Transculturalism in parents' experiences of caring for an autistic child

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Abstract

In the UK there has been a marked increase in children from minority ethnic families receiving an autism diagnosis but there continues to be a dearth in research that has explored the diversity of families' lived experiences. The research sought to address this under-representation by using a transcultural approach to understand how families are drawing on multiple cultural influences in response to having an autistic child. Eleven parents from nine families who lived in one London borough were interviewed using a non-directive narrative approach. The families included two parents who were born in the UK, five who migrated to the UK as children and four who came to the UK as adults. All the families had a child with autism aged between four and seventeen years old, who attended either a special school or a mainstream school in the same London borough. Combining transculturalism with a narrative interview approach made it possible to pay attention to the ways in which families' lives are transformed when they have an autistic child, how parents develop multiple identities in their interactions with professionals and family members across different social and cultural contexts and the impact this has on their sense of belonging to the community and networks of support. Analysing the interviews followed a case-based approach with themes examined within and across all cases. A thematic analysis of the families' transcultural experiences showed that there were commonalities in their experiences of parenting children with autism as well as distinct and relevant cultural values and resources which influenced their individual responses to having an autistic child. The families wanted teachers in mainstream schools and those in their community to have more understanding and knowledge about how autism affected their lives and positive recognition of the solution-focused strategies that they were using to advocate for their autistic child's healthcare and education. The findings from this research supported the development of a transcultural model that will be of value in developing culturally responsive pedagogical practice in autism education. The recommendations are that there is a need to further address culture and ethnicity in research on autism and special education, encouraging teachers to think about how they work with autistic children and the social and cultural realities that are an essential aspect of families' transcultural lives.

Impact Statement

An understanding of how autism as a perceived disability or an aspect of an individual's identity remains culturally positioned within societies and has become a crucial debate within autism studies. Establishing a transcultural perspective on autism and family functioning, has the potential to reduce polarised views about the nature of autism and to focus more on culturally informed treatments and educational interventions. Not only is transculturalism juxtaposed with an increased need for global knowledge of autism across different cultural and ethnic groups, it becomes essential that the construction of autism in any society is understood within the context of the individual's personal and cultural experiences.

With the current considerations in education taking place in the UK to decolonise the curriculum (Arday et al, 2021), there is an opportunity to evaluate how a transcultural approach could make a valid contribution to teacher knowledge about how they work with autistic children and minority ethnic families in inclusive special education. Highlighting the value of fostering transcultural attitudes to teaching in autism education has the potential to create more effective interactions between professionals and families and could make an important contribution to the decolonising debate.

The dissemination of this research has already begun with presentations given at an international BERA conference on global education and a university-led conference on autism education, in addition to specialist subject lectures to undergraduate and postgraduate students in higher education. The response from both the academic and education professional audiences has firstly been an acknowledgement that a transcultural approach to understanding autism is relevant to changing the predominantly White ethnic perspective on autism and secondly that teachers are wanting to develop their knowledge about working in culturally responsive ways with minority ethnic families. The emergence of transcultural teacher education could begin by piloting the use of the transcultural model developed from the findings of this research, with a view to how it can be implemented in a community-based training programme with teachers and families.

Since completing my research I have been invited to co-author a bilingual (Arabic-English) text on special education with an education consultant in Oman and to work with a UK local authority special education team to prepare a practical guide for teachers working with autistic children who are multilingual learners. As a published author in autism education and interactive play for children with autism, I have had a commitment to a sustained area of academic endeavour and undertaking this doctorate has been a further opportunity to express this, both personally and professionally. I would like to continue this commitment by adding to the global discourse on autism and writing up this research as a publication and presenting at conferences.

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List of Abbreviations

Education Health Care Plan - EHCP

Local Authority - LA

National Autistic Society - NAS

Pupil Referral Unit - PRU

Special Educational Needs Coordinator - SENCO

Declaration and word count

I hereby declare that, except where explicit attribution is made, the work presented in this thesis is entirely my own.

