond recognising differences in skin tone, or familiarity of cultural items for example. I mentioned previously that to assess that level of understanding would benefit from a more longitudinal study that falls outside the

capacity of this small-scale study. However, I argue that their recognition alone demonstrates enough of an understanding of difference and awareness of self and others to suggest that they can engage and interact with and recognise their racial, ethnic, and cultural identities when appropriate to their needs and abilities, for some this may only have been at a surface level, and for others more profound.

It is not presumed that other factors, including the child/ young person's mood, my familiarity with two participants (as a previous support teacher of theirs) and my specialist knowledge of autism (i.e., how to work with individuals with autism) may not have had some influence on the results of the interview task on the day, however, I contend that these factors have not obstructed the integrity of the data collection or analysis but rather allowed me the opportunity to use my skills and knowledge to interrogate the themes being investigated. Finally, as explained throughout this thesis, ASD presents differently in each individual and therefore these results should not be generalised to include all Black British children and young people with autism, even if the demographical information and other elements (e.g. someone with a vast knowledge of autism) was duplicated.

### **Understanding (engagement, interaction, and recognition) of racial, ethnic, and cultural identity at home and school | Parents**

*...at home they definitely know, and I'm surrounded by people that look like me, that speak like me, and I speak Somali at home as well...*

(Phylisia, Mother, Black African)

Twelve of the fourteen parents agreed that their child or young person would be able to understand their racial and ethnic identity when exposed to it at home or school in an accessible way. The two who were unsure felt that understanding a concept as big as race would be challenging for their child/ young person. Ava, a Black Caribbean mother felt that her child did not understand their racial identity explaining that *I think my child is aware of people that look like me... he would gravitate to Black people... but I think now he gravitates to people who are nice to him*. Another mother of Black African heritage, Viola, shared a similar sentiment saying,

*I don't think he has the cognitive ability to understand that [race and ethnicity]. He sometimes gravitates to certain people, Black people. I don't think he's fully aware he is a different race... I think he noticed that people are different colours [sic].*

Halle, a Black Caribbean mother, said *"it depends where on the spectrum of autism that child is"* as to whether they understand their racial or ethnic identities. However, as the interview progressed, a few of these same parents changed their minds, suggesting that their child did have an understanding of race or ethnicity even if limited, because they understood difference. Essentially, all parents felt that their child/ young person were aware of their racial and ethnic identities be it through their skin tone or another personal characteristic or reference, such as hair type or the country a family is from and would be able to engage and interact with their racial and ethnic identities in some capacity, if they were exposed to it consistently, in ways that were suitable for their ability and needs.

Most parents felt strongly that their child/ young person had some awareness or understanding of their identities as it relates to race, ethnicity or even culture. Phylcia, explained that she actively and constantly exposes her children to their African culture and heritage despite their autism diagnosis, proclaiming that when they go to gatherings, *"my children will automatically go to our culture because they recognise that"*. There were other parents who were equally as passionate that their child/ young person was aware of and understood their racial, ethnic, and cultural identity. One of the few fathers who took part, Sterling, of a Black African background stated, *"I think they can relate to it because there are a few things we do at home like, learn about Martin Luther King... we actually initiated a lot of those things ourselves"*. Chevelle, a Black Caribbean mother, exclaimed *"Without a doubt and the key word there is accessible. Our kids can do so much more than we think but we need to make it suitable for their ability"*. Another father, of Black Caribbean roots, Morris said *"I think he can tell, or he can see that he is a different colour... he can see characteristics and things he can see in himself"*.

Wearing two hats as a parent and SEND professional means that sometimes I am conflicted with my thoughts and feelings. I expressed in chapter two that my role as a mother is always paramount, however, I have a duty of care to the pupils and students that I work with, as



well as the special school community that I am a part of. I hold a unique positionality because these two roles means that I am often privy to what happens in special schools as a SEND educator in England, which most parents are unable to see, which then as the researcher in this study requires me to critically unpack the personal insider knowledge that I have compared to the knowledge that exists in the experiences of others (St. Louis and Calabrese Barton, 2002; Gill 2022). I was happy that the majority of parents felt that their child/ young person could understand their racial, ethnic and cultural identities, when they were exposed to it in an accessible way, as it highlighted much of the intrinsic socialisation that they are doing at home.

Ambitious about Autism (no-date a) has created an interactive guide for families to start discussions with autistic family members to help understand race and racism. The document is full of resources and helpful information from books, videos, and even podcasts that signposts children, young people and their families in supporting discussions about race. They advocate for honest conversations involving these sensitive topics and recognition of difference through diversity as a way to help understandings of race and identity (no-date b). Several other autism specific organisations and publications provide similar advice on helping children with autism understand race primarily but also in some cases ethnicity and culture also, from working with schools and attending cultural events (Malcolm, 2023), race-conscious parenting (The Place for Children with Autism, 2020) to stigmatisation because of ethnicity and culture (Papadopolous, 2016). The results here from this study provide further insight into how much parents are the driving force behind the development of racial, ethnic and cultural identities at home.

Throughout the interviews it was apparent that mostly all of the engagement and exposure to race, ethnicity and culture that the children and young people were having was taking place in the home rather than in school, which will be highlighted again through other results later in this chapter. Some of the parents commented on this disconnect between what their child/ young person is exposed to and able to understand as it relates to their multiple identities outside of the home, for example at school. Taye spoke about ensuring that his child is constantly exposed to cultural, ethnic, and religious events and practices in their home environment, such as Ramadan and Eid, and *“sees a lot of Black people”* stating,

*“I don’t think that that sort of intense experience [cultural and religious celebrations] is kind of replicated in schools for them to be able to discern the difference”*. Reinforcing Taye’s point, Marsai talked about the consistent work that she does at home to ensure her child is exposed to her African culture and helps to develop her understanding, sharing that *“...she has a good understanding of who she is, and which group she belongs to”*. Chevelle, concluded that:

*we force them to learn maths, science, and other academic stuff but neglect to teach them about themselves and who they are... yes, they can understand it [their racial ethnic identity] and we are the ones to help them do so.*

The findings from the parents related to this theme of awareness/ understanding felt like a testimony of the great work that the parents were doing at home, some of which reminded me of how I work with my son at home to help him understand his multiple identities, as explored in the auto/biographical chapter. What parents perceive that their child/ young person with autism understands and knows is difficult to ascertain for reasons that might include limited literature of their perspectives on the subject, or barriers related to socio-economic factors. However, their personal and practical experiences, whether individual or collective, are desperately needed to help develop missing or incomplete knowledge co-construction (Moore, 2011) of autism and SEND in general, along with that of the individual with autism and other groups that are connected to them as evidenced by this study.

Involvement from minority ethnic parents is especially important as an underrepresented group in research studies. As a parent myself, I was empathetic of all the parents views but especially those who asserted that their child/ young person could understand their diverse identities that included racial and cultural. I was equally invested in their lived experiences that in turn helped me make sense of my own lived experiences with my son, as a parent who is steadfast in the belief that children and young people with autism can recognise their racial-ethnic-cultural identities and must be allowed to explore these dimensions of character not just in the home but also in the school to develop more a more holistic sense of self.

## School Personnel

*Absolutely, absolutely and I know first-hand from doing lessons and projects and teachings with children that they do, they know who they are, they know their race, they know their culture, they know their religion.*

(Andrea, Teacher, White British)

The 12-person school personnel participant group were unanimously in agreement, like most of the parents were that Black British children/ young people with autism can understand their racial, ethnic and cultural identities when exposed to it in an accessible way. For most, however, the caveat was that their awareness and understanding was developed through ensuring their engagement and interaction was both accessible and consistent. Lisa, one of the external professionals who works with children and young people on the autistic spectrum through speech and language in English special schools commented “...with the right ways of supporting their understanding yes, they can... there are ways in which you can help them to understand who they are as a person and also their identity”. This outlook was common among teachers, teaching assistants and other professionals. “I think from my experience with the children I’ve worked with just because they have a special need, just because they have autism doesn’t diminish from their understanding in a lot of areas, [sic] said Dylan, teacher.

Another teacher with over a decade’s experience in SEND provisions Brandon, felt that “it’s how you go about pitching it, you know, trying to find that right level for that child to gain some understanding”. He further acknowledged that:

*on reflection for my own practice, I looked at some of the visuals that we had and you know, well it didn’t highlight the diversity we had within the class... when they see a visual representation of something that belongs to them, they can make the connection... we can show that an ear, nose can be White, it can be Black.*

Earlier in this chapter, and indeed across the entire thesis, discussions of accessible, appropriate and meaningful learning have underpinned supporting Black British children and young people with autism develop their racial, ethnic and cultural identities. The

notion of building connections through meaningful learning to reinforce identity formation was also mentioned by Indira a senior leader from a minority ethnic background she felt that special schools were nowhere near this feat as she ardently declared:

*for our children it's about creating more meaningful experiential learning within context...for them to make those neural pathways and understand that this is where I'm from, this is the community, this is the temple, and for them to actually generalise and apply that context.*

Many other school participants agreed, *"for our children learning needs to be contextual, and for it to be contextual it needs to be about me,"* said Andrea. Maya, a teaching assistant concurs that exposure to their racial, ethnic and cultural identities must be *"appropriate"* and *"consistent"* and also, *"there's no point at home it happening and being exposed to who they are racially and stuff if it's not gonna happen in school because they need to see it in both places, not just one... in schools it can be pushed a bit more"* [sic].

Meaningful learning in an educational environment must be relevant and representative of learners and who they are, their families and backgrounds, as it does not only motivate learners but can also impact their development (Reiter, 2015; Kostianen *et al.*, 2018). When adapted for learners with autism or other learners with SEND in a special school, I assert that meaningful learning can provide a more connected learning experience that bridges the gap between home and school and allows the child/ young person to be feel more valued and the school community to be more accepting of their individual and intersected identities. In 1995, almost 30 years ago, Cochran-Smith emphasised that in order for student teachers to deal with the issues of race and culture in teaching they need to participate and get to know their students, families and communities more intimately, which I agree with and is such a simple way to make teachers connect with who their learners and parents are.

Some more of the comments from the school personnel group when they were asked about whether children and young people with autism are able to understand their racial, ethnic, cultural identity when exposed to it in an accessible way included, Valarie, a senior leader, who assented *"I definitely do, I think it is integral to their sense of identity and their*

*sense of knowledge about themselves, their family members... and how they'll be members of society".* Claudette was one of the few participants who had multi-dimensional experience with SEND, as both a teacher and Educational Psychologist. She stated that:

*I definitely think all children despite what their needs are can understand difference, they can see difference, whether it be colour of their skin, hair texture, I think all children especially children with additional needs can understand and see difference at that level.*

Conversely, as previously explained by a few of the parents, two educators felt that awareness and understanding of one's racial and ethnic identity would prove difficult for those children and young people with autism. Zuri, a teacher commented that *"I don't think they're able to understand the concept of ethnicity, of course they feel like, okay, this person is White, Black"* but she did not think they understood ethnicity. Denise, also a teacher agreed, asserting *"it depends where on the autistic spectrum they are...just because they're exposed to it, doesn't mean they understand it"*.

Research that involves the perspectives of parents (as we first saw in this subtheme) with children/ young people with autism, and school staff who work with autistic individuals, across general topics is increasing (Stone and Rosembaum, 1988; DePape and Lindsay, 2015; Crane *et al.*, 2018; Hasson *et al.*, 2022) although it becomes narrow when investigating more specific topics, such as the intersecting themes in this study. I reflected on the findings of the school personnel, as someone who holds membership within this group, as a SEND professional. Previously, I could only speak of my experiences of working in a special school, however, hearing from peers through this research who work a variety of roles in special education provisions was insightful, as it forced me to put back on my teacher hat and ponder on my own interactions more deeply. The result of this deeper reflection led to some frustration that if school personnel truly believed that Black children/ young people with autism could understand their racial, ethnic, and cultural identities, then why were special schools not doing more to ensure it was happening in their schools. It reminded me of some of the brief encounters I shared in chapter two of working in special schools where I was told that they (children/ young people with SEND) do not know who they are because they have additional, special needs.

Siegel (2003) published a comprehensive book for parents and professionals detailing approaches to helping autistic children learn. They recognise the spectrum of autism as such that not only requires a consistent individual-centred approach but also essential to have multi-disciplinary and collaborative input. This simple guidance from Siegel's dedicated work with children with autism, parents, professionals, and more reinforces the stance of both the parents and school personnel in this study that a consistent, personalised and joint effort between families and schools could help minority ethnic children and young people with autism learn and understand more of their racial, ethnic and cultural identities both singularly and intersectionally. Several other books devoted to educating children with SEND, including autism offer similar advice about collaboration, individualised learning and programmes, repetitive teaching, and more (Farrell, 2008, Hanbury, 2012; Wearmouth, 2019).

There seemed to be no real division between the minority ethnic and non-minority ethnic group at this stage. So, if we, myself included as someone who teaches in a special school, were all mostly in agreement that children and young people with autism could understand their diverse identities that connected to race, ethnicity and culture, which I always believed, the question was what were we going to do about ensuring we did our part?

### **Identity Formation/ Empowerment**

The results in this theme highlight the ways in which parents and school personnel believe that children/ young people might be empowered through a diverse curriculum thus developing a broader sense of self and identity. Many of the opinions shared in this theme, are again mentioned in some of the other areas, such as representation and school socialisation, which will be expanded on in the next chapter.



There were several key words that all the parents frequently mentioned when discussing how their child/ young person's identity might be empowered through a more diverse (racial, ethnic) and cultural curriculum. The first one was 'belonging', *"I think firstly, it gives them, it's that belonging thing again. Where they are, they are part, their history, their culture forms part of their study...they exist in the school environment"* [sic]. Morris continues, *"they aren't just learning about things and people that they can't see themselves in, they have no connection with, it creates a link for them"*. One of the mothers, Nia agreed that belonging was central to empowerment stating, *"I think it would reinforce his identities as a young man and the ideas of belonging... he would see how important he is in this big world"*.

Developing a sense of belonging was touched upon in the third chapter. Ohene-Darko (2021) suggests that a diverse curriculum fosters identity and belonging that recognises and celebrates difference leading to learners feeling valued and seen. In this context, however, the needs and ability of children and young people with autism will need to be considered and as has been highlighted several times, ensuring appropriateness is key to ensuring pupils with additional needs access. Pesonen *et al.*, (2023) challenge established notions of belonging as a personal experience that is permanent instead suggesting that for young people with autism it is complex and shifting and is positioned within different contexts including emotional, social, and space. For some of the children and young people

with autism in this study, such an intricate idea of belonging may not be as accessible as the basic psychological need to feel connected to self and others (Lee and Robbins, 1995). It would posit that the comments shared by the parents above link to their children and young people feeling a sense of belonging through seeing themselves and their racial, ethnic and cultural identities and that of their families represented in school and feeling good about that.

The next word was ‘*confidence*’. Chevelle, who said of her son *“it will give him more confidence in who he is as a Black person, a young Black man, which will develop into a sense of pride... and a sense of belonging”*. This opinion was also shared by Marsai, who said *“I think it gives her probably more confidence”* as well as Angela who announced, *“it would make him more confident as a young man and appreciate who he is, appreciate other people as well”*. Many child-centred organisations and blogs reiterate a similar stance when it comes to empowering confidence in learners without and with a different ability, with a few also touching on autistic children (including blogs by people with autism) such as to build on their strengths, develop social interactions, celebrate achievements, and interactions that are meaningful to them from an early age (Ward-Sinclair, 2021; Early Excellence, 2023; Scope, 2024; The Spectrum, 2024). I suggest also that if children and young people with autism are able to have access to a diverse curriculum that is significant to their race and culture for example, it could make learning more enjoyable because it is about them and who they are, thus leading to more confident learners. Consequently, confidence may simply be presented in other ways for some learners, such as happiness and excitement when they see something that is familiar to them.

‘*Self-Awareness*’ was another common result, with two of the father’s respectively sharing *“awareness of oneself, yeah because that’s important”* [sic], and *“inclusion of such things [race, ethnicity], culture in the curriculum] would certainly make her more aware of who she is”*. This self-awareness he added would lead to *“more acceptance of the fact that my difference is actually, it’s like everyone’s difference. There’s no norm, the norm is all of us together”*. Yara concurs saying *“they have to know where they come from, as far as they don’t have language or communication, but they have a feeling... those [resources] are things they should make, making sure they are using them in the curriculum”* [sic]. Much of



the literature that exists on self-awareness and autism argues that such an emotion is unlikely for many autistic individuals because of the challenges associated with autism (Ferrari and Matthews, 1983; Williams, 2010; Stout, 2019). However, Bertilsdotter Rosqvist, Hultman and Hallqvist (2023) argue that the autistic young people in their study were able to develop self-awareness and that they should not be measured against neurotypical individuals, instead considered in their own right and means. Often neurodiverse children and young people are assessed against neurotypical individuals, further conflating notions of deficit if they do not meet the neurotypical standard. As stated by Bertilsdotter Rosqvist, Hultman and Hallqvist more recognition of neurodiversity within its own right is needed rather than the constant judgement against a neurotypical position, that adds value to the neurodivergent experiences, which is equally important as any other.

**Pride** was another popular word among the parents, as one mother shared that for her child *“it would empower pride, pride in his Blackness and culture his Caribbean roots and his British ones”*. The parents belief that their child/ young person can develop self-awareness, confidence, and belonging through a diverse curriculum, that incorporates their racial, ethnic and cultural identities is both positive and hopeful. Their aspirations require the content of what their child/ young person is taught, to feature their multiple identities so as to help them connect to their sense of self and others as they learn. It relates back to the literature discussed here and in earlier chapters on meaningful learning experiences that are inclusive of a learner’s identities and being able to see oneself as a valuable subject in the learning rather than an observer, excluded all together (Reiter, 2015).

Identity and belonging is one of four central tenets within the Early Childhood Curriculum Framework: Aistear (Curriculum Online, 2009) from birth to six years in Ireland. The 12-principle framework consists of three groups: children and their lives in early childhood, children’s connection with others, and how children learn and develop. The guidance under identity and belonging embraces much of what this thesis is about and what parents have shared under this theme of developing a racial, ethnic and cultural identity; *a commitment to developing strong self-identities, sense of belonging, acknowledging difference, pride, and independence*. It makes explicit reference to partnership working between child and adult to embed learning objectives that will facilitate the different principles. The

framework takes an early-intervention approach to acknowledging multiple characteristics and diversity that can only aid in sustainable identity-formation and could be adapted to be suitable for ethnic minority children and young people with ASD.

Other words commonly used by parents in the interviews include **'motivation'**, *"if it were more diverse that would have really motivated her to want to do more"*, **'independence'**, *"we want our children to be more independent when they grow up, so when they're not with their parents, we want them to continue understanding and remembering things that have been taught to them at home and school"* and **'confused'**, *"my child won't be confused, because if asked a question they would know what they are"* [sic]. Every single parent was adamant that the inclusion of a more racial, ethnic and cultural curricula would enhance the quality and depth of their child/ young person's identities, create greater understanding and awareness of self, and in some ways develop pride in their racial identity as Viola declared *"if the school is encouraging them to explore who they are...they know ok, I'm a Black person in the UK, it's ok to be Black"*. She felt this awareness and acknowledgement was extremely important as *"young people are growing up not understanding their own identity"*, and this idea resonated deeply with her own experiences of growing up as a Black African girl in England, which will be seen further down in this chapter under the theme 'Familial Socialisation'.

I would use all of the same words that the parents did when theorising how a diverse curriculum could empower racial, ethnic and cultural identities. However, the challenge here is moving from the theoretical into the practical so that as parents we would not have to speculate what a diverse curriculum could do for identity formation of our children and young people with autism, we could begin to evidence it. I especially resonated with the words 'belonging', 'pride' and 'self-awareness' as it took me back to me back to the daily affirmations exercise that I do with my son which I spoke about in the second chapter. I fondly recall the pride on his face when I ask him who is a smart Black, and how self-aware he is, when he points to himself as the smart Black man I ask of. While our daily affirmations are not a curriculum activity at school, it still provides my son with a way to develop his identity in a meaningful way that positively encourages him to be who he is with all of his distinct identities.

Finally, on a more personal level, this sub-theme spoke to my inner child and the sense of belonging that I developed as young Black girl who belonged to an active, welcoming, and vibrant Caribbean community through my parents and their peers who established a 'home away from home' when they were brought from the West Indies to England. Most of the responses from the parents felt like I was speaking to myself as the researcher, as in one parent to another parent. Reflecting on hearing the parents speak about supporting their child/ young person develop a racial, ethnic and cultural identity and sense of self and belonging, left me feeling vindicated in having much the same thoughts for my son and no longer feeling alone in those thoughts.

### **School Personnel**

*When Black people are just seeing themselves as slaves, like the message that sends to not only Black children and Black young people, also their white counterparts or their Asian counterparts, it sends a heavy message, and so to be able to see yourself as the Mae Jemison is so much more important.*

(Claudette, Educational Psychologist, Black Caribbean)

The results of participants in this group resembled much of those from the parents, with all school personnel feeling unreservedly that Black British children and young people with autism would be empowered through exposure to a more diverse curriculum. A participant commented that it would develop *"their acceptance of who they are and their place in society, if they recognise their own, somebody that looks like them, has the same food...somebody in the playground, in a resource, in books, it builds a child's self-esteem, their confidence"*.

Lisa agreed, saying *"if there's more of an exposure to these cultures and diversity, I think it will help a child to be better secure in the knowledge of who they are...recognising how they fit into their wider family or the wider community"*. The idea of importance was mentioned a few times also with Brandon expressing *"it shows them you know how important their cultural background is, not only their cultural background but actually they're important... something they should be proud of"*, he reasoned that *"I think that the skill that the practioners need is how to embed that to get those thoughts and feelings out of the*

*children*". One of the other teachers assented to this notion, saying *"guiding them as much as possible to understand identity, I feel like it's a really important thing that we can do"*. Like the parents, sense of importance and belonging was again prevalent with Brenda stating *"I think it will just help cement like belonging for them and you know it links to their home life"* [sic] and *"It'll sort of make them feel I'm important you know, I exist, you know I can achieve, I can do that because I've seen it, I've been exposed to it"* felt Cassandra.

Once again, the reflections from the school participants line up with the parents insofar as both groups talked about Black British children/ young people with autism developing a sense of belonging, identity, and more through a racially, ethnically diverse, and cultural curricula (Esteban-Guitart, 2019). The literature in chapters two and three explored identity formation among minority children and young people with autism, however, parents and school personnel simultaneously agreed here that it was fundamental to expose them to race, ethnicity, and culture consistently and appropriately (to their ability and needs) to encourage and foster pride in who they are in, which would have positive lasting implications for their future self.

The findings from the data analysis also provided some illustrations of how exposure to a diverse racial, ethnic and cultural curricula has empowered pupils that they work with for example one child recognising that he and his friend have different skin tones and when they did a related task, he was able to select his worksheet and his peers, which the participant said *"gave him a push and that enthusiasm as well"* to incorporate diversity into his teaching more. Another example was shared by Andrea who described a lesson with her class where they were doing self-portraits and a discussion about skin colour ensued, and for one pupil she recalled *"the enthusiasm and pride"* when he said he was *"dark brown"*, which led to further questions about his family. She felt that example was important because it shows how involving diversity in the curriculum is impactful as, *they know who they are, they know what they can be and do whatever they want... and that gives them a sense of empowerment... not to feel as though society puts them in a box because of any particular reason, least of all because of your race or ethnicity.*

Lastly, a senior leader summarised many of the responses by stating:

*the more the exposure, the more the experiences, the more the connection between school and home and the world, we all want to belong, we all want to feel like the people that we're around during the day they get us, they understand us, they respect us, and value us.*

My insider perspective as a SEND professional concurred with the comments and experiences of the school personnel participants, while simultaneously, feeling that same air of frustration that I mentioned when reflecting on the previous theme. The vexation comes from knowing that schools can do more and can do better. I was grateful for the examples that showcase the great work that some teachers and other staff were doing to expose pupils to a diverse racial, ethnic curriculum, as I myself have done and continue to do. Laursen and Yazdgerdi (2012) state that it is possible to create a sense of belonging among autistic populations who feel isolated or unable to connect with others through intentional strategies and practices that foster mutual interactions regardless of the social setting or situation. Arguably, this notion of connectedness, relatability and representation is central for children/ young people on the autistic spectrum, especially those from a minority ethnic background to develop a sense of self and belonging that embraces the intersectionality of identities.

Intersectionality connects here (and across all themes in this chapter) with DisCrit, as Annamma, Ferri and Connor (2018) propose that race and disability are equal oppressors used in education through the lens of ability and Whiteness. Utilising DisCrit as an analytical tool in this study was especially pertinent in exploring the discrimination and ableist experiences of the participants but also dismantling the production of inequity in education for Black children and young people with autism and indeed SEND. Whether through the Eurocentric curricula in English special schools, the disproportion of Black African or Caribbean children and young people with a diagnosis of autism or SEND and other difficulties, and the lack of empirical studies about pupil attainment at the intersection of race and dis/ability, as we have seen in earlier chapters, DisCrit must be seen as a critical tool to challenge disparity. It is the autonomous and creative examples of a diverse curricula and the will for change, shared by most of the school personnel that I would

welcome more of in special schools to actively encourage Black children and young people with autism to see beyond their singular identity of ability, which in my experience has been the focus in special schools.

### **Familial Socialisation | Parents**

In the final main theme of this chapter, I begin by revealing some of the candid, raw experiences that the parents shared of growing up and navigating their racial, ethnic, cultural, and other identities and how their upbringing has influenced the ways in which they raise their child/ young person.

#### **Family Ties/ Ties that bind**

*When I grew up in like a Catholic school, like 90% of the pupils were White, most of the pupils came from Ireland, so a lot of things were focused around their culture, we had a handful of Black people. There were some really funny comments about that [race] and I um lost myself a little bit and taken on a lot of racial things, White cultural things, and feeling like my place was just not as important as theirs in the community...a lot of things I didn't understand about my own culture, because it was purely Irish [sic].*  
(Viola, Mother, Black African).

Some of the parents who were born in the UK or those who were brought here when they were younger, associated their personal experiences of being Black and being raised Black in predominately White spaces, (e.g., school, church) with negative undertones, such as sadness, mistrust, and insecurity to name but a few (Tatum, 2004; Chapman and Bhopal, 2019). Kinouani (2021) emphasises that children become aware of race and make their own constructions at an early age. This racial socialisation is also influenced by their parents' and their racial experiences and feelings for example, in turn linked to the way we raise our own children, within the intersections of our identity and history. As a result, the experiences of the parents fuelled their passion to ensure their child/ young person was consistently exposed to their cultural, ethnic and racial heritage in more positive ways. One parent expressed, *"I've had to relearn my cultural identity, like I didn't know about Black history and so for that I'm trying to make sure that my son learns things about his, and that is part of his learning experience, and not to have to start again in adulthood like me"* [sic].