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Reflective Statement

The decision to study for my doctorate came at the end of a long a career in special education. As a teacher, I specialised in teaching autistic children with severe and complex learning needs and set up a family support group as a branch of the Sussex Autistic Society, as it was then known. After 20 years teaching, in a professional career move, I became an education and family consultant in interactive play and developed the s m i l e programme for families and training for parents and professionals working in education, health and social care. My approach was developmentally and therapeutically grounded in the importance of establishing mutually engaging activities with autistic children that could have a positive impact on the development of communication, socio-affective functioning and cognition (Seach, 2007).

I established an international consultancy in autism education and interactive play from which I gained new insights into autism from the perspective of families in many countries, which included Australia, Egypt, Kuwait, New Zealand, Nigeria and South Africa. The experience of talking to international audiences and the UK about a family-focused relational approach was the beginning of my transcultural journey towards seeking a more culturally-informed approach to autism. In wanting to assert families as the producers of knowledge about autism, I began to recognise that while there were distinct cultural influences on families' caring for an autistic child, they also shared profound experiences that were observed across cultures and between families. Re-defining autism through the lens of cultural diversity and evaluating the cultural conceptualisations of autism that were significant to individual families and pedagogical practices became a signifying narrative in the development of my work. I have carried this knowledge into teaching in higher education, where I am a Principal Lecturer in Special Education and Disability Studies, specialising in autism, inclusive pedagogy and disability studies. Engaging undergraduate and postgraduate students in critical discourse about special education, has been a challenge in moving beyond the dominant White ethnocentric view of autism in the transfer of knowledge about autism treatments and interventions. The connections between my work with families and an academic career in special education and disability studies has for me, widened the debate around the need to understand how families construct their lives when they have a child diagnosed with autism, the cultural influences on the family

system and the ways in which education professionals develop culturally responsive approaches to teaching and working with families.

Prior to starting my doctoral studies I completed a Postgraduate Diploma in Systemic Family Practice with the Tavistock and Portman NHS Trust. This helped me to make stronger links between the theoretical concepts of systemic family practice and how I engaged with families who have an autistic child. I have always argued for the need for family-focused and family-led enquiry within the field of autism education and the methodological approach I adopted for my doctoral research grew out my commitment to working therapeutically with families. I learnt that establishing a relational, co-constructed approach to helping families achieve the goals they wanted for themselves and their children enabled me to become a more reflexive and culturally responsive practitioner. I drew extensively on literature related to techniques in qualitative interviewing (Wengraf, 2001), narrative research (Andrews, Squire and Tamboukou, 2013) and narrative analysis (Goodley et al., 2004; Hollway and Jefferson, 2013; De Fina and Georgakopoulou, 2015) which resonated with the therapeutic counselling approaches that I had learnt about previously.

The EdD programme was the appropriate route for my doctoral studies in terms of the taught structure of the modules in Year 1, followed by the Institution Focused Study and the Thesis where undertaking a sustained research focus has enhanced my skills as a researcher in narrative and reflexive analysis. The Institute of Education's Foundations of Professionalism (FOP) module provided a base from which to examine professionalism from a theoretical perspective, its origins within education and the sociological, psychological and political debates about the changing nature of professionalism in education. The module provided a starting point for a closer examination of the rise in professionalism in special education and was a useful platform from which to explore competency-based models of practice. In the FoP assignment I explored how professionals working in special and mainstream schools have been challenged by the need to develop competences that may not previously have been considered within the traditional roots of their profession, such as autism-specific approaches and interventions. Further gaps in teacher knowledge have also emerged with an increase in autism diagnoses amongst the minority ethnic population in the UK that has prompted a demand for culturally sensitive approaches to teaching

autistic children (Corbett and Perepa, 2007). With culturally competent models of professional practice being developed to promote transcultural care in the health and social work professions, I considered why the establishment of similar models had been largely overlooked in educational practice and whether there was the potential for them to be implemented within the field of special education.

During the first year of my doctoral studies I was a member of the advisory group for the National Autistic Society (NAS) on a project aimed at engaging with minority ethnic families to share their experiences of caring for their autistic children. The project was set up in recognition that a campaign celebrating 60 years of the NAS work with families in the UK had under-represented the experiences of minority ethic families. In thirteen nationwide focus groups, 130 families were asked to talk about the challenges they faced in accessing services and interacting with professionals to gain support for their children's care and education and whether ethnicity, religious beliefs and language had impacted on the help they wanted. The report *Diverse Perspectives: the challenges for families affected by autism from Black, Asian and Minority Ethnic communities* (Slade, 2014), while addressing a gap in knowledge about autism and ethnicity, also affirmed how education professionals were demonstrating low levels of autism awareness and a lack of cultural competence that led to cultural misunderstandings and assumptions about families' child-rearing practices. The report's recommendations implied that reducing the marginalisation of autistic children and their families could be achieved by increasing the opportunities for dialogue between health, social care and education professionals and minority ethnic families. These findings affirmed why I wanted to use a methodological approach for my doctoral studies that would privilege the perspectives of minority ethnic families to determine what they regarded as the components of culturally responsive professional practice and secondly, to evaluate how education professionals are developing culturally informed practice in their work with autistic children and families.

The Education doctorate (EdD) modules, Methods of Enquiry 1 and 2, gave me the opportunity to prepare for and undertake, initial research into this aspect of professional practice by obtaining parents' perspectives on their interactions with education professionals and their views about their children's special education provision. The Institution Focused Study (IFS) was an opportunity to refine the

techniques for carrying out narrative research and developing a reflexive analysis of the data. I was fortunate during the early stage of my study to benefit from guidance from Ann Phoenix whose knowledge of narrative research on racialisation, gender and identity from a psychosocial perspective was invaluable. Drawing on notions of decolonising research methodologies (Gunaratnam, 2003; Tuhiwai Smith, 2012) enabled me to gain more understanding of narrative approaches to research, broadening my knowledge of how to culturally situate research (Arzubiaga et al., 2008) and undertake interviews with families across cultural and ethnic differences.

I drew on the feedback from my IFS to take forward into the thesis. In particular, that researching 'culture' needs to include an examination of the similarities as well as the differences in families' experiences and that more emphasis was needed on the socio-economic, social networks, cultural and religious influences that affect family functioning for those caring for an autistic child. I also realised that determining what is meant by 'culturally competent professional practice' remains a contested concept in that professional competencies do not remain static. Much like my own experience, I have realised that ways of thinking about autism, ethnicity and culture have occurred through an interplay between my professional expertise in a career in special education and my experience as an international consultant.

In my thesis proposal I had envisaged extending the research I had undertaken with families, to include focus groups with teachers working in mainstream and special schools with autistic children, to gain their perspectives on how they are working with minority ethnic families. A special school in London where I had worked as an education consultant, consented to the research being carried out in their setting and invited me to talk with parents and teachers about my research. Initially I had proposed two phases for the research. Phase 1 was to involve recruiting families who wanted to share their experiences of having an autistic child, their views on their child's education provision and how they would like professionals to work with them. Because I was interested in teachers' perspectives and what they consider to be the pedagogical skills and knowledge to develop culturally responsive practice and work effectively with minority ethnic families, Phase 2 was to carry out focus groups with teachers at the schools attended by the children. Talking with the parents at their regular parent network meetings developed into a regular research dialogue with parents wanting to

share their experiences of having an autistic child, the challenges they had in coming to terms with their child's autism diagnosis and the impact this had on their families. Within the timeframe for collecting the data, this meant that I arranged interviews with parents from nine families. While seemingly a small sample, the length of the interviews provided detailed accounts of the family, their response to their child's diagnosis, their interactions with professionals, their views about education and how they were advocating for their child and family's future. As a consequence, the research design was changed and subsequently led to a more nuanced approach to researching families' lives.