A mother said *“most of my teachers were White and I couldn’t relate to them. They didn’t understand my culture, they didn’t get references to Black culture and ways of being and living, and that got me in trouble sometimes”*. She continued, *“They made comments about my hair and skin tone, and I didn’t have a Black teacher to speak to, who would understand what it was like for me, I don’t want that for my son”*. Likewise, another parent reflected on his own time in school saying:

*I think for me growing up and stuff and going through school, and stuff like that, you know the one time there was a Black teacher at school it was huge, it wasn’t the norm, he stood out...he became our focal point, you know he understands us... he gets it a bit more, you know why certain things are a bit more challenging for me than maybe my pal John...it gives you a feeling, and it’s important that you can see yourself there, you’re not alien in that environment [sic].*

One parent who was born in England, spoke about her mother taking her and her siblings back to the mother’s Caribbean island of birth. She said:

*I want to bring you up in Grenada where you’re going to experience the culture, so we were told to cook, clean and do it all... so in my home, we did exactly the same thing as my parents did... this is our culture, and I want my children to remember my culture.*

Return visits to the parental birthplace are not new and often seen as a way to facilitate a sense of belonging and connection to ‘home’ for migrants and their children. It is exciting that these transnational practices are evident in this cohort of parents who continue this practice with their own children therefore demonstrating the ties that bind across generations, and the meaning they hold for both parents and their children and their constructions of identity (Stephenson, 2002; Conway and Potter, 2007; Reynolds, 2010; Marschall, 2017) that cannot be broken because of their child, young person’s autism diagnosis.

A father shared this comment about being born and raised in Africa and not caring about race but things being different in the UK. *“I grew up in Nigeria...we are basically raised to not really care about race, so we just think that we can be whatever we wanna be, wherever you know”* [sic]. He went on to further explain *“here [in the UK] it’s, I think something that’s*

*done to you, you know minority kids where they seem to have a limitation in terms of how far they can go. So, we challenge our kids at home, you can become whatever you know, and show them examples” [sic].*

Relating their own childhood to the study’s themes evoked mixed feelings among some parents and their own identity/identities. Moreover, they used experiences from their upbringing to shape the ways in which they raise their child/ young person with autism, keeping them grounded in their racial, ethnic and cultural roots. As with all the results so far, there were no stark differences between the African and Caribbean parents including their experiences of attending predominately white schools (Troyna and Hatcher, 2018), the lack of multicultural curricula (Male, 1980; Swann, 1985), racism in school (Graham and Robinson, 2004) and distinct parenting styles (Griffith and Grolnick, 2014; Habecker, 2016) to name a few. I suggest that consideration is given to the political and social context happening during these times (1960s-1980s) that many of these parents refer to against the current climate in which they have been raising their children/ young people today (2000s- to present day). I make this crucial point to assert that while there have been improvements in areas such as race relations and education, progress is slow and there is still significant evidence to suggest that many of the challenges and disparities these parents faced as children are still present in society today, evidenced in past chapters.

Breaking generational cultural attitudes and beliefs was paramount for a few parents as they attempted to not let their upbringing have an adverse effect on their child/ young person. One of the mothers of African descent explained:

*I feel like because she [her mother] grew up in war, hardship, her mind is not as open-minded as mine, because I went to education...In my culture it’s more like forcing...I like my culture but there are certain things we need to change [sic].*

When it comes to raising and teaching her children about their cultural heritage she said *“they love it, and they are teaching themselves more because I am not forcing it. Once you just leave it to them and expose them to it, they start to love it”* . Not all generational rearing was negative as one parents enthused: *“I absolutely loved my childhood. My mom exposed us to our culture quite a lot and we saw everything, parties, food, clothing. So, I want my children to experience what I experienced because I found it fun. I don’t want them to lose*



*the identity” [sic]. Another parent was in full agreement explaining, “I have tried to raise my son the way that I was raised, and my family used to immerse us in West Indian culture all the time, we always had it around us, I think that is why I love to proclaim I’m a proud... [slang name of people from this particular Caribbean island] [sic].*

The responses from the parents here began to demonstrate a real commitment to racial, ethnic and cultural socialisation at home that for many is wrapped up in their own upbringing, which echoes with some of the experiences and stories that I shared about my own childhood and how it has influenced the way that I raise my son. Bauer (2018) insists that Caribbean mothers work hard to instil in their children the customs and values with which they have been raised. Once again in this study, parents articulated their desire to maintain family ties to their roots and ancestral/ parental home as a way to stay grounded in their cultural and ethnic identities (Ralph and Staeheli, 2011; Rishbeth and Powell, 2013). What was most salient in the parents responses was the presence of a deep emotional attachment to their own parental heritage and their desire to ensure their child/ young person was exposed to it. Autism was not barrier that hindered the parents from including their children/ young people in customs and traditions from their culture. The racial, ethnic and cultural pride and childhood memories that they experienced are mostly synonymous with happiness and they wish to recreate or duplicate these experiences with their own children (Hughes *et al.*, 2006). Their desire to ensure their child/ young person was exposed to their ethnic and cultural traditions was instinctive and intentional. Equally, for the few parents that recalled some difficult experiences they choose to turn the negative to a positive for their child/ young person.

I revealed in my auto/biographical chapter that I often felt that I was alone in wanting to help my son connect to his/ our roots, I simply did not think it was important for other Black parents because no one spoke about it. Whatever we were doing at home to support our children learning about race, ethnicity and culture was not being shared among parents. As parents of Black children and young people with autism the journey can be isolating, there are few opportunities to develop a parental community in which we can share what we are going through, especially in a safe space that will acknowledge disparities because of race and ethnicity for example. I can see now, however, that I am far from alone and it may

require us as parents to be more proactive is connecting with one another and making the time to support, learn and lean on each other.

The barriers, struggles that many of the parents faced when they were growing up led them to wanting to improve the outcomes for their child/ young person by exposing and teaching them about race, and culture in meaningful and sustainable ways with lasting positive effects. By the same token, what is known about SEND, especially autism has evolved exponentially over the last 40 years (Ekins, 2015, McPartland *et al.*, 2021; O’Nions *et al.*, 2023; National Autistic Society, no-date e) and it is this relationship between race, ethnicity, and culture and identity formation among children and young people with autism that requires both the theoretical perspectives of intersectionality and DisCrit to unpack what is known and understood, and is still to be uncovered about these themes.

Valdez and Golash-Boza (2017) reason that distinct concepts such as race and ethnicity can be developed through intersectionality to provide better meaning and understanding of the subtle complexities that exist among them collectively, not just separately. They continue *“that an approach that considers race as well as ethnicity is an intersectional approach insofar as it looks at two distinct axes of inequality- race and ethnicity- within a structural context of white supremacy”* (pg. 2259). In the same way, Collins and Bilge (2020) assert that intersectionality understands race, gender, class and ability (to name but a few) as connected and influencing aspects of social life built upon social inequality and structural power. In this thesis, awareness is drawn to the idea that individually the themes of race, ethnicity, and culture provide only a glimpse of the disparity that impacts the identity and lives of Black British children/ young people with autism, however, their joint meaning is necessary to tackle issues on a broader scale. The children and young people in this study, are not only Black, but also African or Caribbean through the parental and generational heritage that binds them. They are also male, female, Muslim, Christian, as well as autistic, navigating their own construction of identity as well as society’s, in which dis/ability is synonymous with deficit and where these identities will more often than not interconnect.

Through some of their stories I was transported back to my life as a Black girl in school surrounded by a western culture that was different to my home life. I remembered the

taunts and cruel jibes about my dark skin and ‘nappy’ hair, which at the time I was too young to fully process as ties to racism (Chapman and Bhopal, 2019). I recognised some of the sadness in their memories from memories of my own. Equally, I understood the desire to take any pain or anger and channel it into proactive ways to change the narratives for our children. Our recollections of childhood were similar in nature, despite the different parts of the world that we came from, we were bonded by our Blackness and cultures, which moulded and reshaped our identities over time. Whether Black Caribbean or Black African, in England we were Black and that meant navigating our racial identity in a space that saw us as lesser than, including when ethnicity and culture was included. However, as the parents have expressed through the results, the intersectionality of what it means to be Black Caribbean or Black African or Black African and Muslim are central components of their identity/identities that they are passing down through the next generation to their families.

### **Racial and cultural socialisation at home | Parents**

In the final subtheme of chapter five, I detail how parents expose their child/ young person to race, ethnicity, and culture in the home.

*Around his family! Who he sees, who he knows, around the food he eats, the music he listens to, the language he hears. It's the culture you have in your home that he lives with, he understands, he knows. The smells, the voices, the music, the vibe in a way that he picks up. And that's his life, and that's his home [sic].*

(Morris, Father, Black Caribbean)

It was clear in all the interviews with parents that they work diligently to incorporate race, ethnicity and culture into their child/ young person's home life on a regular basis. The parents worked hard, irrespective of their child's autism to ensure that they were always included. Food, music, clothing, cultural events, religion, family, artefacts, and using native language were just some of the different ways that ethnicity and culture featured in their homes. Chevelle became animated as she expressed:

*Oh, it's all day, every day in my house. He [her son] gets Caribbean food to eat, which he loves and regularly asks for, I take him shopping to the West Indian grocery stores and*

*show him the produce and where it is from. I take him around the family some of which have strong island accents and dialect [sic].*

She continued, *"I have even created symbols that represent our culture and ethnicity...it's very much our everyday world"*. Beaming with pride, Sanaa exclaimed *"music, food, everything really, shows. Carnival definitely was a big thing, so we play that every day in the house"*. In Angela's home, music is also commonplace in connecting her son with his culture, she said:

*we sing songs, because [child's name] is very musical, and he loves that African kind of beat" [sic], and also clothing [child's name] loves clothing. We normally have like this cultural clothing when my own people are coming over [from Kenya to the UK] and wearing that it makes him feel, oh this is not a normal t-shirt, I really like that.*

Kerry's son also has some *"Yoruba clothing to wear"*. Yara gushed that *"I take him to Africa every year, he doesn't see himself as different there"*. Many parents spoke about taking their children/ young person to cultural events such as *"carnival", "community events" or "specific African events"*. One of the mother's said, *"I'm West African, so we go to events, and we dress up in African clothes, I let him see, 'cause most of the time you're at home in normal stuff, I want him to see other sides to him"* [sic]. She explained why seeing this 'other side' was so important asserting, *"sometimes it's hard to explain stuff to your children, but they see, and they join the dots. You've got to give them exposure and help them pick up the cues, as much as they can, eventually they find a way to navigate themselves"* [sic].

The pride that the parents felt in their culture, ethnicity and race was unmistakable and despite their child/ young person's autism diagnosis they made sure to consistently keep them exposed to these identities, which has been a common thread running along many of these subthemes. Whether it was through food, music and clothing, the home and family were dynamic agents of racial-ethnic socialisation. I was deeply moved by the depth that many parents went to ensure their child/ young person was exposed to and could recognise their race, ethnicity and culture despite autism, although it was not always made explicit how their autism factored in. It was at this point that I started to acknowledge through the stories of the other parents that my role as a mother was much more profound than even I had given myself credit for, which I will talk about more in the next chapter.

Religion and language were also significant findings, which fits with the literature in chapter three, with a participant stating, *“we definitely celebrate Ramadan and Eid at home, I get the girls to help me do some arts and crafts... we make lanterns together and we hang them up to cover the whole ceiling of the living room”*. Another parent said *“church, religion, his faith and all that [child’s name] has always loved to be in church, he goes to Sunday school... when he is going to church, he is very happy”*. *“I take him to the Mosque, um there is a Mosque for autistic children, once a year”* explained one proud parent. Sharing the same outlook, another parent said that their young person is exposed to their racial, ethnic, and cultural identity around religion, *“so we’re Christian, so we tend to incorporate that into our lives so that they can at least learn this is our way of life, this is what we do, this is when we pray”*.

The parent’s identities are intricately linked to the foundations that they are laying for their children/ young people, as highlighted through their lived experiences in the findings. Their own connections to race, culture and ethnicity, such as religion, as seen in chapter three, is manifested in the most appropriate ways for their child without losing any of the value or traditions that have been brought up with, simply adapted to meet the needs of their neurodivergent child/ young person. Several participants placed emphasis on *religion* (Peek, 2005; Taylor and Chatters, 2010; Oppong, 2013; Segre, 2021), *music* (Frith, 1996; Lidskog, 2016; Sladek, *et al.*, 2022) and *food* (Hughes *et al.*, 2006; Vallianatos and Raine, 2015) for example in the construction of racial, ethnic and cultural identities of themselves, which they then pass down to their child/ young person to keep the heritage alive, which is consistent across literature. However, it is recognised that children/ young people with autism can find the sensory input such as texture and smell of food and sounds from music challenging (Caldwell, 2017; Laurie, 2022) and may require further adaptation to meet their needs, without having to lose the link to the cultural, ethnic identity.

The use of language or *“mother tongue”* in the home was fundamental to one father who remarked *“I’m radical with this. I never speak any English at home, so yeah Arabic”*. He goes on to explain the rationale for his staunch view is that it allows his children to *“not only stay connected to their heritage”* but also *“communicate with their grandparents and other elders”* whose first language is not or do not speak/ understand any English. This view was

also shared by another parent who defended teaching her children Somali *“for my parents to understand it because they don’t speak English. So, for my parents to understand them if they are babysitting, they [her children] need to know my culture, my background, my language”*. Many children/ young people continue to be raised as part of multi-generational families, with grandparents providing valuable, vital support for families (Goodman and Silverstein, 2002; Tan *et al.*, 2010; Burgess and Muir, 2020).

In chapter three I discussed some of the increasing research evidence around racial-ethnic, and cultural socialization (Romero, Cuéllar and Roberts, 2000; Hughes *et al.*, 2006; Priest *et al.*, 2014; Wang and Benner, 2016) which can be used to help understand some of the findings from this theme and how parents keep their children/ young people connected to their heritage and race through different traditions and values. Based on their responses, much of the racial-ethnic socialisation with their children was intentional, particularly the use of language and cultural stories, which falls within cultural socialization (Hughes *et al.*, 2006) and as we see below, preparation for bias (Iqbal, 2014) by having honest discussions about racism and discrimination, and self-worth and pride (Williams and Smalls-Glover, 2014) which was especially important for parents of older children/ young people.

For many of the participants, it was not only about connecting their child/ young person to their own ethnic and cultural heritage, for example through cultural tales and stories like *“Anancy, the spider”* and *“folk tales”* but also Black history on a broader scale, including the struggles and successes. Sterling exclaimed *“we want them to be proud of Black people. So, we’ve got things like cookery books that’s focused on Black people, we’ve got stories of important Black people like Martin Luther King and Maya Angelou”*. With a more serious tone, a parent expressed *“I sit down with them [her children] and I’ll make them understand people don’t like us because of our colour. Sometimes they will discriminate against you because of your colour, even though you didn’t do anything”*, which resonated with another response that said *“for young people to grow up these days they need to know it’s ok to be their colour, because you know the children experience colourism... whatever they’re born into they need to be okay looking in the mirror”* [sic]. One participant recognises the hard work she has done to embed *“culture in our home like from day one”* as she recollects fondly on an interaction with her son where he told her that *“I’m glad I’m Black”* to which

she responded *“so am I, because we need to promote ourselves and not be scared and be confident, regardless of what anybody says, we have to fight harder”* [sic].

It must be again acknowledged that ethnic-racial socialisation among populations with autism remains underexplored, as does the approach of ethnic-racial (or vice-versa) socialisation in England. I propose that such socialisation is possible for Black-British children and young people with autism when basic principles of consistency, exposure, and appropriateness (for their ability and needs) are met, and that these actions are intimately connected to familial beliefs and customs. While parents and families may determine what and how they engage their vulnerable child/ young person with their diverse identities, the autonomy ultimately still falls to the individual who decides whether they want to participate or not. However, like me, the parents are consistent and thorough with their efforts to ensure they include race, ethnicity and culture into their home life. They are creative and determined caregivers who are passionate about their rich heritage, which they work hard to involve and instil in the lives of their children and adolescents.

## **Chapter Summary**

In this chapter, I have shared some of the results that begin to illustrate the intersectionality of racial, ethnic and cultural identities on Black British children and young people with autism, as well as their families, and staff in English special schools. The overarching focus of this chapter has been *identity* and how it has been constructed and reconfigured through socialisation, upbringing, and exposure. The multiple identities of Black British children/ young people with autism and parents from Black Caribbean and African backgrounds have been laid bare through the lived experiences of the participants, which has also included my reflections as parent to a young man with autism and SEND professional linked to some of my own experiences shared in chapter two.

The discussion has continued through a critical analysis of current literature related to the study's themes and the theoretical underpinnings of intersectionality and DisCrit where appropriate. Some of the results in this chapter indicate that Black British children and young people with autism can understand their multiple identities connected to race, ethnicity, and culture, as well as the instrumental role of parental socialisation on their

child's identities. The gravity of the experiences shared across all participant groups throughout the themes provided much-needed preliminary insight into race, culture, identity and autism predominately at home but starts to look at the work being done in special schools where little is known. In the next chapter, I will discuss the next set of findings, which leans more into the role of the **institution** and whether special schools in England are empowering racial, ethnic, and cultural pride in their Black pupils and students with autism. The themes in chapter six still feature the perspectives of parents and school personnel who provide the main context, along with my reflective thoughts.



## Chapter Six: The Institution

### Introduction

The chapter examines the next set of findings from the study and how the *institution* is involved in identity formation of Black British children and young people with autism. While the institution centres predominately on special schools (special education) in England, the family, as an institution of socialisation continues to provide significant and additional context as has been explored in chapters two, three, and six.

There are five main themes with nine sub-themes in this chapter that include ‘school socialisation’ and ‘racism, discrimination, and ableism’. Some of the main highlights in this chapter include:

- *Lack of racial, ethnic, and cultural diversity in the curricula used in special schools in England*
- *BAME teachers and senior leaders are underrepresented in special schools*
- *White school personnel do not feel comfortable or equipped to teach about race*
- *Black British children and young people with autism and families have experienced racism, discrimination and ableism in special schools and the wider community*
- *The role of the mother as fighter, advocate and activist is prominent*
- *Black school staff in English special schools have been victims of racism*

### Teaching and Curriculum Challenges

This first theme delves into the thoughts, feelings and experiences of parents’ and school personnel about diversity in special school pedagogy and curricula, as well as the challenges involved with teaching about race in English special schools, as shared by school staff.

#### Decolonise the curriculum | **Parents**

*It can't just be about ummm you know the White curriculum, or you know English Curriculum because it's not representative of who they are, cause they're adopting a persona that's got no space for their racial identity [sic].*

(Viola, Mother, Black African).

The lack of diversity within the school curriculum, resources, teaching practices and more in relation to race, ethnicity, and culture was a huge discussion point for parents. Decolonise the curriculum is a demand that has mostly been synonymous across the academy and mainstream school provisions in England (Begum and Saini, 2019; Arday, Zoe Bellugi, and Thomas, 2021; Akhter and Watson, 2022; Race, *et al.*, 2022a; Race, *et al.*, 2022b; Winter, Webb and Turner, 2024) but not in the special schools. All parents felt that their child/ young person's school or education provision could be doing more to ensure a more rounded and diverse experience to help develop not only their child's racial, ethnic, and cultural identities but that of all learners. In the quote above, Viola, reasoned for a decolonised curriculum. She continued, stressing that it was important that *"basic things, like making sure the school celebrates other cultures and religions"* were happening, as this would *"make sure children are brought up to understand that they live in a multi-cultural community"*. In addition, another parent said *"you can incorporate culture and diversity into the curriculum with ease... I don't expect culture to simply be a one-off history lesson, it should be part and parcel of the curriculum and not an afterthought"*. Nia, Black Caribbean mother said, *"If the school has books that have Black and Brown children, children that are Muslim, or have a disability, it represents the children at the school and who they are, there is something so special about seeing yourself in the environment"*.

As we discussed in chapters two and three since George Floyd's murder in America the call to abandon the Eurocentric colonial curricula that is taught in education provisions across the nation have become louder and unwavering. Although, the call was sounded long before from the death of Trayvon Martin and the birth and rise of the Black Lives Matter movement due to the continued state of global racial unrest and injustice and even further back still (Méndez, 2016; Hillstrom, 2018; Joseph-Salisbury, Connelly, and Wangari-Jones, 2021). However, special schools seem to operate as a separate entity with the structure of education at times, perhaps because of the focus on ability, therefore sensitive and prevalent issues such as racism and decolonising the curriculum rarely make the headlines in this space. One of the mother's, Marsai, (Black African) alluded to this view as she expressed that *"it's really enriching not only for people who belong to these groups, but for the whole class. It opens new horizons, it gets them to think that there are different people"*

*who have different celebrations, different beliefs, just because they are autistic doesn't mean they do not understand"* [sic].

Parents remained adamant that it was crucial for special schools to decolonise the curriculum and make a conscious effort to incorporate diversity into all areas of teaching and learning including the resources (e.g., symbols, AAC tools, books, toys etc.,) used in school to not only support how their child/ young person see themselves but to also help them better understand the world they are a part of. Kerry, a mother of Black Caribbean heritage argued that *"it's definitely important that different ethnicities and cultures need to be addressed and taught in school... for the child to understand the world around them for when they leave school"* [sic]. While both agreeing and expanding on Kerry's point, about the importance of teaching, and the need for a diverse curriculum to expand his child's understanding of self and others, Taye, (father, Black African) declared *"my child needs to normalise her presence within society in general... if it's not normalised, it's always perceived as something that the others do for us, then she would never be able to identify as someone who can contribute..."*.

It is an intricate, yet necessary charge to help children/ young people to prepare and cope with the diverse environments they interact within, whether it is the home, school or the wider world, which the parents acknowledge through their responses. When thinking about the lack of diversity in the curriculum at his son's provision, one father dug deep, asserting:

*when you peel the veil [on the academic system] and actually look broader, it's a systemic issue because in the UK, and they've done a good job at it, your taught everyone is the same, we all serve the King, everybody is fine. Until you go out in the real world and see that everything was masqueraded, it becomes a lot of confusion. Black kids are confused...and then you have an issue in society that you're gonna have to spend a lot of money building a lot of prisons to fix, which you can fix just by changing the curriculum.*

Barrett (2018) cites schools as a place where intercultural skills and understanding thrives, through building friendships and experiencing life through the cultural and diverse lens of others, which reconciles with comments like these from a few parents. Yara, mother, Black

African, suggested that during reading lessons children should be able to *“bring the books of their backgrounds”*, and have *“Black dolls, songs... and something related to home”* during role play and other sessions. She continued that these resources and books should be used more than during occasions like Black History Month, *“it should be there every day, the books should be on the shelf every day, I think that would be very good”*. Another parent concurred stating *“I expect him [her son] to be seeing children of all nationalities... dolls of all nationalities, Black dolls, White dolls, you know dolls with straight hair... he should be seeing children of all colours, ethnicities, and disability [in the curriculum]”* [sic]. We will continue to delve further into diversity and the curriculum, as we have done earlier in this thesis, later on in this chapter.

Cabrera *et al.*,(2016) acknowledge the pivotal role of parents and the family in teaching children about diversity in the world around them through ethnic-racial socialisation, which featured in the chapters two and three. Meanwhile, Harris (2009) argues that multiculturalism must recognise the everyday lives and spaces enriched with diverse cultures that young people interact with daily, which influences their ideas of identity. So, everyday multiculturalism would acknowledge Angela’s, (one of the Black African mothers) suggestion that *“for special needs it [a racial, ethnic, and cultural curriculum] needs to be built up from a very tender age, that they integrate into it slowly, and they grow into it”* rather than when they are older and become young adults and may find it difficult to understand. Finally, Chevelle shared some of the suggestions that she made to her child’s school:

*I have spoken to my son’s school about using communication symbols that look like my son, with brown skin tones, brown eyes, and afro hair. The books should represent different races, ethnicities, religion, ability... you can teach about numbers in math using fruit from an island, like sugarcane.*

She further added *“there are just so many ways of doing it, if teachers and schools really cared about diversity then they would be doing more. I think they talk the talk but don’t follow through with action”*. What is key in the narratives from parents intertwined with the above scholarly contentions from Cabrera *et al.*,(2016) and Harris (2009) is that for children and young people with autism to develop a greater awareness of themselves and

others they require careful, appropriate instruction through a diverse, decolonial and representative curriculum (Lebenhagen, 2024).

Much has been written about the fights, rights and involvement of parents in challenging the curriculum taught in American schools (Antony-Newman, 2019; Bajaj, 2022; Parent Bill of Rights Act, 2023-2024) yet here in England, the perspective of parents of the English school curriculum is limited. As a parent to a child/ young person in a special school provision in England we are not always given full access to the curricula that is being taught. It has been my experience that some schools will provide a general overview of the topics and subjects, but it is unlikely that parents and families will know how much (or even if) race, ethnicity and culture features in lessons and activities for example, or in the everyday life of pupils/ students at school. We will have pieced the 'how diverse is the curriculum' conundrum together based on our interactions with teachers, staff, meetings, events and our own enquiries.

Literature pertaining to parental involvement in English education, including the curricula, emphasises both positive and negative implications on children and young people, such as academic success, SEND, behaviour, socio-economic challenges, and differences in parental engagement based on ethnicity (Harris and Goodall, 2008; Hornby and Blackwell, 2018; Schmid and Garrels, 2021; Bates, Finlay and O'Connor Bones, 2023; Haisraeli and Fogiel-Bijaoui, 2023) but as previously explained more research is needed to explore the links between race, identity and autism in English (and global) special education. The parental responses in this study from the last chapter emphasise that a more diverse curriculum representative of the child/ young person's race and culture provides an opportunity for that individual to develop a broader sense of self and others, as well as an awareness of the multi-cultural society that are a part of. By excluding their multiple identities across the whole curriculum, children and young people are at risk of becoming more vulnerable by not feeling as though they hold an equitable space in education or recognising the value of their diverse identities in the school environment (Alexander and Weekes-Bernard, 2017), where they spend sometimes more time than they do at home. Parents have often been deemed the voice for their vulnerable dependants thus their advocacy in fighting against a Eurocentric curriculum in English special schools needs to be

amplified louder.

The parents and I were of the same opinion that what we do know of the curriculum that our children access in special schools, is and has always primarily been Eurocentric, thus the call to decolonise it. I recalled meetings I had with my son's teachers requesting them to use symbols that were representative of my son's racial identity or giving them suggestions on how to incorporate his Caribbean and British identities and culture into activities as a way to motivate and represent him, as the findings show that some of the parents in this study did. Parents had simple yet inspiring suggestions and comments on how to diversify the curriculum that would reinforce much of the work that they do at home, as seen in the previous chapter. As a parent, I agree that special schools could easily implement some of these suggestions, if they indeed see the value in the diverse identities of their learners, which in turn would help prepare them for the diverse world beyond their special school and home.

However, I recognise that on the other hand, the parents are also speaking to me, as someone who teaches in a special school, and I am encouraged by the fact that, as shared in the second chapter, I regularly and keenly find ways to ensure the pupils and students that I teach interact and engage with their race, ethnicity and culture, which included non-Black learners with autism. My life as a parent and time working in a special school almost runs concurrently, so my knowledge of the curriculum taught in this and similar learning environments is founded mostly on my experience as a SEND professional, which I will reflect on next.

### **Decolonise the curriculum | School Personnel**

The curriculum in maintained English schools (mainstream), including state-maintained special schools is imposed by the government. For these schools, the National Curriculum (Department for Education, 2014) is the curricula taught in schools, not including academies and free schools. Decolonising the curricula has been the topic of current education discourse for a number of years (Begum and Saini, 2019; Charles, 2019; Arday, Zoe Bellugi, and Thomas, 2021; National Education Union, 2022) and the consensus among the school personnel participants was that it was an important debate that demanded

change.

Each of the school personnel who were interviewed agreed that their specialist institution's curricula needed to be diversified and required more work to improve and make it more representative of the multicultural society/ world from a racial, ethnic and cultural standpoint. Rampton (1981) and Swann's (1985) historical reports, as well as Wallace and Joseph-Salisbury's (2022) more recent work, which recognises Coard's (1971) book, all suggest that a Eurocentric curriculum (among several other factors) disadvantages Black West Indian children to present day. I would further include all Black ethnic groups in this assessment, and as indicated by parents in the previous section and school personnel here, it is equally important in special schools. However, it was visible in this theme that there was a difference between the experiences and feelings of those from a BAME and non-BAME background. Participants from a minority ethnic background were more critical and vocal about the lack of diversity in the curriculum, resources, lessons, and events at their school than their White peers.

*Working in special schools, race hasn't really featured in the curriculum, in the curriculum delivery [sic].*

(Indira, British Indian, Senior Leader)

Cassandra, a Black Caribbean teaching assistant stated, *"Black Caribbean is sort of done once in a while... when you do around the world, it's nothing to do with the Caribbean or Africa"*. She also mentioned that when she has voiced her concerns, *"it's just been I'm listening to you but not gonna act on it"* [sic], leaving her deflated and frustrated. She also felt that *"kids need to identify with their cultures... if you're doing something which relates to their culture, they're more likely to be interested, engaged and want to find out more"*. We spoke about the influence of religion in earlier chapters, and a few school staff commented that diversity in their teaching and learning was mostly focused on learning about different religions. The staff shared comments such as the *"curriculum isn't diverse enough"* [sic], it is diverse only in relation *"to RE and religion"*. Reports written by academics and education professionals, such as *Teaching Migration, Belonging, and Empire in Secondary Schools* (McIntosh, Todd and Das, 2019); *Race and Racism in English*

*Secondary Schools* (Joseph-Salisbury, 2020); and *The Black Curriculum* (Arday, 2021) all bolster the position of the BAME school participants that the English school curricula must be more racially, culturally diverse and inclusive. *“We weren’t even celebrating Black History Month until um myself and my colleague brought it to senior leadership’s attention, and then we did it for like the first two years”* [sic], or *“I haven’t seen many opportunities to generalise things to do with race, religion and culture, things like that”* [sic] said two teaching assistants.

In 2021, a debate took place in the Houses of Parliament following a petition calling for the curriculum to include Britain’s role in colonialism and slavery (Kulakiewicz, Roberts and Long, 2021). Almost 270,000 petitioners demanded that Black history and cultural diversity be taught in schools to which the Government gave a blanket response. In summary they said that the history curriculum deals with the broad themes of political power and empire, but schools have the autonomy to be more explicit with what they teach within these areas. While this and other debates surrounding the curriculum in English schools continues, there remains little to no focus on special education and what decolonising and diversifying the curricula looks like in English special schools. As the results of this study indicate there is an urgent need to shine more of a spotlight on special school education overall, particularly at the intersections of race, ethnicity and culture if we are to empower pride and sense of belonging in Black British children and young people with autism and other SEND, which arguably can also increase better awareness, acknowledgement and acceptance in society at large.

Across literature, academics have been calling out tokenistic practices in the curriculum and schools, in favour of more relatable significant pedagogy (Dennis, 2017; Cooper, Major, and Grafton, 2021) like we discussed in chapter five, as well as in chapter two. Here the BAME participants had strong feelings that any work of decolonising the curriculum and embedding diversity into it was *“tokenistic”, “performative”* and *“not meaningful”* especially because *“race and identity and culture just don’t feature at all”* [in the curriculum] stated one participant. Another participant seemingly confirmed a similar stance at their school as they revealed *“it’s tokenistic, it’s all let’s celebrate Diwali... and then it’s the same recycled stuff it’s just the same, let’s take out the Diwali box of saris and*



*get some samosas in”*. A small handful of non-BAME school personnel held similar views to those mentioned above, specifically that any diversity in the curriculum *“was very tokenistic”*. A further insight from a senior leader who mentioned *“I noticed that after George Floyd lots of schools were thinking about decolonising the curriculum... there was a huge offering of courses...but there weren’t any focused on SEN”*.

Much has been studied about the role of educators in the design and delivery of the English school curriculum (Priestley *et al.*, 2012; Barrow, 2015) with decolonising the curricula increasingly becoming a leading talking point in all arenas, from parliament to Higher Education (Begum and Saini, 2019; Gandolfi, 2021; Long and Roberts, 2021; and Kulakiewicz, Roberts and Long, 2021; Race *et al.*, 2022b; Akbar, 2023). Most of the non-BAME staff that I interviewed were keen to highlight, acknowledge and emphasise the work that their schools had done to diversify the curriculum. Brenda a teacher with additional responsibilities spoke about the work in her school declaring:

*I think it is becoming more diverse and a lot of work is being done at the moment with our school curriculum...I think people are more aware of the need of a diverse curriculum...  
I’ve definitely seen a change in the last year or so compared to when I first started teaching.*

Wilder, Dyches, Obiakor and Algozzine (2004) acknowledged the challenges that multicultural pupils with autism face at the intersection of their ethnicity and culture, for example, teacher expectations and cultural awareness. They made several recommendations for the inclusion of strategies that recognised the importance of valuing their multicultural identities, such as working with community mentors and embedding culture relevant to the pupils into the curriculum, which these participants state their respective institutions are trying to do. Dylan said, *“I definitely feel like compared to how it was when I started, it is a massive difference in diversity, culture or celebrating you know all these different walks of life”*. Brandon also shared that at his school *“the curriculum at the moment is on a journey...we’ve had to put extra development into our curriculum”*. Finally, Valarie felt their school’s curriculum was *“diverse, broad, and balanced”*, citing more awareness and work has been done *“due to the really important work of the Black Lives Matter movement and our awareness of that as a staff group and how that is actually*

*being brought into schools”.*

In chapter three I spoke about some of the different initiatives and strategies working to change the landscape of race and diversity across schools and institutions in England, for example the Anti-Racist Schools Award (Leeds Beckett University, no-date). School recipients of this award have successfully started to embed culture and race into their curriculum and teaching practices providing tangible and concrete best practice models with which many schools can develop and implement their own tailor-made programmes. At present there is no information on any special schools in England with this award. However, without any such award or diverse initiatives, Denise stated that *“even if my class has no Black children in it, they should still be exposed to that... I believe in providing all the resources and making sure they’re aware of like the other races that out there as well, 100%”*. While Andrea insisted that *“... every single child should look at where they are in their education and see themselves reflected in that”*.

Indira consented that a racial, ethnic and cultural curriculum in special schools was *“definitely important, without a doubt ...but there needs to be a commitment and follow through, robust and thorough analysis embedded in the monitoring”* to ensure the diverse changes in the curriculum, such as using symbols with different skin tones, for example at her school is happening and *“happening well”*. Another comment spoke of the importance of a diverse curriculum stating that *“we need it [diversity] in our curriculum, so it becomes fundamental and part of our everyday life to give that empowerment to children”*. Finally, it was Maya who stressed the importance of diverse curricula in all forms as she questioned:

*how do our children know who they are? In regards to books, symbols, visuals, anything we have in school. If they can’t see something that relates to themselves, skin colour... just a symbol around them, how do they know who they are, who am I, yeah there’s no identity... they may see it at home but in school, I don’t see it, so what, who am I at school?.*

Identity has a profound relationship within notions of representation, as explored in chapters two and three. Although Hall’s (1997) notion of representation is complex, he

reasons that it is *“an essential part of the process by which meaning is produced and exchanged between members of a culture”* (pg.15). In addition, he propositions that this meaning is reliant on the use of means such as language and symbols that are symbolic and representative. This uncomplicated classification fits with the descriptions from the school personnel who maintained that the relevance of having diverse representations in the curriculum and at school generally is a tangible and accessible way of connecting their learners with autism to their race, ethnicity and culture.

Not only did I feel the divide between the BAME and non-BAME school personnel when discussing decolonising the curriculum in English special schools, but I also understood the tensions that the BAME (and a few non-BAME) staff felt, as a Black member of staff who teachers in these provisions. Their frustrations are reminiscent of my own experiences, which have led me to call out inconsistent, tokenistic or performative actions related to race and culture and the absence of rich diverse curricula (Alexander and Weekes-Bernard, 2017) in special school environments. From using the tired resources box of cultural materials to not celebrating Black History Month, the findings have caused me to reflect on the practice in my school and question what more I can do.

The minority ethnic participants in this group recognised the significance for Black children/ young people with autism of seeing themselves consistently represented in the curriculum or their school experience through race, ethnicity and culture. The perceived influence of decolonising and diversifying the curricula in English special schools was discussed in the previous chapter under the theme, *‘Identity Formation/ Empowerment’* with both school personnel and parents speaking about children/ young people feeling a sense of belonging and self-awareness, with similar comments recurring in this subtheme also.

It has been my first-hand experience through working with many special schools in London that the curriculum remains Eurocentric and the feedback from the adult participants in this study confirms such. There is still much work to be done in special schools across England that acknowledges the intersection of race, ethnicity, and culture and the influences of such on Black children/ young people with autism. However, with a plethora of resources and guidance readily available to help schools diversify their teaching (Pollard,

2022; Thompson, 2024; Pillai, no-date) there leaves little room for excuses that do not recognise the cultural value that diversity weaves into the fabric of the school community, especially for its learners, staff, families and society at large.

### **Teaching race in the classroom | School Personnel**

Separate to decolonising the curriculum was teaching, specifically how school staff and other professionals felt about teaching and engaging pupils about race, ethnicity and culture in special schools while acknowledging any unconscious or conscious bias that they may have. As with the previous subtheme, there was once again a disparity in how the BAME and most non-BAME staff felt about teaching lessons about race or interacting with the subject. As might have been expected, ethnic minority staff felt the most comfortable and confident teaching about race or featuring ethnicity and culture into their lessons more than most, but not all, the White teachers.

Howard's (2016) book titled "We can't teach what we don't know: White teachers, multiracial schools" discusses the discomfort that White teachers feel when having to confront their own bias and White privilege, as well as their lack of cultural and racial knowledge. The author's assertion matches the experiences of the majority of White teaching staff.

*I have to be completely honest and say definitely at points in my journey, challenges have arisen, and I have felt maybe not as equipped as I want to be. When we're dealing with race and diversity there's lots of thoughts and different opinions on the same thing... and that can be linked to sort of unconscious bias [sic].*

(Brandon, Teacher, White British)

Brenda admitted, "I wouldn't say like I'm fully confident in it... like I don't know whether you get to that point, I'm open to learning more and knowing more about different cultures, how to approach things, what to do". Different studies have explored a variety of reasons that White teachers do not feel equipped or comfortable to teach about race that include shared experiences with Black students (Ullucci, 2011); race-evasiveness (Chang-Bacon, 2022); white racial identity (Tanner, 2019); and whiteness (Flintoff and Dowling, 2019). Valarie shared that over the last few years (since learning more about the

Black Lives Matter movement) *"the actual reality ...I haven't been doing enough, it has made me think yeah, I can do more"* [sic].

Christopher Emdin (2016) adopts a flavourful style in his book, 'For White Folks Who Teach in the Hood ...and the Rest of Y'all too: Reality Pedagogy and Urban Education' that provides guidance on teaching in multicultural provisions, based on his school experience as a Black male. He infuses reality and applicability into teaching that reminds educators of the importance of content that is relatable and representative of its ethnic minority learners (Henfield and Washington, 2012) as well as challenging White teachers to find the courage to look beyond the curriculum to develop deeper connections with their pupils and students that require them to recognise and defy their bias (Starck, *et al.*, 2020). Andrea (White British teacher) called out letting bias or fear become barriers to stopping her teaching about race stating, *"I feel comfortable. So, me being scared, scared to make a mistake, or scared to challenge my own bias is not going to be a boundary to me not doing it"*. She adds *"There are many people in my life, I can consult with and who I know if I get it wrong will call me out, rightfully so... that's the whole point of learning"*. Dylan also felt more comfortable because of race-related training that has extended his knowledge asserting, *"as a White male my knowledge and understanding of the world is to a limited extent...so having people that you can go and ask who know about this is definitely a benefit and enhances the kids learning as a result"*.

However, feelings of fear and uneasiness were a factor for the majority of White teachers, as they revealed, *"it's a topic that is difficult umm sometimes that people are scared to like approach"* [sic]. Black teaching staff also explained why they felt teaching about race is difficult for White staff, *"people are scared they might say the wrong thing, am I gonna offend you, say the wrong thing"*. Some of the other comments alluded to feelings of pride, a lack of interest in diversity and race, whether pupils would understand these topics, and also whether diversity, race, and culture in special schools was important:

*they probably think that the Bob Marley's, Usain Bolt, and Mo Farrah is fine to do, why should I dig deeper... they may feel they are educated enough...their pride is a big thing, I don't want to go to this person and ask this question because I know the basics, so I'll just roll with that.*

Another comments suggested that, *“I think they don’t see it [diversity] as important...the motivation to want to make a difference or to be committed to making a change isn’t there because it isn’t somebody’s lived experience”*. One of the White teachers was quite aggrieved as she recalled an experience of staff in her school wanting to resist including more culture in their teaching. She declared *“It’s really sad because people say well, we don’t need to do that because they don’t know about it, or they won’t understand it, because they have a fear of teaching it. It should be a reason you do so, you challenge yourself to grow and learn along the way”*.

White teachers make up the majority of the teaching workforce in English special schools, with BAME teachers still significantly underrepresented in education on a whole (Ofori, 2023) therefore, White staff and other professionals are going to have to find a way to overcome any fears, lack of knowledge and training associated with teaching or engaging with race in the classroom. They will also need to develop racial literacy and acknowledge their Whiteness and biases in order to teach children of all backgrounds, but especially minority ethnic children and young people about race and the many dimensions of the term (Lingras, 2021) as a few of the White school teachers in this study did. These three teachers exercised their agency and a willingness to conquer fear and limited knowledge to learn more about race and diverse cultures to connect their learners to more inclusive teaching, representative of their cultural backgrounds, which leads to growth on both sides. There is a developing body of information, resources, and guidance available to support talking about race to those on the autistic spectrum (Melendez *et al.*, 2020; Malcolm, 2023; Ambitious about Autism, no-date a) recognising the intersections of race and autism, and the responsibilities of families and educators to challenge social inequalities.

Teaching pupils and students about race seemed to conjure up lots of different emotions and feelings among the BAME school personnel, as a few of the following examples illustrate. For some what they shared was connected to their heritage and identities and in other cases a personal desire to drive change forward. Cassandra shared her experience of briefly leading a class as a teaching assistant and teaching them about countries around the world. She focused on the Caribbean, because of her background, choosing a different

island each week, teaching pupils about *“the flags, and food, which all the kids liked, we had mangoes and pineapples so they could actually taste it...the kids enjoyed it and I even got great feedback from the class teacher”*. Equally, Denise expressed confidence in her ability to teach about African culture because *“I grew up in a very cultural household and my family are still very cultural, so I feel very equipped with knowledge and personal experience”* and for Zuri, *“yes, it has to do with that personal development and you getting to know more about the things that you want to teach”*.

The reflections from the Black and ethnic minority teaching staff who shared their confidence and competence in teaching about race was mostly drawn from their lived experiences of being a racialised minority which could be argued makes them best placed to impart their cultural knowledge and experience, as well as support minority ethnic students (Maylor, 2009b; Tembo, 2021). Claudette told me that for her learners, *“I would be able to say, okay, let’s think about this from a real cultural perspective”*. However, while the experiences and stories from Black, ethnic minority school personnel are clearly juxtaposed from the White staff there was also acknowledgment of gaps in their own cultural knowledge. Maya expressed, *“I feel comfortable and if I didn’t, I feel like I’m quite confident enough to have a discussion with someone about culture, race or whatever it may be... I prefer to teach the right thing than sort of teach the wrong thing, if you get what I’m saying”*.

Gaps in knowledge and training went hand in hand, as a small handful of the participants had recently undertaken equality, diversity and inclusion (EDI), unconscious bias, and other race related training either at their school, through external partnerships, or their own initiative. One participant said, *“over the last two years the work we’ve done as a school and the training we’ve had, and particularly the Black Lives Matter Movement, I’ve looked more on social media, and maybe I pay attention more... the actual reality I haven’t been doing enough, I can do more”*. Another similarly admitted, *“if you asked that question [do you feel equipped and knowledgeable to support/ teach about race...] maybe a year ago, I’d probably say no, but because...I guess focus on equality, diversity, inclusion, there’s been training opportunities to help raise knowledge and understanding... so I feel like I have the basics”*. All the training mentioned took place in the last couple of years (since 2020) and

mostly non-BAME participants, felt that the training improved their confidence and helped them find ways to include more cultural and racial content in their lessons. The murder of George Floyd (BBC, 2020) in America, and the Black Lives Matter movement (no-date) also came up in a few of the interviews as the catalyst for their schools deciding to provide cultural awareness and racialised training and on a personal note, some non-BAME staff wanted to enhance their knowledge about race and cultural affairs.

While in most cases the participants that undertook some sort of EDI or specialist race-related training found it helpful in some way, a few of the Black participants did not think it was suitable for purpose for their provision or provided any additional benefit stating that *“I’ve only had one [training session] in eight years”* and *“I wouldn’t call it training. I just thought it was somebody speaking at me the things that I sort of already knew”* or *“I’ve been here for 17 years and only had one session on race, in the last 2 years, nothing else at all”*. The differences between how minority ethnic participants and some of the White participants felt about teaching race draws parallels with my experiences in the auto/biographical chapter. I have used my teaching autonomy to find novel, accessible ways to approach the topic of race to learners with autism. Whether through art-creating self-portraits celebrating our different skin tones and features, which seems to be a common idea (as it was mentioned by one of the participants), history- famous Black people from around the world, and geography lessons- exploring where children and their families are from. These are just three simple ways that I have created race, ethnicity or culture related lessons, similar to some of the examples shared by some of the participants.

There will always be challenges related to teaching learners on the autistic spectrum, which is one of the reasons that this thesis continues to emphasise the importance of accessibility and appropriateness (Pittman, 2007). Seeing that the majority of participants, mostly those from BAME backgrounds but also some of the White teachers were comfortable teaching about race, was positive, and shows that there is good practise happening in a few special schools in England that others can learn from.

### **School Socialisation | School Personnel**

There are two subthemes within this main theme: *‘Racial, ethnic, and cultural identity at*



*school', and 'race, culture, and social differences vs performance'.*

### **Racial, ethnic, and cultural identity at school**

This subtheme spotlights the experiences of school personnel only and how race, ethnicity and culture are incorporated into aspects of school life beyond the curriculum, including celebrations, events, and initiatives.

*If you want to reach children there's no better way than to reach them through the means they know and understand, and that is linked to your culture, your race, and your ethnicity...that's all about how we talk to each other, how we behave with each other, how we socialise with each other.*

(Andrea, Teacher, White British)

All the schools (with staff who took part in this study) have begun to include some cultural events and initiatives around diversity, race or culture, which we have explored from the parents perspective in the preceding chapter. Although for some staff it was more of an individual effort whereby diversity 'happened' through a specific lesson for example. Moreover, they admitted that a few of these events have only been introduced in the past 2-3 years, have been inconsistent, or have always been a part of the school makeup. *"We do Diwali, that's always done every year, because the staff are mainly Asian and Muslim"* stated a teaching assistant. A teacher explained at their school *"we can pinpoint celebrations for the different religions particularly, so we do celebrate Diwali, Ramadan, we do Christmas and assemblies for active and collective worship"* [sic]. Equally, at another school, they, *"try to look at the community that we have in school... try and look at the different celebrations and plan. For example, Christmas is a big thing that is celebrated at school, but we know we have lots of religions in school, lots of cultural backgrounds"*.

Earlier we discussed the work being done with the curricula and teaching in special schools, and celebrating culture and religion is an additional way to help children and young people develop their diverse identities. Religious events were the most popular response to celebrations and initiatives in special schools. A search of religion or religious education (RE) in special schools brings up a vast number of comprehensive resources and guidance

from local authorities (Ealing Council 2020; Oxfordshire County Council, 2023; Brent Council, 2023), charities and religious bodies (Religious Education Council, 2023) and more. RE is not part of the national curriculum but is required to be taught in English schools, including maintained special schools (Department for Education, no-date), although parents can choose whether they wish their child/ young person to take part in lessons and other supplementary activities.

Therefore, schools seemingly take guidance from their local authority, deciding on the different celebrations and cultural events that are most meaningful for their learners. Harrow Council's (2023) *'Widening Diversity: Harrow agreed syllabus of Religious Education 2023-2028'* states that *"special schools should ensure that every pupil receives RE' as far as is practicable"* (pg.5"). One of programme's aims is to *"enable the development of a sense of identity and belonging of individuals and communities and the ability to flourish in an increasingly diverse society"* (pg.6) among several other objectives. As the above responses in this subtheme show the most common events that have consistently been a part of the school community for many years, according to school personnel were associated with religion and faith, for example, Diwali, Eid, Christmas, and Easter, however, for some there has been a slight shift. One teaching assistant said, *"we do Windrush, but in saying that this is a new thing, so it's not something that's been done in the eight years I've been there... and Black History Month is something we've done for 3 years, umm again this is not something that is done consistent"*. She further expressed her frustration at the lack of consistency and the perceived impact on the pupils, stating *"so in order to help our children, we need to make sure these things are implemented and are done consistently... it needs to be in everyday work, in structure. It just needs to be done all the time otherwise how do they know who they are?"*.

It is encouraging that a few special schools are working towards some type of racial-ethnic input through different cultural events and initiatives. The admission that anti-racist, diversity training, work on cultural diversity and other actions has taken place in the last few years across education and other sectors, particularly since the murder of George Floyd and global calls that Black Lives Matter is similarly reflected in literature (James, Joseph-Salisbury and Gooden, 2021; Pilkington, 2021; Tedam and Cane, 2022; Parsons, 2022) as

we have already discussed. The introduction or reinstatement of events that celebrate diversity in specialist provisions was sporadic as the participants continued. An instructor at a special needs' college declared that *"we never celebrated Africa and Diwali, and all that but I think after Covid, things began to change, and we do more of that diverse cultural celebrations"* [sic]. A few schools held similar events but were called different names such as, *"International Days"* and *"Cultural Days"*, which some participants mentioned, *"we don't do anymore"* or *"we've only done it once"*.

There was a marked difference between the work on race, ethnicity and culture that took place in the home compared to what was happening in schools (beyond the curriculum), which reconciles with my experiences as both a mom and SEND professional. While it can be argued that school has a responsibility to education, should this education not be personal social education that acknowledges parts of who they are and not solely academic instruction? Having parents involved in cultural events featured a couple of times, a teacher commented *"so we've got international day celebrations... and the big thing with them is we're trying to get as much parent involvement as possible"* [sic] and another remarked that they have *"international days for the parent input so we do, we do try"* [sic]. Through these events there is the real opportunity to include parents, families, community leaders, and other members of society who come with rich cultural knowledge, skills, and a willingness to be involved, as we will see in the parents and staff recommendations for partnership working in the concluding chapter.

Overall, there was only one initiative/ strategy that linked to race, ethnicity, and culture and that was the introduction of a diversity group, initially created at one school to combat the fact that the school was not celebrating Black History Month. *"Probing a little bit further [to set up the group] it's realising that actually teachers and middle leaders and senior leaders don't have the knowledge, skills, or confidence to be able to set up this celebration"* a senior leader explained. Although it has had some success, there have been some obstacles in progressing the group, as two participants admitted *"we've still got people that don't understand the purpose of diversity, the diversity group, or why we are doing it"* and *"we had this diversity group... it didn't feel for the right reasons, it didn't feel authentic"*.

If special school communities in England are firmly committed to diversity fully and social equity the regular inclusion of cultural events and activities (e.g. International and Cultural Days), and initiatives such as a Diversity Group mentioned by a few school participants, could begin to establish a more racially, ethnically, and culturally diverse environment (Rowbotham, 2013; Pillai, 2024). However, to avoid such events, activities, and groups being labelled as ‘tokenistic’ and ‘inauthentic’ schools must learn how to deliver sustainable, equitable solutions that are important to pupils, families, and the wider school community rather than simply being performative to trending topics or for short-term reaction, reward (Karatas *et al.*, 2023).

Looking at my own provision I can acknowledge that there have been small steps taken to embed more cultural, race-related activities into school, but along with this acknowledgement comes the honest admission that it is still not enough, which matches what other school participants have said about their special schools. According to the findings and what I have witnessed, special schools seem to still be taking the safer route and providing their learners and families with a few events that represent their school’s diversity, here or there, and in some cases not at all rather than committing to fully embedding race, ethnicity and culture as a permanent fixture. Without the inclusion of more diversity across school events and specific programmes, pupils, staff and families miss out on essential opportunities to embrace and share their racial, ethnic, and cultural identities with everyone in the school environment.

### **Race, culture, and social differences vs performance | School Personnel**

The findings presented here explore whether or how school personnel acknowledged and recognised social, cultural, and racial factors that may influence performance/ attainment/ behaviour of minority ethnic pupils.

*I think as a teacher you sort of; I feel like once you wear that hat, you’re the social worker, and everything. You get to know the family and the home situation for every single child. So, you know who’s who, whose family might not be doing well with money, and who’s missing breakfast... [sic].*

(Denise, Teacher, Black African)

There were several challenges mentioned by almost all participants potentially impacting minority ethnic pupil performance and behaviour including: financial/ economic issues, housing, language and communication, accessing formal education, community isolation or access and more. Moreover, they suggested that many of these issues were often interconnected. Brenda commented *“they might be economically at the you know lower end and have a lot of social problems that comes into you know, like housing, financial stress, accessing communities”* [sic]. She added *“and then what can lead into going into school and how they present in school, whether they have slept well, for example and ready to focus on their work, you know things like that”*.