Throughout the thesis I reflected on the methodological approach I had chosen was key to establishing trust and building relationships within the context of the research space. Giving prominence to their lived experiences through their narratives was the method I used to achieve this. One of the challenges in researching across cultural and ethnic difference is the potential for the 'cultural-gaze' to influence how the research is conducted. In particular, I was aware that the ethical considerations for researching the intersectional lives of families, positioned me as 'other', as a White British woman who does not have a child with autism. I needed to examine how my own cultural attitudes and beliefs might influence how the data was interpreted and subsequently, what I chose to analyse. It was important for me to acknowledge how my personal experience of living and working with families from different countries had influenced how I approached the research. I wanted to remain focused on researching 'with' rather than 'on' the families who participated in my research. I have reflected on this throughout the research process to ensure that the research remained culturally situated and with an ethic of responsibility towards analysing others' storied lives.

My decision to use a transcultural paradigm as a framework for understanding the multidimensional and dynamic nature of the cultural influences on families' lives was essential to this research. A crucial component in analysing the uniqueness of their lived experiences was wanting to shift from exploring the cultural comparisons between families to recognise the similarities in experience that are a global feature of parenting an autistic child. Working transculturally throughout the thesis has enabled me to develop an awareness of the multiple identities, contexts and cultural influences which families will draw on in their responses to having an autistic child. This has

emerged as one of the key contributions that I would like my thesis to make in developing professionals' knowledge about working transculturally with minority ethnic families.

Chapter 1: Introduction

1.1 Introduction

This chapter provides an introduction to the research and the context in which it took place. An outline of the methodological approach is presented with the rationale for undertaking research that was culturally situated and focused on the lived experiences of minority ethnic families living in the UK, their views on special education for their autistic children and the nature of their interactions with professionals. In the following sections, a discussion on what is meant by transculturalism will establish the epistemological justification for this research and exemplify why a transcultural discourse on autism was relevant for research involving minority ethnic families. Key terms are defined that are pertinent to researching individuals' cultural lives and consideration is given to the ways in which terminology relating to autism, ethnicity and culture have been globally understood. It then sets out what will be covered in the following chapters to provide an overview of the thesis and establish my approach to the research which was culturally informed and grounded in my professional practice.

1.2 The research focus and aims

The emergence of research on minority ethnic families' experiences of caring for an autistic child is a fairly recent phenomenon in the United Kingdom (UK). Increasingly researchers have sought to gain a deeper understanding of the particular challenges experienced by families and highlighted how many families have felt marginalised by professionals because of the cultural, social and religious influences relating to their perceptions of autism, language barriers and accessing systems of support (Corbett and Perepa, 2007; Doig, 2012; Gilligan, 2013). Overcoming misunderstandings and avoiding essentialism about autism and ethnicity were a key driver in wanting to undertake this research with minority ethnic families. Adopting a transcultural paradigm made it possible to pay attention to the ways in which families move within and between different social and cultural worlds when they have an autistic child. This innovative approach was based on the premise that the globalisation and diasporic movement of people from Global South countries to the UK has highlighted the need to understand autism from a multi-dimensional, sociocultural perspective because of the unique ways in which families respond to diagnosis, treatments and educational practices.

According to Arzubiaga et al. (2008:309) one of the challenges to researching across cultural and ethnic groups using 'traditional' research methods has led to 'research *on* cultural groups' (authors italics) resulting in research outcomes that perpetuate assumptions, oversimplifications and stereotypical views about the particular group being studied. The rationale for focusing on transculturalism was therefore, to create a different dialogue about autism and minority ethnic families' experiences of caring for an autistic child that moves beyond an investigation into cultural differences to explore the similarities that are a feature of parenting an autistic child. Another aim was to examine families' transcultural lives in the context of the social and institutional systems in health, social care and education which they have access to and their experiences of family-centred, culturally responsive professional practice.