An example from Maya reinforced the importance of knowing more about pupils and their families. She shared:

*last year I was with a child who wasn't sleeping at night because they had a younger sibling around, so letting him if he needs to go for a sleep in the corner. If he can't do the work, if he can't focus let him have his sleep, when he's ready he'll come back and do the work. So, it's giving them the time that they need.*

A large evidence base of literature, covering a variety of topics exists that studies social and economic factors, such as education, income, and housing and the impact they have on racially minoritised groups (Emerson, 2012; Roe, Aspinall and Thompson, 2016; Taylor, 2018; Hu, 2020; Witteveen, 2020), which strengthens the arguments of the participants in this study. For Brandon, financial challenges were at the forefront of his thinking stating:

*I think the first thing that springs to mind would be pupil premium children. So, it's addressing you know economic difficulty children may face, not being able to have the biggest breakfast in the morning for example, you know, one of the things is with our children we have set eating times, but actually, if a child is requesting food at different times, you know we are able to provide that because a child needs a full belly.*

He went on to explain that providing the food was only part of the challenge, *“these children with autism struggle with food textures...so, you know these challenges also, it's very important for us to recognise that and put strategies in place”*. It would appear from the results that while many participants acknowledged different racial, social and cultural differences that may affect the performance or behaviour of ethnic minority pupils with

autism, it was more of a personal call rather than a school directive. Which tallies with my own experiences.

Denise's quote at the start of this subtheme went on to say that:

*a child might be hungry because they haven't had breakfast, or they've had to share breakfast and it's not the most fulfilling meal and they're hungry and they don't wanna sit down but they just walk around and look for food and grab food from other children and that leads to behaviour.*

Most of the school personnel participants showed an awareness of social, racial, ethnic, and cultural differences that could affect behaviour and pupil performance based on their responses, although more so social and financial (e.g. free school meal recipients). As indicated in chapters two and three, when we do not take the intersection of multiple identities into account, we can end up disadvantaging groups that are already marginalised further (Crenshaw, 1991; Gilborn, 2015; Collins and Bilge, 2020). Andrea felt that at her school financial matters are considered more than any other factors declaring, *"I feel like financial perhaps is considered, but not much beyond that, not much on your behaviour being linked to your culture, so you know the child might seem loud and outgoing that's just part of their home culture or family culture"*. By and large, Indira agreed with Andrea's view but went even further sharing *"I feel like there's lots of socio-economic factors at play that we don't always consider, it's poverty, it's family structure, it's the isolation, it's actually navigating a system which is quite complicated to understand and interpret..."*.

In her response, Valarie explained *"we break it down into like saying simplest terms, so boy or girl, or pupil premium. I think we could break it into ethnic groups, definitely, particularly for attainment, that would be interesting to look at"*. Her comments are interesting, and I want to challenge them with my own experiences. In chapter three, I mentioned the term, 'identity-exemption', which I use to describe the intentional omission of one (or multiple) identity strands (e.g., race/ ethnicity, gender) except when used negatively to highlight issues. It is my opinion that identity-exemption happens often in special schools, where the focus is seemingly placed on the child or young person's dis/ability, in this case autism, until a problem arises (i.e., behaviour challenges, performance issues) and then their race,

ethnicity or gender is then thrust into the spotlight.

My experience is that identity-exemption is utilised in the same way that colour-blindness (Vargas, 2014; Winter *et al.*, 2022) is, that everyone is the same and equal, in this case, we only see ability, we do not 'see' race/ ethnicity that is until something is wrong. Rarely is this an issue among White groups, but common among Black children/ young people. Thus, the issue then becomes overshadowed as a racialised and/or gendered one, which had the intersections of multiple identities been acknowledged all along, then the situation may have been looked at differently and a proactive solution available from the beginning. What I am saying in essence here is that prejudice and bias are always at the core of education because of the prevalent systemic racism that operates in this institutional structure. Thus, the messages that are imparted about Black children and young people through teaching and learning, policy and more shapes not only how they see themselves, but how they are perceived and understood by others (Tatum, 2007).

Cultural differences that were acknowledged by some of the school personnel were language, eating, cultural nuances and expectations, celebrating special events and observing religious holidays and practices. One participant mentioned:

*if English isn't their first language, all of a sudden, they're in the classroom, all they can hear is staff talking English, even though we use short words and have strategies that can be very challenging. If it doesn't feel familiar, you know it gives those anxiety feeling they're not going to be able to learn, and they're not going to be able to reach their full potential.*

Another example was eating with hands with a teaching assistant explaining:

*this particular child used to want to eat with his hands, but they [school staff] always wanted him to use a knife and fork. I said the food he is bringing is his home food, which he is used to eating with his hands, so trying to teach him to eat it with a knife and fork is confusing and making him frustrated, they didn't understand.*

The Educational Psychologist stressed that it was *"highly important to think about cultural, social factors"* when she worked with a young child from a traveller background. She recalled

*they had never gone to school before and then all of a sudden, they were put in school, they had social communication difficulties...they had never been made to sit down before...they had no experience of school, the culture of school, the expectations, all of that had to be thought of.*

One participant also confirmed:

*I know in some Black communities you know children, if you look at an adult in the eyes when you're being told off that's considered rude to an adult, eye contact is not a thing for some children with ASD, so the idea that sometimes some children with special needs may be perceived as challenging when actually there are social communication difficulties and cultural differences that are not being seen or understood [sic].*

There were some great examples from school staff that demonstrate how important it is to recognise the influence of multiple identities and other social differences, such as children/ young people using their hands to eat traditional food at home and being forced to use cutlery with the same food when at school, instead of teaching the child the differences between types of food and ways to eat them. Such experiences can adversely impact the ways identities are shaped in different contexts for minority ethnic children. It could also conflict with what is being taught at home. Whether it was letting pupils sleep, sending work home for pupils so that they did not miss out because of absence due to cultural reasons, or even giving them food outside of scheduled times to get the best out of them, some participants demonstrated a commitment to supporting their pupils. Often, but not always, school personnel seemed reactive to socio-economic issues dealing with these challenges as an interim measure without considering what long-term support for not only pupils but also their families, and the school community at large could be implemented. Little information is known about the perceived influence of racial, social, and cultural factors on the performance and behaviour of ethnic minority children and young people with autism in English special schools, yet as discussed in earlier chapters there is a range of studies that consider achievement and attainment of Black pupils with SEN and/or other challenges (e.g. Social Emotional Mental Health) more generally (Demie, 2022; Ricketts, Kambouri and Majors, 2022; Strand, 2022).



As one of the participants from this study, a senior leader explained, special schools could look more closely at the attainment of BAME pupils, as is done in mainstream and higher education because this information could provide valuable insight into several areas, including whether disparities based on race and ethnicity, and also culture exist in these provisions and what could be done about it as a starting point. It would also serve to emphasise that children and young people in special schools have diverse identities beyond solely their ability (e.g. autism), which was touched on in one of the earlier themes, that includes their ethnicity and gender and there can often be implications at the margins where they intersect (Blanchett, Klingner and Harry, 2009; Annamma, Connor and Ferri, 2013; Gilborn, 2015; Chatzitheochari and Butler-Rees, 2023).

### **Racial, ethnic, and cultural underrepresentation**

The subtheme that follows presents the perceived influence of the underrepresentation of BAME staff, diverse curricula, and cultural and race-related events and initiatives in special schools.

#### **Representation Matters | Parents**

*All they see are like White people who are caregivers, and I think this can be a bit detrimental in a way a child might just think or associate the White person with being the caregiver, a kind person, and the Black person is just the people that I'm familiar with, and like my parents and their friends.*

(Marsai, Mother, Black African)

Representation across different areas (e.g. staff and pupil population, position, curricula, resources, cultural events, and more) mattered significantly to all parents, however, it was the underrepresentation of BAME staff in special schools and their job position that generated the most conversation, with words such as belonging and representation reappearing once more as they have done in earlier themes in this and the last chapter. Morris explained, *"I think it's [pupil and staff representation] important that it is diverse. I think any child, or every child wants to see, wants to see themselves in that, in that school, to feel you belong somewhere, that, you're a part of something"* [sic].

The underrepresentation of BAME staff, which was covered in chapter two, confirms that this underrepresentation has been a long-standing and prolonged issue across all of education in England (Coard, 2005; Bush, Glover and Sood, 2006; Wallace and Joseph-Salisbury, 2022; Demie and Hau, 2022; Demie and Huat See, 2023) and not just special schools (of which little data could be found). One of the parents acknowledged that different factors affected the lack of BAME staff in his son's school but as he offered:

*you know we want a lot of things, but we know it's not going to always be feasible, it's basically who is available, what resources are available, so it's very difficult, you will always have an incongruity...but it is ideal to have that [diversity] to be considered, at least to make sure that they try [sic].*

When thinking about BAME staff representation at her son's school, Yara said:

*"it's very important... he will go more to the Black teachers, he touches them, and he makes it a very good bond and that means he relates to somebody at home, maybe they look like my friends or my cousin"* [sic]. The comments that follow are similar, highlighting the parent's concerns regarding Black children/ young people not having staff at their school who they could relate to on a racial, ethnic or cultural level. The parents felt such representation brought support, protection, as well as a sense of familiarity and understanding for their child/ young person from someone of the same race and background (McKinney de Royston, et al., 2021). Like Yara's association to family, Nia expressed *"I think when he sees people that look like him, as in same race at school that may remind him of his family, and then he feels safe and a sense of belonging"*. She justified this stance by continuing:

*Black people can relate to other Black people, so Black teachers and staff can understand and appreciate Black pupils in a way that other staff cannot. They may be best placed to manage certain situations and contribute to conversations, discussions about race and culture in a meaningful way, that is powerful in a school setting.*

When Angela's son becomes upset at school, school staff rely on one of the only Black staff members at the school to help, she shared *"every time [child's name] feels a little bit dysregulated at school or a little bit anxious and all that, they always call her to come"*. Like responses above, Angela believes that for her son this Somali member of staff *"probably*

*looks like mommy or aunty... every time he sees her, he just brightens up and he's so happy to identify".*

Equally, it was reiterated a few times that when Black and minority ethnic children/ young people are only taught by White teachers, or schools are led by White leaders, the power structure remains unequal, perpetuating White people as caregivers and saviours and Black people as those in need (Matias, 2013; Emdin, 2016). One of the father's explained the perceived dangers of not having Black teachers or senior leaders in schools:

*it's unconsciously this picture of you being the recipient of services, someone who needs to be saved by some kind, some other superior being from a different ethnicity or race. That idea will unconsciously be constructed in your own mind and that will form part of the way in which you perceive yourself and your position in society.*

He further suggested that,

*when that's challenged by diversity in the leadership teams at school a distorted idea of itself cannot be easily constructed. And I think in that respect the school, or the educational institution will be fulfilling its obligation of ensuring equality, not equality just for now, but equality for constructing a society where we all have equal access to different positions and things like that.*

The extent to which parents considered the impact of the current lack of BAME teachers in their child/ young person's special school provision included not only present-day problems but potential long-term effects. These problems included children/ young people not seeing themselves represented in the teaching workforce, including senior leadership (Alexander and Shankley, 2020; Elonga Mboyo, 2019) therefore leading to feelings of invisibility and like they do not belong in that space. In agreement was a mother who affirmed, *"I want him to see people that look like him... to see Black people in important roles. There is not enough of that representation of ethnic minority staff in special schools. My son's school only has one Black teacher. Not one in the senior team. That is abysmal and disappointing".*

By not seeing themselves in teaching or higher roles, they could perceive these positions as unattainable or inaccessible which could negatively impact any future aspirations that

they may have of going into the profession (Tembo, 2021; Edwards, 2024), as a mother shared, *“you want our Black children to see somebody in a leadership position to aspire to and they don’t get that”*. Taye shared the same consensus, *“I think it’s really important that you need to see somebody like you in some sort of formal setting, someone in a leadership position to be able to perceive yourself being there in the future”*. Although it could be argued that the underrepresentation could also serve as a motivator to the opposite and encourage Black children with autism into such roles.

Finally, representation mattered as a way to foster a wider perspective of the world around them, which had been mentioned previously by parents and school personnel. Kerry and Viola respectively, shared that it was important to them that staff and pupils at their child/ young person’s schools are diverse because *“I think you’ll help the child to understand, even accept other people from different ethnicities and culture”* and *“it’s all about representation. Even though my son doesn’t recognise the concept of race, he still needs to see people that look like him...to know this is the make-up of the world, and not just school, if you have ethnic diversity in your staffing it brings a different level of understanding”*.

The participants also discussed racial, ethnic and cultural underrepresentation in the curricula, as highlighted earlier in this chapter, under the subthemes, decolonise the curriculum and racial, ethnic, and cultural identity at school. We saw in the latter theme that religious festivals and celebrations were commonly celebrated and observed namely, *“Ramadan”*, *“Eid”* and *“Diwali”*, as well as the more traditional Christmas and Easter. Most participants shared that a few race-related events were run at the child/ young person’s school or college, however, as previously mentioned in those earlier themes by school personnel, some of these events had only been introduced in the last couple of years or recently started to gain traction again. *“International day, we had that once”* stated one parent, *“culture days here and there”*, said another, and a few parents said their child/ young person’s school has started to celebrate *“Black History Month”* and *“National Windrush Day”*.

The remaining parents shared that no events or initiatives that focused on culture, ethnicity, or race took place at their child/ young person’s educational provision.

Ultimately, parents wanted to see more diversity throughout the curriculum, resources used in schools with their children (e.g. symbols that accurately represent their child's race, ethnicity, culture) and the opportunity to celebrate their rich cultural heritage in school with their child/ young person and the entire school population in special and frequent ways, not just once a year, if at all.

### **Representation Matters | School personnel**

*If you think about what the roles are that the staff are in, there are a lot of teachers that are White, I don't see many black or ethnic minority teachers, you see more maybe in teaching assistants... .*

(Lisa, Speech and Language, Black Caribbean)

The results indicate that most participants felt that overall the pupil population at their institution was diverse. One participant commented *"We have a high Asian, Eastern European and Black population, pupils are more diverse than the staff"*. Someone else said *"the pupil group, yeah they are diverse, they are changing all the time"* [sic]. *"You know we definitely got children from you know African countries to European countries, so you know we've got a very diverse population at [name of school]"* remarked one of the teachers.

The comments are in keeping with data presented in chapters one and three that highlight that pupils in special schools in England are from a diverse range of backgrounds, predominately White, Asian and Black groups (Department for Education, 2024c). Another participant stated that in their provision, *"I tend to see mostly White and Asian, Indian Asian...I don't see many Black individuals"*. However, with migration trends (Sturge 2024) across the country changing all the time and the political landscape around immigration a contested discourse over many years (Leruth and Taylor-Gooby, 2019) geographical location and pupil populations in special schools are naturally impacted. Other responses about whether the pupil population at their institution was diverse include, *"Yes, I believe it is diverse, we have people from all walks of life, religions, cultures"* [sic], *"our pupils are over 78% from a minority ethnic background"* and also *"if I look at it, we have more of Asian population than African"*.

School personnel recognised the lack of BAME teaching staff through their differing lens of race and ethnicity. Minority ethnic staff emphasised that in most cases they were often the only Black or Brown member of staff in their school (Sherae, 2023) they had no BAME leadership (Miller, 2020) and lower-grade positions such as teaching and lunch time assistant roles were occupied by ethnic minorities, as has already been confirmed by the literary evidence. One participant recalls:

*when I first started at the school, I was a TA [teaching assistant] seven years ago, and at the time there was only one other Black member of staff, now I'm a teacher, and I'm the only Black teacher at the school, and that's two teachers from a minority ethnic background now.*

A similar story was repeated by other teachers, one shared, *"I remember when I first started, I was the only Black person, there about only 2 of us now, me and the guy in the kitchen"*. And another teacher shared *"when I joined, I asked, you know were there any other Black staff and they said no, I'm probably the first Black teacher that was present at that school"* [sic]. Only two White school participants called out the disparity they witnessed in staffing at their school. A senior leader admitted, *"I think we could do better, looking at you know the ethnic minority groups amongst our teaching staff and senior teaching staff"*. Highlighting a pattern between ethnicity and job role (Department for Education, 2024d) in their school, this teacher shared the underrepresentation issue as they saw it, *"it tended to be like groups of people linked to job roles. I don't think it will come as any surprise to learn who were the people on the lowest pay scale and who were the people in the highest pay scales what the colour of their skin may have been"*.

Once again, the majority of the White participants highlighted positives, such as the actions their provision was taking to address the underrepresentation issue including blind recruitment (Stewart, 2016) which is removing personal information from an application like name, age, ethnicity. One participant offered insight into what their school and leadership team were doing to tackle the problem declaring *"we're doing some changes. The blind shortlisting is something an external practitioner suggested and it um made me think actually, this really works"* [sic]. Another teacher admits at their school, *"I suppose when you look at it, it would probably be more diverse in a teaching assistant role,*

*compared to maybe say um senior leadership. I think with that it's hard because it's a national thing you know with particularly teaching as well...*[sic]. This comment matched what was said by a BAME senior leader who remarked, *"the support staff are representative of the pupil population, the teachers and teaching assistants are not, and the senior leadership is definitely not representative, and that is uncommon, especially in those areas of London"* [sic]. For one of the White teachers, they felt that the question was challenging *"in terms of what we're considering diverse or not, you know. For example, one of our SLT (Senior Leadership Team), if we're looking higher up is [name of European country] so that's quite diverse"* [sic].

The dichotomy between the two groups (BAME and non-BAME school personnel) has reared its head a few times across the results and suggests possible underlying and unresolved tensions around the contentious subject of race in their schools which if left unsettled can only make matters worse for all in the long run (Tereshchenko *et al.*, 2022). I described my thoughts and experiences of the lack of BAME representation in areas that include staffing, school events and the curriculum in special schools back in chapter two and in some parts of this chapter. The responses of both the parents and school personnel participant groups mostly corroborate what I shared while calling for change. When this underrepresentation of race, ethnicity and culture is missing from all areas of school life, including staff, the curricula, or events, there are both implicit and explicit messages being transmitted. Some of what these messages mean were discussed under racial-ethnic socialisation in the third chapter and also by parents and staff in this chapter.

If considered through the lens of DisCrit, I propose that this underrepresentation is saying in English special schools, we do not value the intersectionality of race, ethnicity, and culture of our learners with dis/abilities enough to embed them within the fabric of the school, and this is problematic for many reasons already outlined. For the main subjects of this study, Black-British children/ young people with autism, this message can negatively impact the ways they are treated in school (Duncan, 2019), their identity, sense of self, and ways they view the world. Likewise, for parents and families, school staff, and society at large, a similar message is gathered about how we treat, acknowledge, accept, and understand these active members of society with different and diverse abilities who have

so much to share and offer.

### **Racism, Discrimination, Ableism**

In this penultimate theme, parents share their experiences of racism, discrimination, and ableism against their child/ young person and school personnel discuss racism in special schools. *Some of the following excerpts from the interviews may be upsetting.*

#### **Racism, Discrimination, Ableism | Parents**

*I have witnessed him being left out of activities at school and teachers segregating him from others, when I have called them out, they make up other excuses but when you point out a white child who is behaving the same way, all of a sudden, they want to include my son.*

(Chevelle, Mother, Black Caribbean)

This theme incited an abundance of emotion and discussion, as the impact of discrimination had a profound effect on the parental participants because as one participant warned “*no-one thinks about stuff like this [discrimination, racism] in special schools but they should more than anything because our voices are not always heard, and our children’s voices are definitely not heard*”. Only one parent, out of the fourteen interviewed in this study said that their child/ young person had not experienced discrimination because of their (a) *race or ethnicity*, (b) *ability*, or (c) *both* (race/ ethnicity and ability), which were discussed through literature in the first three chapters of this thesis. The most common discrimination shared by parents was because of both race/ ethnicity and ability (c), followed by ability (b) and then race and ethnicity (a), which I will discuss in the same order below. Places that some of these instances of discrimination have taken place were mostly in schools/ education, the community and during medical appointments to name but a few and include specific interactions with teaching staff, members of the public, medical or other professionals.

One mother who felt that her son had been discriminated against because of his race and ability shared, “*I’ve been called to school several times for my son’s behaviour... the assistant head made comments about children from my culture, her words finding it difficult*



*to adjust to school*". She was also one of the few parents who called out racism in her son's school as she expressed *"there have been other instances where it was discrimination, and I would go as far as racism because I have asked if they mention race or culture when speaking with non-Black families and they don't answer"*.

Due to a safeguarding issue, one parent had to remove her son from his school for his own safety and she felt that the school were not taking her concerns seriously, she explained, *"If this was a White child, they wouldn't have done that. I'm not a big fan of running around waving the race card but sometimes you have to call it what it is...you just don't expect it from an environment like a school [for special needs children] aware of these things"*. Similarly, a dangerous incident at one child's school left him with a serious injury, which his mother was not told about, she disclosed that *"[Name of child] came home with a burn on his cheek from school, it wasn't reported, he was supposed to have one to one in school, and nobody said anything"*. She continued *"when I challenged it, then that is when they start opening up, I said why are they doing this, are they doing this because he is a Black child?"*. Both the individual and combined social construction of race and dis/ability, as well as other characteristics such as gender and culture are constantly reconstructed to enable powers of prejudice and inequity in education and other societal structures (Annamma, Connor and Ferri, 2013; Callendar, 2018; DeMatthews, 2020).

Two of the father's shared instances where their boys were subjected to racial and ableist abuse out in the community. One told me that *"a parent just lost it, and it was a combination of race insults to offering some statements you know that almost like calling [son's name] 'retarded' in front of us"* [sic] when his son did not wait before entering a play area ahead of another child. Something almost identical happened in the story shared by the other father whose son accidentally knocked against someone when out in a busy area and was told to *"go back where you came from"* and other derogatory comments about being Black and having special needs.

The dual discrimination of race and disability that children/ young people and their parents endured in settings like the community is insufferable, yet sadly not uncommon according to the literature from chapter two. The experiences in special schools are difficult to locate

in empirical literature, however, and need thorough investigation. It is necessary to also acknowledge that different levels of abilities can further conflate the issue, as explained by one of the parents who believed their child experienced racism at school as a non-speaking, Black male with autism. Belonging to marginalised groups because of your race and ethnicity presents its own tribulations and so when parents spoke of their child/ young person's encounter with discrimination based not only on their race but also their ability, it multiplied the marginalisation and intensified the problem(s) (Gilborn, 2015; DeMatthews, 2020; Morgan *et al.*, 2023). Although Stuart's (1992) assertion that being a Black person with a disability is a "simultaneous oppression" (pg. 179) sits comfortably within the intersectional stance of this thesis, it is important to acknowledge, as the next set of comments suggest that they may not all play out simultaneously or obviously in all contexts.

Parents also retold of experiences that involved discrimination based on their child/ young person's ability in different settings. One mother explained, *"within the medical fields, you know, hospitals, doctors...we've been ignored you know, there is this thing where they assume that [child's name]'s got a very high pain threshold and they go, he'll be fine, take two paracetamol"*. Another parent was adamant that her young daughter faced disability discrimination as she shared, *"So, when she went to college, and I said to them that my daughter has autism, the first thing I got was she doesn't look like somebody that's got autism... and if she can't access it, then why did she apply"*. Quite a few of the stories disclosed by the parents that they considered discriminatory because of ability included their children/ young person being *"looked at funny"* (Kersten, *et al.*, 2020) when out in the community because of 'stimming' or other behaviours that are associated with autism (McCarty and Brumback, 2021), *"secluded at school"* (Williams, Gleeson and Jones, 2019) or *"sent home due to behaviour"* (Sproston, Sedgewick and Crane, 2017), not being able to access or communicate with key services (Radev, Freeth and Thompson, 2024) or support (e.g. one to one support, school place) unless they raise a complaint. This struggle with accessing their child's school place was the case for this mom who had to stay home to look after their child a few days a week because the funding from the local authority for a full-time place for her son was refused by the provision who told her *"it was too much for them"*

*to take on, so he ended up going only 3 days a week instead of 5”.*

Racism in schools and education more generally is not a new discourse (Coard, 1971; Rampton, 1981; Swann, 1985; Tomlinson, 1983; Macpherson, 1999) yet little empirical data is available on racism and experiences thereof in English special schools, including parental voice. Wallace and Joseph-Salisbury (2022) revisited Coard’s (1971) pivotal work on the educational classification of children of West Indian heritage in *“How still is the Black Caribbean child made educationally subnormal in the English school system”* emphasising the permanence of systemic racism that today still consistently frames Black Caribbean children as an underperforming, failing group. Relevant to this thesis and as discussed in earlier chapters, the authors point out that Black Caribbean children are regularly overrepresented in SEN programmes and schools, not only because of academic underachievement but as well as having behavioural and emotional needs, mirroring Coard’s argument.

The authors recognise that much of Coard’s concerns and findings regarding Black Caribbean and ethnic minority children in education from over 50 years ago are still relevant in the present day because English education is systemically rooted in racist, outdated policy that remains unequitable. It is imperative that the work of Coard, Wallace and Joseph-Salisbury and others continues to challenge the narratives that disadvantages Black children and young people’s outcomes across all education settings, which includes special schools in England, whether through their performance, exclusion practices, overrepresentation of SEND and more. Equally, as identified by Coard and the experiences of racism described by parents in this thesis, there is a critical need for parents/ caregivers of Black British children and young people with autism to be fully involved and knowledgeable about all aspects of their education. In the final chapter, I provide several recommendations, such as policy reform to ignite change in special education schools to disrupt these narratives.

In 2024, it is almost impossible to avoid conversations and discussions about race. Across diverse educational settings from specialist to mainstream, race-related discourses are imperative and have remained persistent over time in unpacking national and global

educational inequality (Crozier, 2009; Tomlinson, 2014; Bhopal, 2016; Tatum, 2021; Lewis and Arday, 2023). The ways in which a few parents defined and understood racism (Blum, 2002) resulted in a reluctance or uncertainty to claim their experience as racism. One parent said, *“yes [that their child has been discriminated against], yes in general, it won’t go straight as racist, but you feel, you feel they are being left out you feel it is different, the treatment you get is different. So, everything is a yes, definitely, I could say either way, you just feel it”*. Someone else explained, *“I know it is hard to say but immediately when something don’t feel right, I just immediately think both like he’s Black and he’s got autism”* [sic].

One child was supposed to get one to one support in school that was funded by their local authority, and the school kept missing deadlines, which delayed the child being able to go to school. Her mom shared that she was told *“this is discrimination against [name of child] because of her race, her ethnicity”* [sic]. She went on to say, *“I can’t tell for sure that this was the main kind of motive for that, but it took them so long and it made me think if that was a White, wealthy person it wouldn’t have happened to them, but because [name of child] she’s different, maybe that happened to them”*. For one mother connecting her son’s hair to cultural and religious beliefs led to feelings of discrimination, she described:

*one specific incident that has always stayed with me was the teacher asking me if I was going to do something with my son’s hair. We started him on a loc [dreadlocks] journey, and the teacher said people were commenting that his hair was unkempt and dirty. I was livid, and I thought they had no cultural training or awareness. I told them would they say that to a White child, and they didn’t answer, that was an answer in itself.*

Experiencing discrimination is one thing and having to cope or deal with it is another. When asked how they have dealt with the discrimination or racism, there were mixed results. Many participants challenged the school, person, or service where the incident took place. When it came to help or support, the participants admitted that they either had little to no support, apart from that of trusted close family and friends, which influenced how differently people coped with things. All the fathers conceded that they *“just deal with it”* or *“compartmentalise it, you put it in a box... and you try and keep on”*, although they

agreed that this was not a long-term option. A few mothers also agreed, *“we’ve just run out of steam”*, or *“I push it deep down inside. I have to just get on with it, what other choice do I have, who is gonna help me”*.

The National Autistic Society (no- date f) provides detailed advice on dealing with disability discrimination in English schools from defining different types of discrimination to tackling it head on with the school or seeking legal action or guidance from another agency. Most mothers applied this advice to their situations and expressed the will to fight for their child. One mom said, *“I feel like for most of my son’s life, I’ve been fighting to keep him alive”*. Another one exclaimed, *“I’m tired. So, like I said before, I pick my battles”, “I cry, I cry a lot, after I challenge it... I don’t know if I really cope but I will write letters, send emails, and take it to the highest channel for not only for my son but also for others!”*. She continued how she was feeling by sharing that, *“he is a young man now, and I know as an adult there is limited support, the world showed us how they see Black men, just look at George Floyd’s murder in America, but we see it here in England also, Black men and people with disabilities are treated unjustly all the time*. The commonalities continued with yet another mother telling me that *“I had no one to speak to, I would go home and cry, after I cried, I became stronger and I’m like you’re not going to get away with this”*. This mother asserted that, *“I may not be as outspoken as I used to be, but I speak up, there are parents I know are scared to because they don’t want to be accused of playing a race card but if there is discrimination or racism, they shouldn’t be afraid to call it out”*. Finally, one more mother held a similar view as she declared *“for me and my son, we’re like a team. I know what the rules are, I know what my rights are, and I’m not embarrassed standing up for myself or my son”*.

Fighting for their child or standing up for their young person, no matter how they said it, the parents were ready and willing to push back against racism, discrimination and ableism at all costs. Drame *et al.*, (2020) sensitively tackled some tough accounts of parents dealing with racism and advocating for their child and more through the lens of Black parents raising children with autism in the US. Their lived experiences, through each high and low, provides the knowledge that ‘outsiders’ can find beneficial in knowing what autism is like at the intersection of race and ability from the ‘inside’. There is more research of similar stories among families with autism, including Perepa, Wallace and Guldberg’s (2023) study

in England, where parents shared experiences of racism and bias in the education system and Udonsi's (2022) research article features a second-generation young Black African neurodivergent male in the UK who has suffered considerable hardship along with his family through bias, discrimination and the failings of appropriate care, support and assessments from the health and social care system in place to help them because they failed to acknowledge the intersections of race, intellectual disability and neurodivergence.

It was through this theme and many of the above comments that I found a sense of sisterhood and even more solidarity with the mothers in this study, as their resilience and strength in fighting for their child/ young person against racism, discrimination and ableism felt like looking at myself through their stories, which kept us connected (Reyes, 2020). Chapter two was an introduction of sorts to parts of my journey as a mother to a young Black male with autism, which is a central facet to this research study. The pivotal role of Black motherhood has been chartered across literature through an array of lived experiences that conceptualise motherhood and mothering as influential and indispensable. The stories told by the mothers in this study encompassed many other roles such as, *teacher/ educator* (Bush, 2004; Turner, 2020), *protector* (Collins, 1990; Elliott, Powell and Brenton, 2015), *advocate* (Ocasio-Stoutenburg, 2021; Morris and Matute-Chavarria, 2022) and *activist* (Kakli, 2011; Roebuck Sakho, 2017) to name but a few alongside their everyday job of provider, supporter, and comforter. Yet, they are also mothering at the intersections of race, ethnicity, ability and more, which I contend, and as we have seen across this thesis, adds multiple dimensions to the role. The crossroads of these identities are regularly constructed and reconstructed by influence of different factors that include knowledge and supremacy.

Every tear that I cried, the lack of sleep worrying about my son's future, the frustration at schools weaponizing his race, yet simultaneously ignoring it when it suited them, along with his ethnicity and cultural background started to make sense because these women had cried those tears too. When I wrote about 'mothering autism... while Black' in chapter two, I was writing as a mother who was taught that being strong was the only option, as my mother had taught me (Abrams, *et al.*, 2014; Oshin and Milan, 2019). So, armed with this socialisation from an early age, I became centred in my role as a mother raising a Black man

with autism, recognising that it would take all my might to protect him, especially as he became older. I felt much the same forces of strength alongside the will to overcome any obstacles from the mothers in this study. As McHale *et al.*, (2006) posit mothers significantly influence cultural socialization in older children/ young people, which affects the ways in which their identities develop.

The ramifications of some of the above mentioned discriminatory, racist and ableist incidents and other situations have left parents feeling traumatised, scared, unsure, and worried for their child/ young person's future, especially parents of older children/ young people. *"That's really heightened my concern [a safeguarding issue], I think also the fact that he's Black, he's got special needs and he's essentially non-verbal...it makes me worry for his future because I can't be around forever, and I can't protect him forever"* worried Viola. As her young adult son ages, Chevelle is preoccupied with his future declaring, *"as he gets older, so do I. I worry that he is seen as a Black person, that creates its own challenges and then with his autism, it's even more limiting. If society is not accepting or acknowledging of the nuances of his race and ethnicity or even cultural upbringing and differences, then that causes me to worry."* As he pondered, about when and how to explain racism and discrimination to his teenage son, Sterling conceded, *"what we haven't been able to crack is how to explain to [child's name] that this happens in the world that basically, you have two for the price of one, because you're Black and then you've got autism as well. So, this is going to be very difficult to explain to him"*.

Noticeably, these concerns all came from parents to teenage or young adult Black males. Their views link back to some of the literature in chapters two and three that recognise the multiplex relationship between race and the male gender that manifests in discrimination, academic inferiority, and hyper-masculinity in this group for example (Archer and Yamashita, 2003; Davis, 2001; Williams *et al.*, 2017) and any impact that such issues can have on identity. However, the additional identity of ability through autism significantly increased a few parents' fears of when to have discussions with their young person about race (Hughes and Chen, 1997) or the intersection of race and disability in their lives (The Alliance for Inclusive Education, 2024). I state once again that more research is needed into the impact of racism, ableism and gender in young people with autism in special schools

and beyond. For most of the parents in this study with younger children, but largely those with boys, these worries may not have taken up space enough in their minds to share yet, as they contend with simply raising a Black child with autism, but as their boys become young men, being fearful for them all the time, can become a constant thought in their mind. Palumbo (2020), Stringfellow (2023) and Polk (2024), are just a few of the Black mothers sharing some their insight into how they are teaching their young Black sons (and daughters) with autism about interacting with the police, racism or the constant fear and worries they have around their teenager/ young person's safety as a Black individual on the spectrum. Like some of the parents in this study they are having to navigate discussions about race and indeed racism deliberately (Priest *et al.*, 2016), especially as their dependent grows in both age and height.

I felt like I was reliving my son's experiences with racism, discrimination, and ableism through the stories that the brave parents shared. It did not get any easier but instead caused me to reflect once again on not only how the incidents made me feel but ponder what damage they have done to my son. As a parent, your primary instinct is to protect your child/ young person. Their autism makes them vulnerable, their race and ethnicity alongside their autism makes them extremely vulnerable. Some of the stories made me cry in the safety of my home, away from the participants, and while this study is not short of emotion, I accept these feelings as an advantage to learn from because my role as a mother, is the most important role of all. Upon reflection some of the stories shared provided me with a different outlook in some cases that was less linear, positioned in my own experience but that of the wider structural context in which things happen, which I was able to rationalise as a researcher, and SEND professional but not always as a mother. And to the mothers especially, I am grateful for this insight. Racism, discrimination and ableism do not get any easier to deal with and depending on the child/ young person's cognitive abilities, parents are constantly in protect mode, yet with little protection for themselves and their own wellbeing and mental health.

### **Racism in special schools | School Personnel**

*You know there's racism deliberately going on, it's so blatant. I have told people, about*



*you know, take it further but they don't want to rock the boat, they haven't got the confidence or feel supported you know [sic].*

(Cassandra, Teaching Assistant, Black Caribbean)

Once again, all participants in this group, except for one, confirmed that they were either a victim of racism, racial discrimination, or a witness to it. The incidents ranged from microaggressions to overt racism. Participants from a minority ethnic background describe experiences that took place at school (their place of work), during childhood/ schooling, or at another stage in their life. I will focus mainly on the incidents in special schools. As previously mentioned, some of these accounts may be upsetting.

Senior leaders from BAME backgrounds have been the subject of increasing research into leadership disparities including racism, underrepresentation and unequal treatment and discrimination (Arday, 2019; Elonga Mboyo, 2019; Miller, 2020). As a senior leader this participant was not exempt from dealing with racist comments and remarks at a school that she previously worked at. She shared a small snippet of some of the instances, and there were many, in her own words, she recalled that, *"there were derogatory comments made about the children coming into school smelling of curry and how I needed to do something about that, because it was my community and comments being made that my face doesn't fit, I don't belong in the school, and that I needed to leave"*. Such comments and treatment happened regularly and took their toll on her, as she continued, *"when you're being racially abused, you go into defence mode, fight, or flight. And when you can't do that and you can't stand up for yourself and you can't say how you really feel out of fear, fear of maybe losing your job, or where you're gonna go next, you become depressed"*.

Accounts of racism and discrimination were shared among other staff members, also. A teaching assistant recalled an incident at her school where *"a teacher and another member of staff fabricated something about me. It made me feel annoyed, angry and from the investigation, you could clearly see it was racism and victimisation, but it was allowed to go on because they believed an English [person from England] teacher over me"*. Another TA explained that flippant comments were being made about Black History Month celebrations at her school that left her troubled. She explained, *"to me, it was hurtful and*

*obviously I had to speak to my colleagues about it because it wasn't nice to hear. Whether or not it was meant in a malicious way or whatever way, there's ways of saying things".* One of the teachers exposed disparaging comments that were made in her presence about people from a certain country who *"just come to the country and take all our money"*. She goes on to explain that *"I was just getting my foot in the door, and I didn't say anything, I sat there and thought why would you say that you don't know the situation"*. Both external professionals who work in and closely with children/ young people with autism, and in special school settings, also shared their experiences with racism. The first person discussed experiencing micro-aggressive behaviour from a White colleague when talking about the *"mixed-race"* hair of a family member. She said, *"I think it's those microaggressions that people experience... they obviously then don't appear to even realise that it's something that is wrong or rude they don't have that awareness of it being an issue"*. She described it as *"it's like the small things, like the facial expressions... tone of voice"*.

I was not shocked at the stories of racism and micro-aggressions in special schools shared by BAME staff because some were similar to that of my own encounters and discussed in earlier chapters of this thesis as being experienced predominately in mainstream and higher education (Pole, 1999; Brown, 2019; Mahony and Weiner, 2020; Bradbury, Tereschenko, and Mills, 2023). In addition, I know that these experiences could replay in their minds over and over again and that certain words or people could trigger painful memories. Studies have discussed the impact of such racism on BAME staff across different strands of education, which include staff leaving the profession, or as was just mentioned in the excerpt from an Indian senior leader, they experienced struggles with their mental health (Tereschenko, Mills and Bradbury, 2020; Arday, 2022b; Rice, 2024). It saddens me as a SEND professional to witness and call out microaggressions on a regular basis against Black children and young people with autism and staff in English special schools. And while I feel confident in calling it out, what about those that are not so confident as well as the vulnerable children and young people that we are there to nurture and support, who may also be experiencing racism, ableism, and discrimination in their educational setting? What damage could these encounters that they might be experiencing or witnessing do to them?

For one of the participants, racism does not have a time-limit with which you forget what happened. Although of the instances of racism shared by this participant, none were in a special school setting, she shared a personal story of her Black daughter experiencing racism for the first time in her mainstream setting and her fears for the long-term implications on her child (Berry, Londoño and Njoroje, 2021). Her words aptly summarise much of what most of the other participants divulged when speaking about the effects of racism on them, many of the incidents were not fully resolved, or given a suitable outcome. Sharing her final thoughts of racism, she disappointedly shared that:

*my concern is the lasting impact that it could have on her [participant's daughter]...but my daughter has to live with it, because, I as a big adult, remember my first time that I was told I couldn't do something or somebody didn't want to be my friend because of the colour of my skin...so the fact we've moved on 30 odd years and this is still happening, we're [the family] heartbroken.*

Most participants from a non-BAME background explained that they had been witness to some sort of racism, in both their personal and professional school lives (Berlak, 1999; Kailin, 1999), which a few of them shared from their special school. One participant spoke of a friend who was offended by a post that targeted their religion on social media that many of their work colleagues saw. They described witnessing that incident and all that ensued thereafter as *"awful and hurtful"*, adding *"I don't have the same experience as someone with that religion and that identity, but still reading it, it was shocking and hurtful to read it"*. Scholars argue that Whiteness can prevent White teachers from acknowledging or recognising racism in education (Smith and Lander, 2022; Crozier, 2023). A teacher explains that she has felt uncomfortable at school when colleagues are not speaking English, and how she construes this behaviour as racist, stating *"to flip it back to me being White British, I think particularly like say people I've been in a room where people are just speaking in their own language, which I don't understand"*. She explains further *"I feel uncomfortable speaking up about it because it's like if you say something you don't want to be seen as racist"*. Another witness account took place when a group of staff were planning events for Black History Month where this participant shared, *"a few comments left me feeling super uncomfortable and when they were said, I would just outright say to*

*them, you can't say that, that right there is racist, this is why people get offended".*

Not everyone felt comfortable enough to challenge racism when they have witnessed it, as openly admitted by another White participant, *"I think it's the lower-level things that actually has made me feel, um so it always makes you feel uncomfortable, you know those kind of lower-level statements that you maybe have ignored, I feel embarrassed to say, like hearing 'those people', 'this is the way they go'".* She concludes by stating *"it's really difficult isn't it, I continually think I should have done more or did I do enough there, and it's not right"*. Finally, when asked about whether their institution had a policy on racism and how to report any complaints, a few participants were unsure and unaware of any such policy but stated that they would *"raise complaints with senior leaders and management"*, while the rest were clear on their school's policy regarding racism or discrimination.

### **General findings: Identity and Institution**

There were no notable differences related to gender among the British children/ young people with autism that took part in this study, although as already mentioned, the participant sample was predominately male. Both groups performed the same on the interview task across their different functioning levels of autism. The same can be said of the parental group, despite being made up of both Black Caribbean and African parents there were no major dissimilarities in how their experiences shaped their own identities and that of their child/ young person through their understandings of this study's themes.

Fathers were just as involved as the mothers were and active in their caring responsibilities. They were all passionate and prideful of their race and deeply connected to their ethnic and cultural roots in their own unique ways, which they were determined to share with their child/ young person regardless of their different abilities. However, the role of the mother was especially amplified earlier for their resilience and strength when dealing with issues of racism, discrimination and ableism.

The results brought to life mostly similarities between the groups with such minute differences between them. The differences that were noted related to the gender and age of the participant's child/ young person and was the same between Black Caribbean and Black African families. Parents of older male teenagers and young adults spoke more about

their fears as their child gets older, which they contemplated with how society views Black males. As some of the parents explained they were not only worried for their young person because of their race and gender but also because of their autism and different abilities. The school personnel group is where there were notable differences of views and experiences explained in the summary below.

## **Chapter Summary**

Findings in this chapter centred around the institution and whether school as an agent of socialisation act upon this authority to incorporate race, ethnicity and culture into this space. The main findings suggest a lack of diversity in the curriculum, teaching staff and race-related, and cultural events. The work of racial-ethnic socialisation that took place within the home in the previous chapter was not mirrored within the schools although a few staff members took it upon themselves to find creative ways to incorporate children's racial, ethnic, and cultural identities into their teaching and learning. Racism, discrimination, and ableism was a major talking point with parents and school personnel sharing their stories of how they have been subjected to racist abuse and microaggressions.

It was among the school personnel participants, however, that there were the most visible differences, which have been highlighted in their respective themes. They were primarily between BAME and non-BAME participants experiences of working in a special school and how they were influenced by the study's themes of race, ethnicity, culture and identity among minority ethnic children and young people with autism or other SEND. While more investigation is desperately needed, the inner workings of special education in England must no longer be overlooked or ignored in educational policy, pedagogy, and practice, as will be summarised in the concluding chapter. As I did previously with the first set of results, I included some brief reflections among the discussion that connect to my experiences as a mother to a Black son with autism and SEND professional. By researching others, I have uncovered a deeper sense of self through reflection and the interconnectedness of our stories due to the intersectionality of race, ethnicity, culture, identity and autism, which has provided me with an opportunity to learn from the insight of others. Chapter seven is next and concludes this thesis.

## **Chapter Seven: Conclusion**

### **Introduction**

The intersections of race, ethnicity, culture and identity among Black British children and young people (from Caribbean and African backgrounds) with autism that attend special schools in England is underexplored. This research study was developed to investigate the relationship between these distinct themes in two parts. First, through my positionalities as the mother of a young Black man with autism and my desire to proactively help him understand his racial, ethnic, and cultural identities, as well as my lived experiences as a SEND educator in English special schools. I chose to utilise an auto/biographical approach within this thesis to allow me to reflexively engage with my own experiences through the next part of the study, an in-depth exploration into race, ethnicity and culture in special schools in England. Specifically, if and how these specialist provisions empower Black British children and young people with autism in developing their racial, ethnic and cultural identity/identities at school.

The participants in this study included children and young people with autism with diverse needs and abilities, such as non-speaking communicators, who are often missing in empirical research. The adult participant group included parents of Black African and Black Caribbean backgrounds and special school personnel. In addition, while autism and special educational needs have been the subject of numerous of studies, the educational experiences and treatment of Black-British children and young people with autism, their parents and teaching staff perspectives thereof in special schools remain scarce, particularly in the context of England. With over 1000 special school institutions in England with a large Black African and Black Caribbean population of learners with autism, a gap exists that investigates the development of their identity/ identities connected to their race, ethnicity and culture both at home and school. As primary and secondary agents of socialisation, the findings from parents and school personnel respectively suggest that Black British children and young people with autism can develop an understanding of their multiple identities, when they are exposed to it consistently, through meaningful learning that is appropriate to their needs and abilities.

It has been repeated throughout this thesis that there is a scarcity of literature that explores how children and young people with autism understand race and ethnicity, which is also the case of the perspectives of parents and school personnel that have a connection to autism through their child/ young person or as educators. Many of the studies that explore understanding in children with autism are within hard sciences disciplines like biology and psychology, leaving the sociological aspect extensively under-researched. They also feature heavy in American literature or refer to mainstream and higher education provisions. The absence of research that unpacks the phenomena of the autistic mind at the margins of race, ethnicity and identity is critical to the development of a stronger and more profound understanding of the substantial neurodiverse population in not only special schools in England but in mainstream and other education settings. Such knowledge also serves to disrupt inequality and disparity among marginalised, vulnerable groups in education and society at large, advocating for equitable change that in this case recognises Black children and young people with autism as more than their ability but active members of different groups and cultures with multiple identities.

There were three research questions critically examined against empirical literature, the theoretical foundations of Intersectionality and DisCrit, and the thematic analysis of data from three participant groups:

- *In what ways have my own lived experiences of raising a young Black British man with autism helped construct his racial, ethnic, and cultural identities?*
- *To what extent do Black British children and young people with autism 'understand' (are aware of, engage/ interact with and recognise) their racial, ethnic, and cultural identities through exposure at a) home and b) school?*
- *How do special schools in England incorporate race, ethnicity, and culture into all aspects of their pedagogy, and wider school community.*

The literature reviewed against the study's main themes revealed various information and issues that include ethnic-racial socialisation, the underrepresentation of BAME staff in education and racism, discrimination and ableism to name but a few. While much of the literature was not always relative to autism or SEND, or the intersections of race and autism for example, especially in England, it served as a foundation for this thesis with which to

both construct and seek more knowledge about the multifaceted world of special education, particularly it's learners of Black Caribbean and African heritage.

### **The Empirical Findings of this Research**

The findings from this study not only add to the growing body of literature among the individual themes of race, ethnicity, identity and autism but they also suggest new information at the intersected margins of these themes that have significant implications for Black children and young people with autism and other SEND, educated in special schools in England along with their families and the wider school community. The results were split into two main ideas as discussed in the previous two chapters: *identity* and *institution* and reconciled with much of my own auto/biographical experiences while also both challenging and enhancing some of the literature in chapters two and three.

Some of the key findings under *identity*, discussed in chapter five suggest that:

- *Black British children and young people with autism from Black Caribbean and African backgrounds can understand their racial, ethnic and cultural identity/identities.*

This assertion is coupled with the guidance that their exposure and interactions must be consistent, as well as, both accessible and suitable for their neurodivergent abilities and needs. It is also important that the information is meaningful and representative of who they are, culturally, ethnically and racially. Equally, there was no evidence to suggest that children/ young people with autism who were non-speaking could not engage with their multiple identities or were any less able than speaking participants. They simply communicated in a different way, which should be celebrated and welcomed.

- *Parents and school personnel felt that a diverse curriculum could inspire a sense of self and belonging.*

Both adult participant groups agreed that teaching and learning in special schools that acknowledged and recognised the multiple characteristics of its learners would empower a racial- ethnic identity and cultural pride in Black children/ young people with autism.

- *Parents were the main contributors to identity development of Black British*



*children and young people with autism.*

The home was the primary site of meaningful and consistent opportunities for ethnic-racial socialisation. Parents connected their children to their heritage through food, music, religion, clothing, trips 'back home' and so much more. Much of the parental socialisation was delivered with an implicit desire to share their culture and encourage racial and ethnic pride in their child/ young person, regardless of their autism.

- *Parents raised their children and adolescents shaped by their own upbringing*

Parents were motivated by their own racial, ethnic and cultural experiences, which in turn influenced the ways in which they are raising their child/ young person. Their lived experiences, both good and adverse, are constructing the foundation upon which they are building a stronghold that develops and fosters their dependents multiple identities, particularly as they relate to race and culture.

Within the *institution* chapter, the findings focused on special schools and whether their role as a space and place empowered racial, ethnic and cultural pride among Black British children/ young people with autism. The family as an institution also continued to feature in this collection of results. As most ethnic-racial socialisation was happening at home, the results shone a spotlight on the work needed in schools and education, including the:

- *Need for a more diverse curriculum in special schools.*

Both parents and school staff suggested that teaching and learning in special schools does little to incorporate race, ethnicity and culture, which they feel influenced how Black children/ young people with autism see and understand themselves and others in this space. It is imperative, however, that this diverse curricula is carefully planned and embedded into policies and pedagogy so that it is sustainable and significant, not tokenistic.

- *Underrepresentation of BAME staff, cultural events and initiatives.*

The diversity shortage was not only highlighted in relation to the curriculum but also the shortage of BAME staff, especially as teachers and senior leaders, which was not representative of the pupil population. There was also a desire for more events and initiatives that celebrate race, ethnicity and culture, such as Black History Month or

diversity groups, which as the previous finding suggests requires schools to actively include such ideas consistently and not as an add-on.

- *Most White school staff do not feel confident teaching about race.*

Only a few White staff in this study felt confident enough to tackle and teach about race in their provision, highlighting the need for training and a deeper understanding of race, Whiteness and bias in education. Even though Black teachers and teaching assistants felt confident and ready to teach and incorporate race into the pedagogy of their learners, Black and minority ethnic teachers are underrepresented in special schools and the onus must not fall on them. All children/ young people in special education can benefit from learning about race in ways that are accessible to them.

- *Black British children/ young people and their families have experienced racism, discrimination and ableism.*

This was one of the more sensitive and difficult findings of the study, with the most common form of discrimination due to race/ ethnicity and ability combined. There were examples shared of experiences at school, but also within the community or through other services/ professionals, for example doctors. The lasting impact of these issues is still being felt by parents and families who have little resources or support to help them deal with things. Similarly, Black school personnel participants also shared that they had been victims of racism in special schools, and their White colleagues witnesses to some such occurrences.

- *Parents of Black teenager, young people with autism were more explicit in their racial, ethnic socialisation.*

For a few parents the inclusion of gender and age alongside race meant that there was more intention from families in preparing their older males for encounters of racism and other challenges.

The personal stories that were shared were only a snapshot of the participants experiences involving education in special schools in England that are currently difficult to find in research studies. It is a stark warning that more investigation is urgently needed to not only better protect these groups by disrupting and tackling racism in the fight for equitable

justice but to ensure tailored and considered support is available when they need it. By understanding the lived experiences of Black children and young people with autism and their families especially, we can begin to recognise the complexity of the relationship between autism, race, and ethnicity in its own neurodiverse right, without the need to always compare or contrast against a neurotypical lens. The findings were also considered further through my own experiences from chapter two, which I weaved into the discussions. Each story shared by the participant, as well as the interactions of the children/ young people allowed me to reflect on my role as a mother, SEND professional and researcher in a subjective way, that has in turn helped me construct my own meaning and knowledge of my experiences more profoundly through those of the participants.

Finally, and of utmost importance, findings from this study demonstrate that conducting research with children and young people across the broad spectrum of autism is indeed not only possible but also invaluable and rewarding. Despite the different communication styles, ability levels and needs of the children/ young people with autism, when studies are carried out within ethical guidelines and respectfully catered to meet the appropriate levels of each participant, they are able to contribute indispensable knowledge and information first-hand.

### **Study Limitations**

Despite the significant findings from this study, there are a few limitations. The study primarily focuses on the African or Caribbean parental/ ancestral backgrounds that have influenced the children/ young person rather than a British identity. The next limitation relates to gender disproportions among the child/ young person and parent participant groups, which if were balanced would allow for better comparison between groups. Another limitation is that of geographical location. All but two of the parent participants were from London and if the reach were spread out across the country it would have provided more insight into any striking similarities and differences between rural and city populations. The next limitation relates to generability. Due to the nature of individuals on the autistic spectrum, results are not representative of the wider population of Black British children and young people with autism. Finally, the study only considers the influence of home and school on racial, ethnic, and cultural identity/identities and does not include

other agents of socialisation such as the media or peers, which could provide an additional layer to identity construction in this population.