1.3 What is transculturalism?

The term *transculturacion* originated from the work of Fernando Ortiz in 1940. As an anthropologist, he studied the processes of cultural reconfiguration in Cuba with the aim of conceptualising an alternative to the term 'acculturation' (Lewis, 2002). Ortiz's view was that acculturation as a process in which an individual adopts, acquires and adjusts to a new cultural environment, did not take into account the nature of the interactions between different cultural groups and the impact they would have on an individual's sense of identity and belonging. According to key scholars (Welsch, 1999; Lewis, 2002; Epstein, 2009), transculturalism is seen as having the potential to redefine what is meant by 'culture', not as fixed but open and transformative and occurring through a synthesis of previous cultural experiences and the development of more than one set of cultural attitudes, beliefs and practices.

Since its original concept, transculturalism has been applied to the study of cultures across many disciplines such as, migration studies and globalisation, cultural and family studies, literature and global arts and healthcare practices (Lee and Canagarajah, 2018). As an increasingly influential discipline, Disability Studies has also established its relevance across these disciplines (Gabel and Connor, 2009). Disability Studies is an area of academic inquiry that challenges the way in which disability is constructed in society and involves listening to and involving disabled people to develop the models necessary to remove the legal, physical, policy and attitudinal barriers that exclude people with disabilities from society (Swain, French

and Cameron, 2003). As Disability Studies literature (Ahmad, 2000; Goodley, Runswick-Cole and Mahanoud, 2013; Hussain, 2014) has highlighted, there is a growing need for critical debates about how disabled people and their families continue to be positioned within UK society, particularly when they continue to be marginalised and minoritised due to their migration status and ethnicity. For this thesis I have theorised how transculturalism could offer an approach to developing cultural knowledge about autism and contribute to teachers' understanding of families' transcultural experiences and the cultural values that influence their lives.

1.4 A global definition of autism

The identification of autism as a distinct neurodevelopmental disorder is referred to in two key documents, the Diagnostic and Statistical Manual, (DSM-5) (American Psychiatric Association (APA), 2013) and the International Classification of Diseases (ICD-11) (World Health Organisation (WHO), 2017). According to the National Autistic Society (NAS) the ICD-11 is more widely referred to in the UK and defines autism as 'a spectrum disorder characterised by persistent deficits in the ability to initiate and sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests' (ICD-11, WHO, 2019: Section 6A02). The WHO categorisation of autism spectrum disorder, whilst identifying deficits in the development of social communication and interaction, also acknowledges that there are individual variances that will have social, educational and contextual implications and as such, the characteristics of autism will be manifest at an interpersonal as well as an intrapersonal level. Expressing this more succinctly, Singh and Elsabbagh (2014:754) state that:

> Autism, both as diagnosis and as lived experience, does not sit outside society; the condition is embedded within and interwoven with the social materiality of persons, families, institutions and communities.

This concept of autism reflects an emerging cultural shift in thinking about autism that is being initiated to a significant extent by autistic individuals and family advocates who want an autism narrative that reflects an aspect of an individual's identity, rather than a deficit categorisation within the medical model of disability (Broderick and Ne'eman, 2008; Kapp et al., 2012; Milton and Bracher, 2013). According to Grinker (2015), this has implied an imperative for researchers to challenge ontological theories that focus

on the medicalisation of autism and consider the concepts of 'culture' within autism research.

This thesis acknowledges that like 'culture', there are multiple conceptualisations of autism which will be reflected in the terminology used when discussing autism. It also considers how autism has been positioned within the disability discourse and that families will use 'autism' and 'disability' to describe their children who have developmental difficulties. Throughout this research I have given preference to using 'autism' to denote a specific diagnosis and have avoided terms such as 'disorder, 'condition' or 'syndrome' unless referred to in a cited text. In accordance with preferred terminology (Kenny et al., 2015) I have also used 'autistic person' to reflect how some individuals prefer to be identified.