### **Researching self and others: researcher reflections**

I have been quite impassioned about my role as an ‘insider’, ‘outsider’ and ‘in-between’ in this study, which is interesting, because at the start of this PhD, I felt petrified about how I was going to write myself into this research. Conducting educational research that involves my personal life, interwoven with my professional life, in areas that I am deeply connected to, such as race, culture and autism, have required me to be vulnerable in much the same ways that the participants in this study have been. However, it has been important to me that this thesis provides a valuable and worthy contribution to educational research that amplifies the voice of vulnerable and marginalised groups such as Black children/ young people with autism and their families, and also probes special school education in England, where there lies a shortage of research.

This study proudly includes Black-British children and young people with autism with varying needs, communication styles and abilities as participants, who are considerably marginalised and excluded from all types of research. I have had to draw on existing and new skills as a researcher to ensure that I navigate and own my personal bias throughout the research process, while at the same time drawing strength from this same subjectivity as an acknowledgment that it allowed me to better connect with the participants. Without my knowledge and experience with SEND, as a parent and teacher, I would not have been able to comprehend the nuances and complexities involved with conducting research with children and young people on the autistic spectrum or be able to recognise that their neurodiversity does not mean they are not able to understand who they are, including at a racial, ethnic and cultural level. Additionally, I also recognise that I have also been afforded access to certain spaces and stories because of my positionality, in this research. Such access has been built on trust, mutual understanding, and cultural nuances, meanwhile always respecting ethical considerations to allow the participants experiences and stories to be at the heart of this study. While the personal rationale for doing this research was a significant factor to this study, the timeliness remains equally pertinent to the enduring structural racial inequalities, injustice, and inequity in the contemporary world today.

As a researcher, the results illuminated such a multi-dimensional look at race, ethnicity, culture, identity, and autism. Whether it was the pride that radiated from the children and young people when they recognised a cultural item or an image of themselves during the interview task, the accounts of racism and ableism in special schools, or when parents and school personnel spoke about how a diverse curriculum could empower Black British children/ young people with autism. Knowing that this study starts to fill a significant gap in knowledge and literature across the themes of race, ethnicity, culture, and autism is humbling. Among the parental participants especially, even though none of them met or knew each other and I was the only link between them all, there was a real sense of comradeship that is difficult to explain but something I felt as they each shared parts of their own lives raising and championing for their child/ young person with autism. With every challenge that I was able to overcome as a researcher, namely the shortage of research in some of the study's themes, especially from an English or UK context, I was reminded why this research is critical and that I consider it part of my job as a researcher to disrupt inequity and shed light on what is in the dark. It is my hope to continue further educational research that explores race, ethnicity, and autism in some of the areas that I have recommended for future study later on in this chapter.

### **Parent and school personnel recommendations**

I have chosen to concisely summarise the parents and school personnel's recommendations on developing collaborative working between parents and schools to empower racial, ethnic, and cultural pride in English special schools in this concluding chapter as much of what they shared has been covered extensively across the two findings chapters.

From diversifying the school curriculum, increasing BAME staff representation in special schools, creating parent groups, and having more cultural celebrations and events, parents are eager and willing to share their cultural richness and distinct heritage and backgrounds with schools, which suggests a desire to build strong connections and relationships between home and school. On the other hand, school staff suggested more parent involvement and engagement as a way to develop meaningful partnerships between school and home and having the parents share their racial, ethnic, and cultural knowledge and

experiences with schools. It was evident that both groups wanted to work together where possible, especially as the majority of children that attend special schools are mostly commuted to and from school by bus, so parents and school staff only have the opportunity to meet during formal meetings or if there are events at the school.

Seemingly in this study a few of the barriers to parents and schools working together were the result of poor communication between the two groups, unclear expectations, lack of opportunity for parents to be involved, and schools not understanding the nuances linking race and ethnicity to parent involvement, advocacy, and engagement. These findings correspond with literature on parent advocacy, engagement, and interaction with education and other services. Equally, while there is a shortage of studies that include the Black parent voice about special schools, notably in the UK context, those that do look at parent involvement and engagement acknowledge issues such as race and class as barriers and that parental involvement among BAME families is often plagued with judgement and assumptions that Black parents are often presumed to be disinterested or having to work against policies and structures that are not designed for them, or their children, requiring them to fight to be involved, therefore labelling parents as difficult and challenging (Crozier, 2001; Cork, 2005; Hornby and Lafaele, 2011; Love et al., 2019).

The recommendations shared by both adult participant groups indicate that they are keen to work together to empower racial, ethnic, and cultural pride in English special schools and simply need clear direction and action to facilitate making this partnership not only happen but remain sustainable also. Many of their comments and suggestions reflect my own views, which I share next.

### **Study Impact and Researcher's recommendations**

As the world continues to evolve so should our understanding of one another and the epistemological meanings and knowledge that can be derived from what we learn and experience. This study has challenged the boundaries of underexplored educational research by investigating the dynamics of race, ethnicity and culture on identity within special schools in England, as well as actively engaging the experiences of Black British children and young people with autism (across the spectrum), their parents and carers and

special school staff. In addition, this study is grounded in the auto/biographical first-hand lived experiences of a Black mother of a young son with autism, SEND professional and researcher, disrupting the dominant narratives of Eurocentric, singular stories that ignore and exclude Black voices. The impact of this study's auto/biographical experiences offers new light to educational research through my diverse positionalities as a parent, SEND professional and researcher, which I hope will serve as an incitement to more people, especially from Black groups and communities to share their stories. The more we learn about each other through the sharing of our experiences, the more we develop a deeper understanding of one another and our differences and commonalities, that is meaningful and respectful. It is also my intention that this study will impact the ways in which Black children and young people with autism, including my son, see and understand their racial, ethnic, and cultural identity/ identities through intentional work at home with parents and families in a positive manner. Finally, I hope that learners with autism will not always be considered as deficient because of their different abilities and encouraged to celebrate and interact with their distinct and multiple identities in education.

Based on the findings of this study, which includes my lived experiences, I make the following recommendations. The first recommendation relates to policy reform of pedagogy connected to race, culture and diversity in special schools, which is thin at present. Special schools must not only recognise, but also reflect the multicultural communities within their school and wider society across their curricula, resources, practices, procedures, events, and workforce. For such a change to be sustainable and genuine there will need to be a complete overhaul of existing policies that fail to recognise the nuances of race, ethnicity and culture and the institutional barriers that persistently disadvantage Black and minority groups, whether in attainment, recruitment or other areas.

The second recommendation calls for zero tolerance policies and procedures that tackle racism, discrimination and ableism in special schools, safeguarding the victim(s) and taking action against the perpetrator(s). It is further suggested that any such policy is regularly updated, with appropriate, frequent training, action plans and performance measures to monitor effectiveness and use.

Third, in conjunction with the last recommendation, all staff in special schools including senior leaders must attend regular mandatory race-related training, which should include understanding diversity, ableism, and racism in the first instance. It is likely to be more valuable if delivered by contributors with lived experience and expertise in these areas rather than an online pre-recorded session that limits interaction and discussion.

My fourth recommendation is for the active employment of Black staff at teaching and senior leadership levels. Although it has been mentioned in this study that the recruitment and retention of Black teachers is a national issue, special schools must do all that they can to ensure their recruitment practices (from application to interview) are not discriminatory. This thesis has discussed the value that Black and minority ethnic staff bring to education, such as rich cultural knowledge and experience. If special schools are struggling to diversify their workforce they should consider other measures such as internal pathways to promotion for Black staff and paid opportunities for parents and other external contributors.

Fifth recommendation calls for more collaborative working between schools and parents. As noted in the suggestions from parents and school personnel above, stronger relationships needs to be fostered between schools and families that allows parents to feel more included in their child's education, as well as an acknowledgement of their child/young person's intersectional cultural, racial and ethnic identities as empowering and equal characteristics alongside their autism.

My final recommendation is for further research into the crossroads of race, ethnicity, and dis/ability, specifically in special school education across England, as this study only scratches the surface. There is a need for more research to be conducted with children and young people across the broad spectrum of autism (including non-speaking individuals as utilised in this study) in England that will construct a knowledge base of neurodiversity that is not reliant of comparisons with neurotypical individuals as the standard. This research should include participatory research that actively involves them in all aspects of the research process also.

The above recommendations have been generalised for the broader field of special



education and will need a tailored approach in practice. However, they are achievable and will require a commitment to dismantling the foundations of inequity for meaningful change. Some changes will be quicker than others, such as changing the skin tone on resources or celebrating more cultural events. For others, such as tackling racism, it will take much more time, a honest and uncomfortable discussions and will need everyone involved in the teaching and learning of children from Black and minority ethnic backgrounds with autism and SEND calling for change, which is no easy feat.

### **Suggestions for further study**

Several gaps still exist within the intersection of autism, race, and special school provisions within the UK context, which this study has brought to the forefront. Suggestions for further study include: the perspectives of Black parents of children/ young people with autism in special schools on attainment; teacher aspirations and expectations of Black learners with autism in special schools; racism and discrimination involving children and young people with autism; racism and discrimination experienced by BAME senior leaders in special schools and investigating parental engagement and involvement among Black families in special schools.

### **Final summary**

Black British children/ young people with autism are amazing individuals with diverse identities, beyond autism. Their racial, ethnic and cultural identities intersect with their ability (and other characteristics) every day in distinct ways, and it is important to recognise how these identities collectively and individually shape not only who they understand and see themselves as but also other people and the world around them. Both parents and educators in special schools play an influential role in empowering racial, ethnic and cultural pride in the lives of these brilliant Black neurodiverse children and young people and must work together to ensure a consistent and suitable approach to teaching and learning that is cognisant of the child/ young person's ability and needs, race, ethnicity and culture to support identity formation.

Through this thesis, it has become apparent that research involving Black children/ young people with autism, parents, special schooling, learners and school staff in England is

underdeveloped, thus leaving crucial gaps in knowledge that limit our understanding of these groups and their worlds. It has been through my own experiences as a SEND professional and Black Caribbean mother raising a young Black British Caribbean son with autism that I have sought to delve deeper into his world to learn how he and other children and young people with similar identities see and understand themselves. These roles as a mother and teacher are more than positionalities, however, I consider them as additional identities that adapt and change over time according to the circumstance and environment and are what have allowed me to critically investigate the themes within these positionalities, auto/biographically.

Through my personal experiences, discussions with other Black professionals in special education, parents, and other practitioners, I recognise that the structural ties of racism are indeed prevalent in special schools, and significant research is needed to fully uncover the depth of the problem and the influence that this issue has on Black children and young people with autism, such as my son, a starting point for this research study. At the time of writing this thesis, there were no qualitative studies that explored how Black British children and young people with autism understand their intersectional racial, ethnic and cultural identities to compare or contrast the findings from my study to, which could be due to several factors, including the vulnerability of the participant group. In chapter three, I discussed a few studies that looked at how young people with autism made sense of their autistic and other identities (e.g. gender), yet there is a void that extends into the intersections of race, ethnicity and culture of Black special school pupils and students with an autism diagnosis, which this auto/biographical study begins to close.

The findings reinforced my view that parents are powerful advocates in the fight for social equity, especially for their racialised child/ young person with autism. The work of ethnic-racial socialisation that was taking place in the home was structured, consistent, necessary and meaningful as a way to foster a sense of belonging and identity. It was appropriate to the needs of the child and young person and inclusive of the diverse features of race, ethnicity and culture from music to food, clothing to language.

There was much to unpack from the experiences of racism, discrimination, and ableism,

which was one of the bigger themes from the data analysis that were shared by both adult participant groups in this theme, which probably do not even touch the surface. Many of the experiences shared by parents came at a cost. I was reminded that some parents did not always have the ability to pour back into themselves after fighting for their child/ young person's rights *or* the safe space to share how they were feeling *or* the help available to manage their mental health and wellbeing challenges from protecting their loved one. When I interviewed the parents, I was a researcher and SEND professional, but most importantly a mother. I hoped that the interviews felt less like a parent trap focused solely on collecting this information for my research and more like a release. The chance for parents to release some of the intimate experiences that connect them and their child/ young person to their heritage, gender, ethnicity, and ability in a safe space, with someone that could empathise with them at many levels.

Equally, the findings highlighted challenges and some successes within English special schools and their work teaching and supporting Black learners with autism through a more diverse lens that acknowledges the intersectionality of race, ethnicity and culture. There is much work to be done, however, as demonstrated by the findings that included the accounts of racism, discrimination, and ableism, as well as the underrepresentation of a diverse curricula, BAME teaching staff and ethnic and cultural events that could empower the multiple identities of Black children/ young people with autism in these specialist institutions. Special schools in England must be more cognisant of their curriculum, systems, practices, and policies that perpetuate injustice and leave no space for or ignore multiple identities. If English special schools fail to acknowledge race, ethnicity and culture as embedded and interlocked identities among Black British pupils with autism they risk failing this already vulnerable, marginalised group, which has both present but also long-term identity implications for their future. The findings overall illustrate first-hand the complex intersections of race, ethnicity, culture and dis/ability faced by some Black-British children/ young people with autism, parents, and school personnel, furthermore they serve as a critical reminder of why additional research, support, and more is needed.

Not everyone will understand or experience raising a Black child/ young person with autism

and having to build and maintain relationships with schools, other professionals and society in a world that still individually categorises race, ethnicity and dis/ability as negative and inferior, only to realise the collective marginalisation that exists where each of these identities intersect. However, for those committed to social justice and equity in education and society overall, unpacking the complexities of race, ethnicity, and ability and other identities should be enough of a motive to disrupt the persistent systemic racism that has long plagued these structures. I embarked on this research study as a Black mother whose identity has been proudly influenced by my Caribbean parents and reconstructed over time through education and school. In turn, it has influenced the ways that I have raised my son to empower his racial, cultural, and ethnic identities as a young Black male with autism of Caribbean heritage. It has been my intention to raise the profile and voice of Black children/young people with autism and their families through their own words. Mine and my son's stories and those of all the participants in this study have allowed for a reciprocal and honest look into the phenomena of autism but through a racial-ethnic-cultural lens that I hope will inspire more discussion, research and support but more than anything impact change.

Change that looks like stronger collaborative partnerships between schools, families and other professionals for a more inclusive environment, tailored support for families, and pupils that have access to appropriate teaching and learning that is representative of their ethnic and racial identity; and prepare them for diversity in their everyday life. Change that tackles racism in special schools, ensures teaching and support staff are equipped to teach pupils about race and challenge any personal bias overt or unconscious. Finally, change that empowers pupils to develop cultural pride, racial and ethnic identities and a deep sense of belonging through diverse and appropriate pedagogical practices that recognises they are more than a singular identity, and know exactly who they are, which for my son is a *"proud Black Caribbean young man with autism"*.

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## Appendices

### Appendix A: Study Recruitment Poster



The poster is titled "RESEARCH PARTICIPANTS NEEDED!" in large, bold, orange letters. It features several illustrations: a boy in a blue shirt and jeans on the top left, a girl in a wheelchair on the top right, a boy in a wheelchair on the middle right, and a group of four diverse children (two boys and two girls) at the bottom left. The text is set against a background of orange circles. The Brunel University London logo is in the top right corner.

**RESEARCH PARTICIPANTS  
NEEDED!**

Do you work in a **British Special school**? Are you the **parent** of a **Black British** child/ young person with **autism**? If you answered **YES**, my research needs **YOU!**

Empowering racial, ethnic identity and cultural pride in British Special Schools

For more information and to register your interest contact: [donna-marie.holder@brunel.ac.uk](mailto:donna-marie.holder@brunel.ac.uk)

## Appendix B: Ethical approval letter



College of Business, Arts and Social Sciences Research Ethics Committee  
Brunel University London  
Kingston Lane  
Uxbridge  
UB8 3PH  
United Kingdom  
[www.brunel.ac.uk](http://www.brunel.ac.uk)

11 April 2022

### LETTER OF CONDITIONAL APPROVAL

APPROVAL HAS BEEN GRANTED FOR THIS STUDY TO BE CARRIED OUT BETWEEN 11/04/2022 AND 31/12/2023

Applicant (s): Ms Donna-Marie Holder

Project Title: Who am I? Empowering racial and ethnic identity and cultural pride in British Special Schools

Reference: 36314-MHR-Mar/2022- 38925-1

Dear Ms Donna-Marie Holder

The Research Ethics Committee has considered the above application recently submitted by you.

The Chair, acting under delegated authority has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- **Section D – Where you have mentioned parent/ carer/ teacher in different places, it suggests that any or one of these people would be able to grant consent to the child's participation. Consent of the parent/guardian of the child must be sought in all cases.**
- **D23 – Under "Who is organising and funding the research?" state that the research is being organised by yourself (state your name) in conjunction with Brunel University London.**
- **D23 – Under "Who has reviewed this study?" Add that the study has been reviewed by your supervisor (give their name) and the College of Business, Arts and Social Sciences Research Ethics Committee.**
- **This is a very thoroughly considered and well-presented application for review. The information is presented with clarity and with a careful eye to a range of ethical issues, including the researcher's own position within the research. The reasons for working with the vulnerable groups identified are carefully explained and self-evident. The content of the research tools included does not cause any ethical concerns and demonstrates a very good awareness of the needs of participants from the different groups that will be involved. Information and consent forms are clear and cover all the necessary information. The Risk Analysis is detailed and well-considered.**
- **You are not required to resubmit your BREO form after making the changes/addressing the points listed above.**
- **The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee by way of an application for an amendment.**
- **Please ensure that you monitor and adhere to all up-to-date local and national Government health advice for the duration of your project.**

Please note that:

- Research Participant Information Sheets and (where relevant) flyers, posters, and consent forms should include a clear statement that research ethics approval has been obtained from the relevant Research Ethics Committee.
- The Research Participant Information Sheets should include a clear statement that queries should be directed, in the first instance, to the Supervisor (where relevant), or the researcher. Complaints, on the other hand, should be directed, in the first instance, to the Chair of the relevant Research Ethics Committee.
- Approval to proceed with the study is granted subject to receipt by the Committee of satisfactory responses to any conditions that may appear above, in addition to any subsequent changes to the protocol.
- The Research Ethics Committee reserves the right to sample and review documentation, including raw data, relevant to the study.
- If your project has been approved to run for a duration longer than 12 months, you will be required to submit an annual progress report to the Research Ethics Committee. You will be contacted about submission of this report before it becomes due.
- You may not undertake any research activity if you are not a registered student of Brunel University or if you cease to become registered, including abeyance or temporary withdrawal. As a deregistered student you would not be insured to undertake research activity. Research activity includes the recruitment of participants, undertaking consent procedures and collection of data. Breach of this requirement constitutes research misconduct and is a disciplinary offence.



Professor David Gallear

Chair of the College of Business, Arts and Social Sciences Research Ethics Committee

Brunel University London

## Appendix C: Participant Information Sheet (adults and child/young person)



### PARTICIPANT INFORMATION SHEET -ADULTS

Brunel University London Research Ethics Committee Approval Ref: 36314-MHR-MAR/2022-38925-1

#### Study title:

How do British special needs schools empower racial and ethnic identity and develop cultural pride in Black British children/ young people with autism: An auto/biographical exploration and reflection from a Black mother and her son.

#### Invitation Paragraph:

I am a second year Doctoral Researcher in Education at Brunel University London in the process of working on my thesis. Thank you for your willingness to help me with my research. The purpose of this information sheet is to clearly outline my research and what participation involves. This is so that you fully understand what I am asking you to do.

#### What is the purpose of the study?

I am conducting research that aims to explore themes of race, identity, and autism, specifically, how British special schools empower racial and ethnic identity and develop cultural pride in Black British children with autism. I am also interested in the pupils perceived understanding and exposure to race, ethnicity, identity and culture within school and home communities, as well as how race is taught in special schools.

The relationship between race, ethnicity, identity, and British Special Educational Needs (SEN) is a significantly under-researched area. This includes exploring if and how, race links with strategies and teaching and learning to shape the identity of minority ethnic pupils in British special school environments. Additionally, there are a lack of studies investigating the implications of institutional racism in British special schools, which is important to the general discussion of disability and education, due to the potential impact on the pupils and their families, schools, policy, and wider society.

#### Why have I (and/or your child/ young person/ pupil) been invited to participate?

You have been invited to participate as you are either:

- parent to a Black British pupil/student that has a diagnosis of autism
- work in a British special school as a teacher, teaching assistant, senior leader or other professional involved in supporting children with SEN.
- Black British child/ young person has a diagnosis of autism

#### Do I have to take part?

Participation in this project is entirely voluntary, and the decision to take part is yours. There is no obligation for you to participate and you can withdraw from the research at any time.

#### What will happen to me if I take part?

Your participation will involve taking part in an online semi-structured interview, answering a series of questions related to the research question and themes above. The interviews will be conducted on a 1:1 basis with myself, as the researcher. I will be asking approximately 15 questions, and this will take approximately 45 minutes to complete, although this may be longer depending on your responses. You have the right to withdraw at any stage of the research process without giving a reason. If you choose to do so I will

further confirm whether you want me to include any data collected up to that point in my research. If you do not wish for me to use your data, it will not be included.

**If your child/ young person/ pupil is taking part:**

Their participation will involve me conducting a brief in-person, semi-structured interview with no more than 5 short questions that will take no more than 10 minutes. These interviews will be tailored to accommodate the cognitive ability and needs of the pupil. I understand the communicative challenges that are present in pupils with autism, however, this research will not require pupils to be verbal. I would like to provide the opportunity to non-verbal pupils who may communicate with Picture Exchange Communication Systems (PECS), objects of reference, or any other specialist communication aid.

**Are there any lifestyle restrictions?**

There are no lifestyle restrictions involved in taking part in this study.

**What are the possible disadvantages and risks of taking part?**

The only perceived disadvantage of taking part is that you will be giving up your valuable time, for which I am most grateful. There are little to no risks to taking part. However, as this research deals with discussions of race and autism, it is understood that these may be sensitive issues for some, and you are reminded that you have the right to withdraw at any time.

**What are the possible benefits of taking part?**

The benefits of taking part in this study is that you will be making a valuable contribution to educational research involving race, ethnicity, identity, and autism. You will also be involved in research that will be amplifying the voices of marginalised, vulnerable groups, who are underrepresented in research that explores the above themes.

**What if something goes wrong?**

I have worked as a special needs educator for more than 10 years and understand that there are complexities involved in working with children/ young people with autism. Brunel University London has strict ethical procedures on conducting ethical research with teachers and students, particularly those who are considered vulnerable, consistent with current British Educational Research Association (BERA) guidelines. Before beginning the research, I will seek your informed consent. Parental consent will be sought for all children/ young people taking part. As the pupils are active participants in this research, I will be seeking their assent, due to their vulnerability to take part. All participants are reminded that they can refuse to take part at any time.

It is very unlikely that anything will go wrong, however, if there are any issues at any stage of the interview process, the interview will immediately be terminated. You will find details of my supervisors below, as well as the Chair of the Research Ethics Committee should you have cause to complain.

**Will my taking part in this study be kept confidential?**

I will ensure that any personal details that can be identifiable, such as your name, position or school will remain anonymous. Pseudonyms will be assumed instead in the data presentation. This also includes the voice recordings from the interviews and notes, which will be stored on Brunel University London's networked drives. All data will also be stored



in this safe and secure location for up to 10 years. This is in line with Brunel's policies and procedures.

**Will I be recorded, and how will the recording be used?**

The adult interviews will be digitally voice recorded only to ensure I accurately capture your response. I will also be making brief notes during the interview.

Pupil interviews will be video recorded to ensure that I accurately capture their responses for transcription. The video recording will focus on the myself and the responses of the pupil, without capturing their face, however, any incidental images of the pupils will not be seen by anyone else or used for research without further explicit permission. A member of school staff or parent, familiar with the pupil will be required to be present during the interview.

**What will happen to the results of the research study?**

I will use the analysed data from the research to present findings for my thesis. The data will only be utilised in this study.

**Who is organising and funding the research?**

The research is being organised by myself (Donna-Marie Holder) in conjunction with Brunel University London.

**What are the indemnity arrangements?**

Brunel University London provides appropriate insurance cover for research that has received ethical approval.

**Who has reviewed the study?**

This study has been reviewed by my supervisors Dr Nic Crowe and Dr Ellen McHugh and the College of Business, Arts and Social Sciences Research Ethics Committee to ensure that it complies with the University's strict guidelines. This is to safeguard all involved parties and ensure that research is planned and conducted ethically. The committee has approved the study.

**Research Integrity**

Brunel University London is committed to compliance with the Universities UK [Research Integrity Concordat](#). You are entitled to expect the highest level of integrity from the researchers during the course of this research.

**Contact for further information and complaints**

**Researcher name and details:**

Donna-Marie Holder [donna-marie.holder@brunel.ac.uk](mailto:donna-marie.holder@brunel.ac.uk)

**Supervisors name and details:**

Dr Nic Crowe [nic.crowe@brunel.ac.uk](mailto:nic.crowe@brunel.ac.uk)

Dr Ellen McHugh [ellen.mchugh@brunel.ac.uk](mailto:ellen.mchugh@brunel.ac.uk)

**For complaints, Chair of the Research Ethics Committee:** Please contact the Chair of the College of Business, Arts and Social Sciences Research Ethics Committee ([cbass-ethics@brunel.ac.uk](mailto:cbass-ethics@brunel.ac.uk)).

## Appendix D: Recruitment email



College of Business,  
Arts and Social Sciences

Brunel University London  
Kingston Lane  
Uxbridge  
UB8 3PH  
United Kingdom

E [donna-marie.holder@brunel.ac.uk](mailto:donna-marie.holder@brunel.ac.uk)

[www.brunel.ac.uk](http://www.brunel.ac.uk)



10<sup>th</sup> May 2022

Dear [REDACTED],

### Re: Research exploring 'race', identity, and autism

My name is Donna-Marie Holder, and I am a second year Doctoral Researcher in Education at Brunel University London. I am contacting you to find out if any members of your school community (yourself, staff, parents, and pupils) would be interested in taking part in my research study looking at how Black British pupils with autism are empowered and exposed to their racial, ethnic identity and culture in British special schools.

I am looking to conduct interviews with Black British pupils who have a diagnosis of autism and school personnel, particularly senior leaders, who have an active role in the provision of teaching and learning and decision making of children with Special Educational Needs (SEN). Participation will involve a 1:1 interview with me. A full participant information sheet is attached explaining the project in greater detail including information on how data will be collected, used, and stored, as well as the contact information for my supervisors, Dr Nic Crowe, and Dr Ellen McHugh.

I hope that by taking part in this study you will feel that you are contributing to the important topic of race, identity, and autism. Please feel free to share this email with anyone you feel may be interested in this study.

If you are interested in taking part, **thank you!** Please contact me by return via email [donna-marie.holder@brunel.ac.uk](mailto:donna-marie.holder@brunel.ac.uk)

Sincerely

A handwritten signature in black ink, appearing to be "DMH".

**Donna-Marie Holder**  
Doctoral Researcher -Education

## Appendix E: Interview schedule Parents

### Semi-structured interview schedule: parent

1. Can you please confirm your ethnicity/ ethnic origin?

*I am now going to ask you to tell me about your experiences related to your child and themes of race, ethnicity, identity, and special education.*

2. Do you believe your child/ young person is able to understand (engage, explore, interact, recognise) their racial and ethnic identity when exposed to it an accessible way at school and home?
3. What do you understand by the term racially and ethnically diverse?
4. Is it important to you that your child/ young person's school pupil and staff population is racially and ethnically diverse? Please explain
5. Is it important that the curriculum (including resources, lessons etc.) is diverse in relation to race, ethnicity, and culture?
6. How might exposure to a diverse (racial, ethnic, and cultural) curriculum empower your child's identity?
7. Are you aware of any initiatives, events, or celebrations that your child/ young person's school run related to race and culture?
8. Do you feel that your child/ young person has ever been discriminated against because of:

a) race or ethnicity b) ability c) both

If yes, can you tell me about a specific incident that took place/ occurred? How did you find out? How did the school resolve it if you complained?

How have you dealt with these experiences?

9. In what ways do you incorporate the following into your home life with your child/ young person:
  - a) racial identity/ethnic identity
  - b) culture?
10. How can British special schools and families work in partnership to support empowering racial and ethnic identity and cultural pride in children with special educational needs?

## Appendix F: Interview schedule: school personnel

### Semi-structured interview schedule: School Personnel

1. Can you please confirm your position and how long you have worked in a special school?
2. Can you confirm your ethnicity?

*I am now going to ask you to tell me about your experiences related to themes of race, ethnicity, identity, and special education.*

3. Do you believe that a vulnerable child/ young person with autism is able to understand their racial and ethnic identity when exposed to it an accessible way at school and home?
4. How diverse is your school curriculum (specifically related to race, ethnicity, and culture? Please explain
5. Do you believe it is important that the curriculum (including resources, lessons etc.) is diverse in relation to race, ethnicity, and culture?
6. How might exposure to a diverse (racial, ethnic, and cultural) curriculum empower a child's identity?
7. Do you feel equipped and knowledgeable teaching about race, acknowledging any unconscious or conscious bias?
8. Have you had any specialist training around race and diversity? Please detail.
9. What initiatives, events, or celebrations are run at your school related to race and culture?
10. Do you feel that your school's staff and pupil population is diverse? If yes, why? If no, why?
11. How does your school tackle issues of racism? If no issues of racism, how would you school tackle/deal?
12. Have you ever been a victim of racism, racial discrimination, or a witness to it? If yes, please explain the situation and how it made you feel in your own words
13. Are you aware of your school's policy on racism and how to report any complaints?
14. In what ways do you acknowledge and understand racial, cultural and social differences that may be affecting student attainment and performance of minority ethnic children
15. How can British special schools and families work in partnership to support empowering racial and ethnic identity and cultural pride in children with special educational needs?

Appendix G: Participant Information Sheet (children/ young people)

Brunel University London Research Ethics Committee Approval Ref: 36314-MHR-MAR/2022-38925-1

Participant information form -child/ young person



who am I?

What is the study for






children  
young people  
To be heard and express my feelings

Why have I been invited?





black boy  
black girl  
autism



special school

Do I have to take part?





I have the right to say no







What will I have to do?




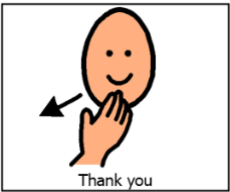


questions  
To be given time to process and respond

Who will be asking me questions?













## Appendix H: Assent form – child/ young person

Participant Consent/ Assent Form-child/ young people



*Study title: Who am I? Understanding my race, ethnicity and identity and culture*

Please **draw a circle around** how you feel about each question

- /
- A. I know about this study  
- B. I understand it is up to me to decide if I want to take part and I can stop anytime I want to.  
- C. I agree to take part in this study:  

_____ Participant's full name (PRINT)	_____ Date	_____ Signature
_____ Researcher's name (PRINT)	_____ Date	_____ Signature

## Appendix I: Interview schedule -child/ young person

### Semi-structured interview schedule – pupils

*Please note that these are the questions that will be asked of pupils with autism, but the format will vary according to their ability (e.g. use of objects, symbols, pictures). Researcher will tailor language, signing and gestural support according to the needs and ability of the child. Additional questions will require some pre- information from parents/ school.*

1. Show me [insert child/ young person's name] picture (\*child/ young person will be asked to make selection of own picture from random pictures of objects (e.g. animals and items).  
(e.g. *Where is Donna-Marie? Point to Donna-Marie*)
2. Show me [insert child/ young person's name] picture (\*child/ young person will be asked to make selection of own picture from random pictures of different races- same gender).
3. Show me [insert child/ young person's name] picture (\*child/ young person will be asked to make selection of own picture from random pictures of different races- different genders).
4. Show me the same as you (match black girl/ boy/ family to same as participant)  
4.a Show me the different one (different race/ethnicity and gender/ family)
5. Show me [cultural/ ethnic item]? Where is [name of cultural/ ethnic item]?

*Researcher to display different objects images (e.g. prayer mat, traditional clothing, food etc) on table related to child's ethnicity and cultural among those from other backgrounds to see what child, young person does.*

\*Additional questions for those with higher cognitive ability

5. Can you show me the flag of the country you/ parent(s) are from?
6. Do you know what this is (show specific cultural item, e.g. ) what is it for? **Or** why is this family same/ different to your family?



## Appendix J: Adult consent form

### CONSENT FORM- Adult



**Study title:** *How do British special needs schools empower racial and ethnic identity and develop cultural pride in Black British children with autism: An auto/biographical exploration and reflection from a Black mother and her son.*

Principal Investigator: Donna-Marie Holder

Research ethics approval has been obtained by the College of Business, Arts and Social Sciences Research Ethics Committee reference 36314-MHR-Mar/2022- 38925-1

APPROVAL HAS BEEN GRANTED FOR THIS STUDY TO BE CARRIED OUT BETWEEN  
11/04/2022 AND 31/12/2023

The participant (or their legal representative) should complete the whole of this sheet.		
	YES	NO
Have you read the Participant Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Have you had an opportunity to ask questions and discuss this study? (via email/phone for electronic surveys)	<input type="checkbox"/>	<input type="checkbox"/>
Have you received satisfactory answers to all your questions? (via email/phone for electronic surveys)	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that you will not be referred to by name in any report concerning this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you understand that:		
• You are free to withdraw from this study at any time	<input type="checkbox"/>	<input type="checkbox"/>
• You don't have to give any reason for withdrawing	<input type="checkbox"/>	<input type="checkbox"/>
• Choosing not to participate or withdrawing will not affect your rights	<input type="checkbox"/>	<input type="checkbox"/>
• You can withdraw your data any time up to <a href="#">Click here to enter a date.</a>	<input type="checkbox"/>	<input type="checkbox"/>
I agree to my interview being audio recorded	<input type="checkbox"/>	<input type="checkbox"/>
I agree to the use of non-attributable quotes when the study is written up or published	<input type="checkbox"/>	<input type="checkbox"/>
The procedures regarding confidentiality have been explained to me	<input type="checkbox"/>	<input type="checkbox"/>
I agree that my anonymised data can be stored and shared with other researchers for use in future projects.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to take part in this study.	<input type="checkbox"/>	<input type="checkbox"/>
Signature of research participant:		
Print name:	Date:	



## Appendix K: Copy of a child/ young person interview (data cleansed)

[Participant info sheet\* | Completing the consent/ assent form\* with the participant-  
DMH reading the questions out loud with the participant]

DMH: [Participant's name] will be asked some questions about [participant's name]

Miles: *I am happy today.*

DMH: Ok, are you happy to answer some questions with DM?

Miles: *Yes*

DMH: Ok, can circle if you are happy to answer some questions.

Miles: *Circle it?*

DMH: Yes, you can circle it. Thank you.

[Miles circles green happy face to indicate 'yes']

DMH: You can choose to say yes or no.

Miles: *Yes*

DMH: Ok, you can circle your happy face again.

If you want to stop, you can say [DMH pauses to allow child to respond to check understanding]

Miles: *Stop*

DMH: *Good.*

Miles: *No stop.*

DMH: OK, but you can say stop if you want DM to stop.

Miles: *Yes*

DMH: Ok, I understand. Do you want to answer the questions?

Miles: *Yes*

DMH: OK.

[DMH checks that teacher is happy to accept child's assent- teacher confirms yes].

DMH: Do you know how to write your name?

Miles: *Yes.*

DMH: OK, write your name where it says, 'your name'.  
[Spells out loud the letters or his name as he writes]

DMH: Well done. Do you know the date today?

*Miles: Today the date is...*

DMH: It's the 18th today of October

*Miles: Tuesday*

DMH: Yes, Tuesday 18<sup>th</sup> October. Well done. That's lovely writing.

*Miles: Tuesday 18th October.*

#### [INTERVIEW BEGINS]

DMH: Thank you very much [participant's name]. Are you OK for DM to ask you some questions?

*Miles: Yes*

*DMH: Thank you. OK. So, I'm going to ask you a few questions. Are you ready?*

*Miles: Yes*

[Gives Miles a subject, verb, object communication board\*\* and a picture of a Black boy]

DMH: What can you see?

*Miles: A boy* [Uses communication board to point to the symbols as he speaks]

DMH: What kind of boy?

*Miles: I see brown boy*

DMH: Ok thank you very much.

*Miles: A girl*

DMH: Where's the girl?

*[Miles points to symbol of girl on the communication board].*

DMH: Yes, girl. Well done.

[DMH puts the communication board away and puts out several images of children's faces on the table. The images are children of different ethnicities and genders, **including** the child's picture]

DMH: Look at all these pictures, lots of pictures. Where is [participant's name]?

Miles: [Selects his picture correctly and says] *It's [participant's name], [participant's name] is brown.*

DMH: Brown what?

Miles: *Skin colour is brown*

DMH: Your skin colour is brown. Thank you [participant's name].

[DMH points to a picture of a White girl]

DMH: What about this girl? What colour is her skin?

Miles: *White*

DMH: Really good. [DMH points to a Black girl next]  
What about this girl?

Miles: *Brown*

[DMH points to a picture of an Asian boy]

DMH: What about this boy?

Miles: *White*

DMH: White. Has he got white skin?

Miles: *Yes.*

[DMH puts a picture of a white boy next to the previous one of the Asian boy]

DMH: What about this boy [participant's name] look at these two boys. Which boy has white skin?

Miles: *This skin, white skin, white skin.* [He points to the White boy]

DMH: So what colour is his skin? [DMH pointing to picture of Asian boy]

Miles: *White*

DMH: Are they both white skin?

Miles: *Yes*

DMH: OK. Thank you. I might need a bit more help. Can you show me the picture of the black boy?

Miles: *That's the black boy.* [Picks up the image of the Black boy]. [Says Black peer's name] *is the black boy.*

DMH: Well done. Can you show me the picture of the Chinese girl?

Miles: *Chinese, Chinese girl* [points to image of Chinese girl correctly].

DMH: Well done. Thank you very much. Can you show me a picture of a boy who is the same as you? Who is the same as [participant's name]?

Miles: *This boy.* [Points to the image of a Black boy]

DMH: Why is this boy the same?

Miles: *He is he is big.*

DMH: He is big. OK anything else?

Miles: *Brown.*

DMH: Well done. Can you show me a picture of a boy that is different to [participant's name]? Which one's different?

Miles: *This one.* [Points to the image of the White boy]

DMH: Why is he different?

Miles: *Is different.*

DMH: Why is he different?

Miles: *Because he is white.*

DMH: And [participant's name] is?

Miles: *Brown*

DMH: Well done. Do you remember where your family is from?

Miles: *From* [REDACTED]

DMH: Where is [participant's name] from?

Miles: 

DMH: OK, three more questions. You've done some really good work. Let's move all of these pictures. Let's move them out of the way so we have some more space.

[DMH places images of different families on the table]

DMH: Look at these different families, lots of families.

[Miles starts laughing]

Miles: *Haha*

DMH: Are you laughing? Lots of different families. Which family is like [participant's name] family?

Miles: *This family.* [Points to Black family]

DMH: Why?

Miles: *It's a brown family.*

[DMH puts a picture of a Black family and White family in front of participant]

DMH: Which family is like [participant's name] out of these two?

Miles: *This one's like it* [points to Black family].

DMH puts different items down on the table – prayer mat, Quran, Bible, images of food and clothing from around the world etc.

Miles: *This is a prayer mat like mine.*

DMH: Thank you. Why do you use it?

Miles: *Because I am Muslim. I eat Sambusa* [points to image] *and plantain at home*

DMH: Thank you so much.. Can DM ask you one more question?

Miles: *Yes.*

DMH: Is [participant's name] the same or different to DM? [Puts my hand next to participant's hand].

Miles: *The same... different,*

DMH: Why are we different?

Miles: *Because DM is brown*

DMH: And [participant's name] is?

Miles: *[Participant's name] is light brown [starts laughing].*

DMH: Well done. Thank you for helping DM. Questions with DM is finished. Good job!

**[Interview finished]**

## Copy of parent interview (data cleansed)

DMH: The first question is, can you please confirm your ethnicity or your ethnic origin.

*Nia: Black British Caribbean*

DMH: Okay, The next question is, do you believe that your child or young person is able to understand (are aware of, engage/ interact with, and recognise) their racial and ethnic identity when they're exposed to it in an accessible way at school and home.

*Nia: Yes, I think my child or any child with special needs for that matter can understand who they are. Understanding can be hard to explain to be honest because my understanding of something differs from yours right, it's a personal thing but if you make things accessible according to what a child can grasp then yes, they can understand their racial and ethnic identity. I don't know if I answered that correctly?*

DMH: Yes, that is great, there is no right or wrong, correct or otherwise, I want you to feel comfortable to share what you think or feel or understand in your own terms ok?

*Nia: [laughs] Yes, thank you.*

DMH: The next question, then, is, what do you understand by the term racially and ethnically diverse?

*Nia: I think our differences due to race, ethnicity, being from different cultures and having different beliefs and so on.*

DMH: Yes, so the presence of people from variety of different cultures and backgrounds and identities, etc. Ok, thank you, the next question is, is it important to you that your child or young person's school, and that includes the pupils, and the staff population is racially and ethnically diverse.

*Nia: I believe it is important because I want my child to experience people and friends that look like him so he can feel comfortable in school and like he belongs. I think when he sees people like him, as in same race, at school that may remind him of his family and then he feels safe and a sense of belonging. He may feel more comfortable and at ease and I think from the other end, Black people can relate to other Black people, so Black teachers and staff can understand and appreciate Black pupils in a way that other staff cannot. They may be better placed to know how to manage certain situations and contribute to conversations, discussions about race, ethnicity, and culture in a meaningful way, that is powerful in a school setting, and because our children communicate in distinct ways because of their special needs, the additional layer of racial and ethnic identity is important to acknowledge.*

DMH: Thank you ok, the next question, looks at the curriculum, so is it important that the curriculum, which includes any resources that they may use any lessons, etc. is diverse in relation to race, ethnicity, and culture?

*Nia: Of course, if the school has books that have Black and brown children, children that are Muslim, or have a disability, it represents the children at the school and who they are, there*

*is something so special about seeing yourself in the environment. The more they see it, the more it becomes a normal and natural part of life and an important one. They become connected to the work and enjoy it and it starts to become something that resonates the more frequently they do it. It is no different to the more we practise something, then it becomes a habit. I am sure there is some science behind what I am saying. But yes, the curriculum and the lessons should be something that helps children connect with their identities and who they are, where they come from, who their families is, what it looks like, what they believe. They push such a British curriculum in my son's school, yet many of the children are from ethnic minority backgrounds. It shouldn't even be something we have to think about or discuss but instead something they do naturally. Even if there were no Black children at a school, or another ethnic group, schools need to expose their pupils and students to diversity through the curriculum, so they are better prepared for the wide world and more inclusive and tolerant.*

DMH: Great thank you, the next question extends on from the last one, how might exposure to a diverse and that means racial, ethnic, and cultural curriculum how might that empower your child or your young person's identity?

*Nia: I would say it would empower pride, pride in his Blackness and culture, his Caribbean roots and his British ones also. I also think it would reinforce his identities as a young man and the ideas of belonging as I said earlier too. He would see how important he is in this big world and space that may not always understand him. His identity is starting to show more now as he becomes more independent and if we teach our children in school or empower them to be proud of who they are, that Black is beautiful that there is richness in their culture from an early age, they will carry that message through life because it has been a continuous message at school reinforced through the curriculum. Many parents that I know are really proud of their heritage and they make sure their children share in their culture at home all the time, if school does it too, that child can see the value in who they are. That is important.*

DMH: Thank you, ok so the next question, then, is are you aware of any initiatives, events, or celebrations that your child or young person's school run related to race and culture?

*Nia: Unfortunately, no, they don't.*

DMH: Ok, has that always been the case do you know?

*Nia: Yes, as long as my child has been there they haven't done anything, I've been asking the teachers and staff and they always say we plan to or some other excuse but nothing.*

DMH: How does this make you feel?

*Nia: It used to make me annoyed but I do what I need to to make sure he is good with his race and culture. We make sure he goes to events, we go to exhibits, we read. It is the school's loss really.*



DMH: Thanks so much for sharing. The next question is, do you feel that your child, a young person, has ever been discriminated against because of A) their race or ethnicity, B) their ability, or C) both.

*Nia: Yes, I would say for sure both, but people are very careful to not make it so blatant, but I am not stupid and can see it for what it is.*

DMH: Do you have any examples that you would be willing to share if possible?

*Nia: I've been called to school several times for my son's behaviour, and it felt like I was being blamed for being a bad parent. The assistant head made comments about children from my culture (her words) finding it difficult to adjust to school. I felt that both my son and I were being judged and he was being unfairly treated because he was a Black boy. There have been other instances where it was discrimination and I would go as far as racism, because I have asked if they mention culture when speaking to non-black families and they don't answer. It happens more than people realise. No one thinks about stuff like this in special schools but they should more than anything, because our voices are not always heard, and our children's voices are definitely not heard. One specific incident that has always stayed with me was the teacher asking me if I was going to do something with my son's hair. We started him on a loc [dreadlocks] journey and the teacher said people were commenting that his hair was unkempt. I was livid and I thought they had no cultural training or awareness; they were not even discreet about it. So, disconnected. I told them would they say that to a white child and they didn't answer, that was an answer in itself. Needless to say, they didn't say anything to me again.*

DMH: Can I ask how that made you feel, if you're ok with sharing?

*Nia: To be honest, it made me feel like nothing has changed in the world and if there is no awareness of culture, race at a school for children with special needs, what hopes do we have. I mean I get comments when I change my hair at work, white colleagues still make smart remarks and think they are not being racist. You learn to pick your battles. I hate that this is the world my son has to experience with the challenges of having a disability as a person of colour.*

DMH: Thank you so much for sharing something so personal, can I ask how do you deal with these experiences?

*Nia: I just do the best I can to shelter and protect my son from any harm. It can hurt me but not him. I push it deep down inside. I just have to get on with it. What other choice do I have? Who is gonna help me? I've complained in the past and no action has been taken or I've gotten empty apologies but nothing changes. I'm tired. So, like I said before, I pick my battles. The people at the top are white and they don't care because when I have complained in the past nothing happens, just promises that are not kept. They need a more diverse senior leadership team and teachers who are actively promoting, discussing, sharing culture and ethnicity within the school, it will help them connect better with families and the children. I may not be as outspoken as I used to be but I so speak up, there are parents I know who are scared to because they don't want to be accused of playing a race card but if*

*it there is discrimination or racism they shouldn't be afraid to call it out but they are because the people at the top do not care and that is wrong.*

DMH: Thank you again for sharing. I appreciate that some of the experiences you have shared are sensitive and upsetting.

*Nia: Thank you. It is actually helpful to talk about it, who else but someone who has an autistic child you can get it, you understand. That helps me.*

DMH: Thank you, thank you that. Ok, the next question is, in what ways do you incorporate the following into your home life with your child or young person. So, your racial identity, your ethnic identity, and your culture?

*Nia: It's in every part of our life from the food we eat, the music we listen to, friends, lifestyle, we go to community events. I have tried to raise my son the way I've been raised, and my family used to immerse us in West Indian culture all the time, we always had it around us and I think that is why I always proclaim I'm a proud [slang name of people from Caribbean island. My son loves dancing to our music and when I talk in patois it makes him laugh. We don't have a national dress from my island, but we have national dishes, flowers and I am always sharing that with him.*

DMH: Thank you. We are down to the last question how can English special schools and families work in partnership to support empowering racial and ethnic identity and cultural pride in children that have special needs.

*Nia: Have cultural events regularly, not just once in a blue moon. Have parents come in and talk about our culture and stories, let us share our heritage with the school. They should find out more about us and our backgrounds and we can help them include this in the curriculum, I sometimes think schools think our children don't have an identity outside of their disability and they won't understand anything about race or culture so they don't care about it but they should. My child is more than an autism diagnosis and I always tell him he is a brilliant and kind, Black boy. The school needs to do more and it starts with including us more.*

DMH: Thank you so much again for taking part. I will end the recording here.

## Copy of school personnel interview (data cleansed)

DMH: So, the first question is, can you confirm your position and how long you've worked in a Special school. Now bearing in mind, I know that you work overseas, but we will be thinking about your position when you were working at special school in the UK.

Andrea: Okay, so I worked in an SEN school as a Class Teacher and the PSHE lead and a Well-Being lead for nine years.

DMH: Okay, and can you confirm your ethnicity.

Andrea: I am White British.

DMH: Great, I'm now going to ask you to tell me about your experiences related to themes of race, ethnicity, identity, and special education. So, the first question is, do you believe that a vulnerable child or young person with autism is able to understand (aware of, engage/ interact with, recognise) their racial and ethnic identity when they're exposed to it in an accessible way at school and home.

Andrea: Absolutely, absolutely, and I know first-hand from doing lessons and projects and teachings with children that they do, they do know, who they're who they are, they know their race, they know their identity, they know their culture, they know their religion. But, I feel, like many places opt out of doing it because it's not easy or they don't know how.

DMH: Right.

Andrea: A lack of knowledge, lack of experience, lack of confidence, to even try. And oh well, they don't understand, so we don't have to do that anyway that's, that's too above them, they can't access that and because they are SEN there's an easy out, there is an easy excuse to say.

DMH: You broke up a little bit there, so I didn't hear your last bit broke up a little bit after you say there is an easy out.

Andrea: Yeah, and I said often people will use that and say, Oh they can't access it, but they absolutely can and I've witnessed that first-hand with multiple learners' levels of learning cognitive ability, verbal ability, you know, different ages, because I've taught the whole way through from lower primary beginning learners all the way.

DMH: Oh, you're frozen.

Andrea: Can you hear me.

DMH: I can hear you now yeah you are frozen it stopped on where you said you worked all the way and then it just went to robot.

Andrea: I was just saying I've worked with all the primary spectrum, and now I work beyond the primary spectrum, and I can categorically say that the students do know who they are,

and what makes up who they are. Just people for some reason think it's not something we have to do with SEN kids.

DMH: What was the catalyst in terms of you incorporating those elements of kind of race, ethnicity, and culture with your learning when you did that. Was it a school directive was it something that was important to you personally?

Andrea: I think it's important to me, personally, I think, because I have two children of mixed heritage myself and I want, I've spent a long time trying to make sure they know both sides of their, all their cultures because then you know we've got such a wide-reaching family. So, for me why wouldn't you? And also, for children to get to learn about a culture, other than their own, if say, for example, you know their whole family's Irish or their whole families, you know Pakistani wouldn't it be great to know about what other people do. It's never, it's just something I've always done, and then, when people said Oh, they don't understand because I hate being told, I hate people putting our know kids in boxes and saying they can't do this they don't understand and that kind of makes me more determined to find a way to show them that they can and that I suppose became a bit of my mission. Okay, you say they can't do it, I'll show you they can do it, and then you'll say, but my class won't be able to access that, okay, again, I'll come and show you that they can.

DMH: I love the passion behind that because it just goes to show, as you said, it's about challenging what people believe children that have autism can and can't do and without that and without people like yourself, it makes it difficult. Okay, well let's talk about your school curriculum and how diverse was your school curriculum, but specifically related to race, ethnicity, and culture?

Andrea: It was very tokenistic. Okay, so there was a little bit of celebration of different cultures and ethnicities, not a whole lot on race really at all. Even things down to and it sounds, maybe it sounds like a very small point, to some people, but when you're doing self-portraits. I remember vividly doing this lesson with my class, we're doing self-portraits and there wasn't enough like skin colour representation in the paint. So, I'm asking my boys and they're all boys at the time to have a look at their skin and choose a paint and we had to mix up paint and I never forget one of my boys. He said he knew he was Brown and I said to him are you light brown or dark brown he said dark brown and the way, that the enthusiasm and the pride, and then we asked him more questions, where your family from and he could tell us, and he tried to tell us a bit about the food that they eat and things like that, and this this was just coincidental learning that quite spontaneous. Yeah, you know I'll never forget that I feel like the curriculum isn't and wasn't good enough.

DMH: Right. Can you expand on that a little bit more.

Andrea: There just wasn't enough opportunity we do. For example, we didn't know the ethnic makeup of our students. That wasn't something we knew about prior to planning in our curriculum because don't get me wrong I'm all for diversity and learning about people from all different countries, and religions and races but for our children, it needs to be contextual and it's for it to be contextual needs to be about me. So, we should, as a very minimum, make sure we're covering celebrations, festivals, religions, anything food, music,



arts, culture, anything should be about where the children that we teach are from. Not, from somewhere that's not relevant to them, because how are they going to access it otherwise? We all know, we're more interested when it's something that's a reflection of our part of who we are, as an individual right?

DMH: Absolutely, you kind of answered this next part of the question, which is really helpful, and I mean if you want to add any more, you can do. The next question is, do you believe that it's important that the curriculum, including resources, and lessons is diverse in relation to race, ethnicity, and culture.

Andrea: Absolutely every child, every single child, should look at where they are in their education and see themselves reflected in that. Because if they don't, what are they aspiring to, now I'm not saying they're aspiring to be in a teacher, but when they're learning about different jobs, for example, the people that help us, those people should be from a wide range of races, and ethnicities, and religions, they should be girls and boys it shouldn't just be stereotypical, the man is the firefighter, the woman is the nurse, you know, because then children can go, oh I can do it gives them like a permission right, it's a permission to say, this includes you, you can be this if you want to be it, I don't mind what you want to be, but I want you to know you can be anything you want to be, your race your gender your ethnicity or religion, none of that is a barrier or should be, it shouldn't be, but it becomes a barrier if they don't see themselves reflected in these professions and in these teachings and we're the people that it begins with. We're the people at the beginning that set those fundamental impressions on their minds to say, this is what you can do as a White male, this is what you can do as a Black male, White female, anything like that female or male you know we're the ones that put these ideas into the children's head so let's at least put equality in there right!

DMH: The next question is, how might exposure to a diverse racial ethnic and cultural curriculum empowers a child's identity.

Andrea: Because they know who they are, they know what they can be and do whatever they want to be they're not put in any boxes, and that gives them the sense of empowerment to go ahead and do that to take that step and do it. Not to, not to feel as though society puts them in this box only because of any particularly reason, least of all should it be your race, or your agenda, or your ethnicity.

DMH: Exactly, I like the idea of like you said that sense of empowerment that's important it's empowering those children and young people to say I can, and I will yes, exactly.

Andrea: This is for me. This is absolutely for me this I can do that I'm going to do that, it's it's the mindset, it gives them right, because then that mindset becomes not that's not something for me, it becomes well yeah, of course, why wouldn't I. You know, like other people they don't have to think by like white people, for example, don't have to think about what I am going to do when I grow up. There's there's not a conscious thought of well, this isn't really for me, or this isn't something that white people do, you know, but you know a lot of Black children probably don't see themselves reflected in many professions and so do they then sit there and think well that's not for me. Whereas, if there was more equality

across the board, it wouldn't be a thought in their mind, why should a child, have to think about oh well, I can't do that because I don't see myself reflected in that. Why should that burden that weight of thought be on a child's shoulders, you know and we, and because the thing is we don't even know that it's there but it's a weight down on them that they may not even know that it's there but it's our job as adults to remove that to make sure it's, not even a thing it doesn't become a thing. And you know, we can do what we want, as parents, but educators and society in the bigger concept, you need to do more because it's you know, at some point in life, your children go beyond you and school then becomes the biggest influence and then it becomes peer group, and so, if any one of those groupings that are so fundamental to their lives isn't you know all about racial equality, then imagine how that would feel.

DMH: Exactly that's what makes racism, and those kinds of tropes persist, because no one's trying to be the person that breaks the barrier or breaks the mould or encourages a discussion etc. Let's think about the next question then and the next question is asking you do you feel equipped and knowledgeable teaching about race acknowledging any unconscious or conscious bias that you may have?

Andrea: I feel comfortable. I would say in the realms of SEN I've had a lot more experience than most but more than anything I know how important it is. So, me being scared, scared to make a mistake, or scared to you know challenge my own bias is not going to be a boundary to me not doing it. There are many people in my life, I can consult with and who I know if I get it wrong will call me out and rightfully so and I'm not going to get all but but but but, because actually, you know, that's the whole point of learning right. There are things that I cannot understand you know, as a white woman that a black woman would have experienced. That's just a matter of fact, and you know if I say or do something unconsciously, without even being aware of it, I will absolutely expect to and appreciate being pulled on it, to be the best that I can be, because then I went, I won't then go make that mistake in my teaching right because I have the experience myself, I then don't go and make that mistake when I'm teaching children.

DMH: Right. Have you then had any kind of specialist training around race or diversity that's helped you with that or you know kind of just any specialist training around race and diversity in general?

Andrea: No, No, I have not. So, a lot of what I know and what I come to understand and try to be better with is all kind of my own research. Based on discussions with peers and friends and things like that, and you know, as I said, I have two children mixed heritage and my husband so there's a lot of learning that goes on there, my circle is very diverse so that helps a lot, because you know with without taking it too cheesy be the change that you want to see right, so it starts somewhere.

DMH: That's it we don't mind cheese, will take the cheese because exactly it needs to start with someone and somewhere. What about any initiatives events or celebrations that will run at your school related to race and culture, and I know you said in the beginning, that a lot of things were kind of tokenistic. Where they you know with a specific were there any

specific initiatives, where people are saying okay, yes, we want to take stock of race and diversity, or where they're special events and celebrations that were run?

Andrea: So, we had this diversity group. But the diversity group kind of is, well, I can say it I don't work there. It kind of didn't get it, it didn't feel for the right reasons, and it didn't feel authentic. We basically as a whole, school totally messed up and didn't plan as well as we could have and have done previously for Black History Month, which is usually something we do quite a good celebration for. We've done some great stuff I can't remember what year it was glad to remember my husband came in, with my little one. We did some great things then but this particular year we we literally just let it come and go, and off the back of that we then we recognise that we you know we're not good enough. So the ideas and the principle behind okay let's look at that's when we started to look at the ethnic makeup of our students, what do we need to celebrate what can we do to help our children understand their race and ethnic makeup and you know, there was a lot of resistance and it's really sad because people just either get really fiery and say, well, we don't need to do that because they don't know about it, or they won't understand it or people say they don't understand it, because they have a fear of teaching it. I think, for a lot of people, they have a fear of making a mistake, so they say oh well, we haven't done it, why do we need to do it now and your own personal thing should not be the reason you don't do something. It should be a reason you do so, you challenge yourself to grow to learn along the way, acknowledge that you, you might make some mistakes, but if your heart is good behind it and there's sincerity behind what you're trying to do no one will you know hate you or you know not go along with you on it um, but we did do some nice celebrations of different kind of cultures and religions but, again, it was all not enough to do with race.

You know ummm and you know, like people will say, like the Black Lives Matter movement, for example, where you know young black people are still being killed constantly for no good reason targets by the police, would probably say some of our kids they don't need to know about that, they don't understand it, or they might say, children are too young. Are they? This is the world we live in. If we can help them understand and if they are young black individuals who can find themselves, is it a shame that we would have to do that for our kids, yes, it is, but does that mean we shouldn't no it doesn't.

DMH: Right absolutely, I think you know it leans to that point that you said before our children don't stay with us forever and they move on, and they experience life in different ways and regardless of what we think in those four walls of safety at school, they then go out into a community where they are seen as a young black person or young black boy or whatever the case may be and if we're not equipping them or exposing them to what the world sees and views and thinks about them, we can't or how can we protect them, how can we support them. So I think you're right I think you're absolutely right.

Andrea: Exactly! It's a worry it's a big worry for any parent you know. As I said, my children are of mixed heritage, you know but I worry for them. Now, imagine if I was the parent of a young black boy, I would be utterly terrified because of the way the world is and how is it that we have to teach our kids, this is the way. It is all just so unbelievably wrong, but then, if it if we start early when children are young maybe one day I don't even know when way way way off. We won't have to have these conversations with our young children, saying



look, this is the way the world may perceive you rightly or wrongly, you may face this that and the other because of your skin colour. And if it happens, you need to do X, Y, Z otherwise you know. You know yeah heaven forbid what can happen to you.

DMH: Thank you, I know some of these questions can bring up quite personal experiences. So, thank you very much for sharing. When we think about your former school, then, did you feel that your school staff and people population was diverse so maybe let's look at your staff population first did you feel it was diverse. If yes, why and if no, why not?

Andrea: Not really. There was, there was a few different ethnicities and races, but not many and it tended to be like groups of people like job roles link to join roles.

DMH: Different levels?

Andrea: Yeah, different levels and unfortunately, I don't think it will come as any surprise to learn, who were the people on the lowest pay scales, who were the people in the highest paid scales, what the colour of their skin may have been. So, no not really the pupil population, a little bit more, but the staff population, not so much.

DMH: So, at your senior leadership level was your senior leadership level diverse?

Andrea: No, not really, I mean, three white women and one Asian woman.

DMH: And that was that over the nine years that you were there?

Andrea: Over the nine years it was it was only, mainly white, three White women. Okay, and prior to that a white gentleman and a white woman, sorry so yeah.

DMH: Okay,

Andrea: So pretty much zilch up there.

DMH: So, it's not representative of the student population, pupil population?

Andrea: God no, not representative of the student population, in no way, shape or form.

DMH: Okay next question is how did your school tackle issues of racism and if there were no issues of racism, how would they have tackled it.

Andrea: How did my school tackle issues that racism? So, the thing about racism right is racism that happened in my school was a lot more, and this is where I may make a mistake, I think it's maybe not as blatant. It's a little bit more discreet. Discreet is a wrong word. There is a word.

DMH: Covert?



Andrea: Yes, it's a little bit more covert. So, if ever it was called out... mommy is in a meeting sweetheart ask Daddy (participant's child enters and leaves the room).

DMH: Okay.

Andrea: Sorry. I'm in a meeting. So if it happens, and it did happen, it would be, and there were some really blatant kind of like, especially in the diversity group, when we had some focus groups, there was no blatant anger and misunderstanding and when you get over the scratching your head, why on earth would someone feel this way you just have to challenge them and say but you're wrong and also what you're saying is wrong that's exactly what we're talking about, this exactly not okay to say things like that you might think it's funny but it's not. And you're wrong But where it was more covert it would be a case of oh, maybe that's how you feel it was but that's not what the person meant, or it's not what they were trying to say, or it's not how they feel, but actually it's not about you, it's about the person, you said that message to, so it really doesn't matter what, because we can all say that right, we can all say when it comes down to an opinion, we can all say well that's not why meant, but the person received it that way and you're responsible for sending that message, so you are accountable. So let me tell you now, how you can communicate with me in a way that won't offend me again, but often the people that will challenge would not want to entertain that, which just then goes to prove the point, yes, you did mean that, yes, you were being racist.

DMH: Right

Andrea: Because if you weren't, why would you have a problem with someone if you know you've done nothing wrong, most people, most adults, because these were all adults here now grown mature adults lots of us with children ourselves, you just kind of go, you know what, can you please tell me, tell me how I can be better right, but when actually you did mean something racist by what you said and you've been called out and you don't like it that's when you get defensive and that defensiveness is a sure-fire sign there's big problems and there were big problems there.

DMH: Well, that's good, because I'll be asking you for an example of that for the next question anyway, and I mean, especially when you think about what you said earlier, so there's the covert racism and then there's those blatant ones that are in your face. Were there any examples of how the school dealt with it, if they dealt with it or any you know anything that comes to mind if not then I'll give you the next question which asks about maybe you are witnessing racism. So, I'll tell you what the next question is it might help it make it easier. So, the next question is have you ever been a victim of racism, racial discrimination or a witness to it. And if yes please explain the situation and how it made you feel in your own words.

Andrea: I don't know if I've been a victim of racism. I do, when I witnessed something that made me feel quite uncomfortable and I know that made me feel uncomfortable as a white person is going to make someone who was black feel very uncomfortable. So, around the time we were starting to plan for what look at the diversity group and what we were planning for, and what we were going to celebrate and how we're going to do it there was

this big misconception that it was because we didn't do Black History Month, so now we're going to like almost do loads of extra stuff to celebrate Black History, that was a real misconception, and I can't, I don't know how many times we explained to people it's not even about that. We said we missed black history month but we're talking about setting up a diversity group, not a Black Lives Matter movement group, no, if that's what it was that's what we call it, it wasn't that it was diversity so, um but I had a few comments that left me feeling super uncomfortable and when they were said I would just outright say to them you can't say that, exactly that, right there is racist, this is why people get offended listen to what you've just said, and then I would say to them, imagine if I said to you, ummm and I wouldn't necessarily be racist, but I think of something, because I knew these people I've worked with these people a long time though I knew where they were from, I knew about their family, I knew about their hobbies. I said, imagine if I said something like this to you how would you feel? Blah, blah, blah, blah? Well, how do you think black people feel when you say things like that. But I don't mean it, it doesn't matter how does that person receive your message? How did the person on the receiving end feel?

DMH: That's really, really helpful and even, as I said, it's the way that it's made you feel then thinking about how that made the other person feel, who was actually receiving that. Were you aware of your school's policy of racism and how to report any complaints.

Andrea: I didn't know, we had one. I still don't to be honest, I don't think there was a policy if I'm going to be honest. And I, if there was, I definitely didn't know how to complain But as an outspoken person I would have had zilch problem with going straight to the top or beyond had it come from, say, the head teacher, I would have had absolutely no problem in making a complaint or supporting someone who was making a complaint that I may have been witness to. None whatsoever, but I don't believe I was aware of it, and I think I would have been aware of it, if it existed, because, as the PSHE lead and the well-being lead and things like that is very closely connected to something I work on. So, I'm sure I would have had part in.

DMH: In knowing about it?

Andrea: Knowing about it or even creating it or you know.

DMH: Okay, great alright well we're down to the last two questions. You are doing absolutely amazing. Thank you so much. The next question is, in what ways, do you acknowledge and understand racial, cultural, and social differences, so those could be socio-economic differences that may be affecting student attainment and performance of minority ethnic children.

Andrea: So social?

DMH: Social, racial, and cultural differences that may affect the student attainment and performance.

Andrea: It is huge isn't it because you know for example, in my class and I, I had a very similar class for about three years, I had a good few of the boys in my class for about three

years and they were boys from India, boys from, of African heritage, boys of Sri Lankan heritage. And the way children respond the way children understand and see messages is so heavily linked to their culture, it you wouldn't believe it and I'll give you an example, right, I'm now, not in the UK I'm teaching in Hong Kong and Chinese culture is so strongly embedded in families that you would not believe how differently my kids appear and I don't mean appear physically, I mean in their behaviour and mannerisms compared to the Chinese children. My children are loud and rambunctious. Chinese children are not.

This is what this is culture, yeah, this is how children are taught to be when they're out in public, when they're in the restaurant, when they're with family. All these neuroses about the culture about my ethnicity, about who I am, where I'm from, how I behave, what I do, it's the same for our children. So, you have to know, because that's how you teach the child according to who they are, which is their race, which is their ethnicity, which is their culture, their religion, their even had a little boy who was traveller okay and other minority groups and he isn't the kind of boy, you can softly, softly with because that's not his culture. And I know a lot because prior to working you know in the school; I was out for nine years I was in another school that had a large Somali and predominantly Somali and traveller population. So, I've spent most of my career supporting traveller children, and I know how they, and I know traveller people outside of work. I know how they communicate and how they engage and if you want the product, the point I'm making is, if you want to reach children there's no better way than to reach them through the means they know and understand, and that is linked to your culture, your race, and your ethnicity. I know for a fact when my husband talks to my children, sometimes, he is using the languages, the words, the mannerisms from his culture, and his race and he's giving that to our children and they'll give it to their children because that's what it is right, it is so rich and it's just like it's in your fibres isn't it.

DMH: The idea of socialisation through the generations.

Andrea: Absolutely that's what it is right because that's what makes us who we are. Yeah, because I'm a girl, because you know I grew up here, it is the culture of my household, the culture of my family, and that's all about how we talk to each other, how we behave with each other how we socialise with each other, you know, the way we celebrate you know and that's linked to your race in your ethnicity isn't it.

DMH: Yeah, do you think there's enough of that acknowledgement of that in special school so again, recognising that may be group that comes from minority backgrounds do you think there's enough of those socio-economic considerations, taken into consideration in special schools and when you look at how children perform, for example, or how they may behave, do you think they consider those factors the same way you have done?

Andrea: Not enough, no. I feel like the financial perhaps is considered, but not much beyond that, not much on your behaviour is strongly linked to your culture, so you know the child that might seem loud and outgoing that's just that that's part of their home culture or their family culture, like my husband is so loud. That's part of his culture that's what we do. Someone who doesn't know (no mommy's in a meeting and so), someone who doesn't know about that and definitely here in China, they just think my husband's crazy and rude. Why is he so loud?



And you know what I have to stop myself, because I get like oh my God be quiet. And I'm like, why should I get I want to be respectful to the Chinese culture but also, we just be is just being who he is he's not being offensive it's not swearing, it's not hurting anyone he's just if anything he's showing you who he is you know. He should not have to be himself to fit in that's the point, why should he have to go, and he shouldn't feel like, and you know, luckily my husband's a mature man and he he he says, well, no. I don't have to, I'm me and good for him, because there are many people though that sadly, that will go okay, and do it.

DMH: Yes, exactly. We're down to the last question, I could talk to you all day how can British special schools and families work in partnership to support empowering racial and ethnic identity and cultural pride and in children that have special needs.

Andrea: We need, if I'm going to be honest in a lot needs to be done in the recruitment level. Because, who you're recruiting they're going to be the people that are delivering this and in special schools, you have teachers and support assistants or TAs, or EAs whatever their role is they are like many teachers being by no means think that it's all done by a teacher in a special school, it's very much a village, everyone's working as hard as the next person and we're all equally, contributing to that child's you know level of understanding, experience and progress right, so who you're recruiting is very important because it needs to be people like do we have a question about diversity in the interview process? For example, there is an important festival in the Buddhist calendar coming up, I don't know I'm just giving an example, cool whatever, can you please tell me or Chinese New Year is coming up, can you please tell me what might you plan as a fun activity for our children to understand Chinese culture and for the Chinese students to understand their culture, better and if you don't know, what would you do to find out? Because their answers going to give you some qualitative understanding about their commitment to supporting basically a whole shift in thinking, in teaching and learning.

DMH: Right.

Andrea: And specialist training would be great because the staff need to understand what is okay and what's not okay and this isn't optional, this is not okay, you're told this is not okay it's not okay, not behind closed doors go and do it, and there needs to be a lot more whistleblowing. Call people out because sometimes people it's a genuine mistake on a person's part, it isn't always malice but that doesn't mean to say you haven't hurt that that person, just as badly with your words, the actions.

DMH: What about how can families work with schools as well, to make sure that you know those those elements of their identity, their race, their ethnicity and their culture have and you know, support the school?

Andrea: I mean it all comes from families in the beginning doesn't it so, the more we have connections with the families, the better it's going to be, it's going to be authentic and it's going to build that parent partnership and you know they could lead us.

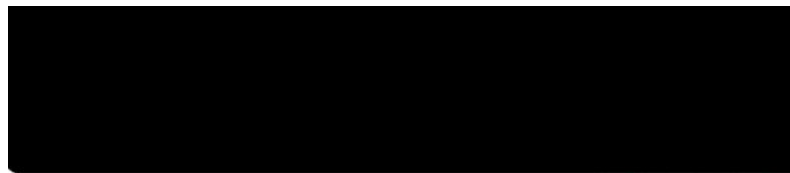
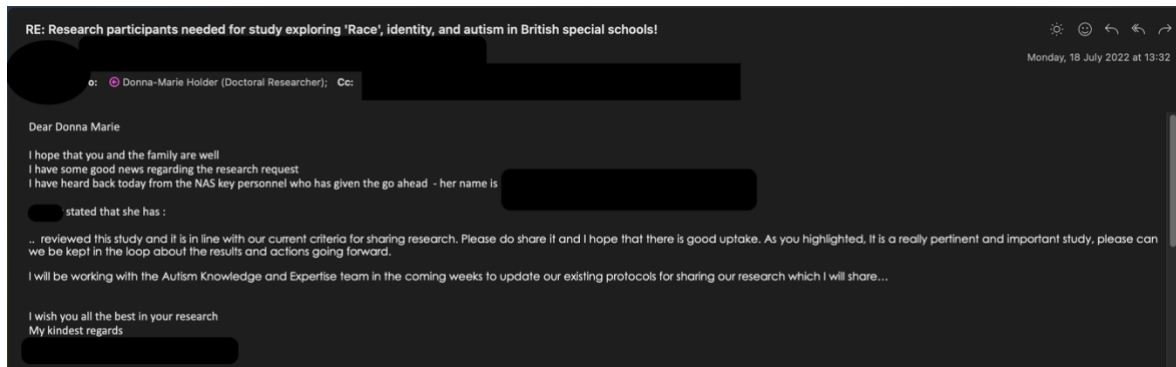
DMH: Definitely that sounds that sounds key. I'm going to stop recording because that is the end of all the questions. Thank you.

## Appendix L: Data analysis- coding frame

Main Theme	Subtheme(s)	Description	Participant Group
<b>Awareness/ Understanding</b>	Awareness of self (racial, ethnic, cultural identity)	Children/Young Person understands (is aware of, engages, interacts with, recognises) the different questions/ objects/ items related to their race, ethnicity, or culture	C/YP
	‘Like me.../ Not like me...’	C/ YP able to identify/ recognise same/ different ‘race’, ethnicity, culture as them	C/YP
	Engagement, interaction, and understanding of racial, ethnic, and cultural identity.	Participant believes that C/ YP can/not engage with, interact with, process, or understand their racial, ethnic, and cultural identity when accessible to their needs and ability.	Parents  School Personnel
<b>Teaching and Curriculum Challenges</b>	Decolonise the curriculum	Lack of diversity in curriculum related to race, ethnicity, and culture	Parents  School Personnel
	Teaching race in the classroom	Teaching and learning challenges around diversity.	School Personnel
<b>Identity Formation/ Empowerment</b>	Developing a racial, ethnic, and cultural identity	Developing a broader sense of identity and self.	Parents  School Personnel
<b>Familial Socialisation</b>	Family Ties/ Ties that bind	Parental experiences of growing up navigating their racial, ethnic, cultural, and other identities and the influence on raising their children	Parents
	Racial, cultural socialisation at home	Exposure to race, ethnicity, and culture in the home	Parents
<b>School Socialisation</b>	Racial, ethnic, and cultural identity at school	Exposure to race, ethnicity, and culture at school	School Personnel
	Racial, cultural, social differences and performance	Acknowledging and recognising social, cultural, and racial	School Personnel

		factors that may influence performance/ attainment/ behaviour of minority ethnic pupils	
<b>‘Racial’, ethnic, and cultural underrepresentation</b>	Representation matters	Perceived influence of underrepresentation of BAME staff, diverse curriculum, cultural and race- related events in special schools.	Parents  School Personnel
<b>Racism, Discrimination, Ableism</b>	Discrimination, Racism, and Ableism	Experiences of discrimination because of a) ‘race’ or ethnicity b) ability c) both	Parents
	Racism in special schools	Experiences of racism, discrimination in special schools.	School Personnel
<b>Home &amp; School Partnerships</b>	Building meaningful partnerships between home and school	Collaborative working between parents and schools to empower racial, ethnic, and cultural pride in special schools.	Parents  School Personnel

## Appendix M: Email of permission for research to be conducted at a special school a from gatekeeper (headteachers)



10.5.22

To whom it may concern,

I confirm that I am happy for Donna-Marie Holder to conduct research at [redacted] School as part of her research into 'Race, identity, and autism in British special schools'.

Yours sincerely,

[redacted]

Headteacher

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## Appendix N: Risk assessment



College of Business, Arts and Social Sciences  
Education

Who am I? Empowering racial and ethnic identity and cultural pride in British Special Schools

### RESEARCH ETHICS RISK ASSESSMENT AND MANAGEMENT

For Completion by the Researcher:

Identified Risks	Likelihood	Potential Impact/Outcome	Risk Management/Mitigating Factors
Identify the risks/hazards present	High/Medium/Low	Who might be harmed and how?	Evaluate the risks and decide on the precautions, e.g., Health & Safety
<i>Vulnerable participant may become distressed (emotionally/ physically) by the interview or unfamiliarity with the researcher or anxious because of their autism or a physical issue and cause harm to self or others.</i>	Medium	All persons	<ul style="list-style-type: none"> <li>-Prior to conducting the interview, the researcher will request the vulnerable participant's pupil pen picture/ risk assessment/ behavioural plan from the school. Any of these documents is suitable and will allow the researcher to mitigate any potential distress to the participant</li> <li>-The vulnerable pupil/ student will be accompanied by a familiar adult teacher/ parent during interviews</li> <li>-In the event that the participant becomes distressed, the interview will immediately be terminated, and the researcher will follow the school's guidance and procedures.</li> </ul>

			<ul style="list-style-type: none"> <li>-Researcher has more than 10 years' experience working with this vulnerable group in a professional capacity and as the mother of an adult with autism and has significant knowledge and training in assessing perceived risk, managing difficult and challenging behaviour presented by those on the autistic spectrum.</li> </ul>
<i>Race/ ethnicity can be a sensitive and contentious topic. Discussion may cause distress and conjure up uncomfortable feelings. Situation may become argumentative.</i>	Low	Participants (adult)	<ul style="list-style-type: none"> <li>-The interview questions are open-ended and are not intended to be contentious.</li> <li>-The participants will be reminded that they only need to answer questions they are comfortable with and the right to withdraw.</li> <li>-The researcher will always seek clarification from participant about proceeding and ensure that they are as comfortable as possible.</li> <li>-The researcher has attended a variety of training sessions on conducting and managing interviews. She also has experience of conducting research interviews for past projects that have dealt with similar themes of race.</li> </ul>
<i>Exposure to COVID-19</i>	Low	All persons	<p>Although COVID-19 restrictions in the UK have been lifted the following measures will be followed:</p> <ul style="list-style-type: none"> <li>-Researcher will wear mask, if required. (The vulnerable participants may find it difficult to understand the researcher or can become distressed by the mask and so the mask will only be worn if necessary).</li> <li>-Only interviews with pupils will be conducted in person and as such the researcher will adhere to social distance measures such as use of hand sanitiser, adequate ventilation, and appropriate space. All other interviews (adults) will be conducted online.</li> </ul>



			<ul style="list-style-type: none"> <li>-Researcher will conduct a LFT the day/evening before the interviews. In the event of a positive result the researcher will contact the school to reschedule the interview.</li> <li>- Researcher will continue to follow coronavirus guidance on keeping safe.</li> </ul>
<p><i>Researcher will be travelling to/ from destinations, be present in unfamiliar environments.</i></p>	Low	Researcher	<ul style="list-style-type: none"> <li>-All in-person interviews will be conducted during the day during school opening hours.</li> <li>-Researcher will provide supervisors with full details of interview (name of school, full address, contact information, date, and time of interview).</li> <li>-Researcher will check in with supervisor upon arrival and when leaving location.</li> <li>-Researcher will establish a 'safe word/ phrase' with supervisors in advance and follow Brunel University London's policy for lone workers.</li> </ul>
<p><i>Confidentiality / anonymity and storage of data.</i>  <i>Participants may be concerned that they will be identified in the study</i></p>	Low	Participants	<ul style="list-style-type: none"> <li>- No personal data will be submitted in any version of the report (draft/ final).</li> <li>-Participant names will be anonymised, and pseudonyms used instead.</li> <li>-Voice recorded data will be stored on Brunel's networks.</li> <li>-Written documents will be scanned to the above location and paper copies shredded and safely and securely disposed of.</li> <li>-All data will either be kept and stored or disposed of in line with the university's data management policies.</li> <li>- The researcher is committed to always adhering to the ethical code of conduct and BERA guidelines.</li> </ul>

<p><i>Positionality and potential power imbalance (researcher's son will be a participant in the study), researcher works in special school and participants may be known to her.</i></p> <p><i>Participants may feel that they must take part because they are friendly with researcher. They may give answers that they think the researcher would like to hear or may expect an incentive for taking part.</i></p>	Low	All persons	<ul style="list-style-type: none"> <li>-Researcher acknowledges her positionality and will ensure it is made clear at the start of the process. She will reassure participants that the interview is about their experience and feelings.</li> <li>-Consent for researcher's son will be obtained by <a href="#">other</a> parent (Father)</li> <li>-Researcher's son will be treated the same as all other vulnerable participants</li> <li>-During the recruitment process, the researcher will be actively seeking participants outside of her professional and personal networks to take part in the study</li> <li>-Participants will be reminded that no incentives will be provided for taking part</li> </ul>
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Appendix O: One of the subject, verb, object communication boards used in interviews with children/ young people