1.5 A narrative approach

In social research, 'narrative' has become an increasingly relevant method for investigating the ways in which individuals story their lives and express their thoughts and feelings about a particular event or experience (Riessman, 2008; Squire, Andrew and Tamboukou, 2013). From an interdisciplinary perspective, using narrative as a research method has also become relevant within Disability Studies because of what the narratives reveal about the social, psychological and cultural lives of disabled individuals and their families (Clandinin and Raymond, 2006; Smith and Sparkes, 2008; Goodley, et al., 2013). The rationale for adopting a narrative approach for this research with minority ethnic families was to privilege those families who have largely been marginalised and under-represented in autism research and to transform knowledge about how their personal, social and cultural worlds have been influenced by having a child diagnosed with autism. Combining a narrative interview approach with the concept of transculturalism made it possible to deductively explore how the storying of events prior to and following their child's diagnosis of autism impacted on how identities were constructed across different social contexts, how their lives were transformed, the nature of their interactions with professionals and family members and their sense of belonging to the community. As Milton (2014) points out, the need for a shift in knowledge production about 'the autistic experience' requires an approach to research that is more dialogic and participatory and involves those with direct experience of autism.

De Fina and Georgakoupoulou (2015) have highlighted how research using narratives is divergent both from a theoretical as well as an analytical standpoint. I drew on the work of Squire (2013) to develop an understanding of experience-centred and sociocultural approaches to narrative interviewing and Goodley et al. (2004) who undertook narrative research with disabled adults, which resonated with the approach I wanted to gain a deeper understanding of families' transcultural experiences and the meanings they gave to the experiences of parenting an autistic child. To achieve this, analysis of the individual narratives focused on the research technique of Hollway and Jefferson (2013) to develop pen portraits and psychosocial interpretive summaries and the identification of patterns of meaning as themes (Braun and Clarke, 2006) within and between their individual case studies. For interpretive purposes this mixed method approach enabled me to attend to the multidimensional nature of family functioning and the potential that their narratives would challenge the dominant discourse on cultural 'differences' and recognise the similarities in families' experiences of caring for an autistic child.

1.6 Terminology

Cuccioletta (2002), like many cultural studies scholars, highlights how 'culture' has become a contested concept particularly when aligned to the global movement of people and the diaspora of those seeking refuge predominantly in Global North countries. Global North and Global South are referred to in this research to describe how countries are positioned in terms of economic, industrial and technological wealth. Predominantly the wealthier countries are in the global north hemisphere, while many countries in the southern hemisphere, with the exception of Australia and New Zealand, have largely been the receivers of imperial power and colonisation that continue to impact on economic and political developments. These global demarcations are referred to in Disability Studies as they go some way to explaining how families who have a disabled child have become culturally separated and economically positioned within individual countries (Meekosha, 2011).

Whilst 'culture' can be referred to as the learned, shared and transmitted values and beliefs of an individual or group (Lum, 1999), it is also recognised as being context-specific in the way that it influences the actions and thoughts of individuals, groups and institutions and the interactions between them. Okazaki and Sue (1995) recognise

how 'culture' and 'ethnicity' have tended to be used interchangeably in research involving minority ethnic families and rather than see ethnicity as defined by culture or ethnic groups as cultural groups, an understanding of how these concepts are formulated by the individual's perceived identity, was essential. Unless used in the literature, or when quoting, I have avoided using 'Black Asian Minority Ethnic' (BAME) to acknowledge that this categorisation does not adequately reflect the cultural variations and heritages of people from different countries (Aspinall, 2002). I will refer to families as 'minority ethnic' to highlight the fact that everyone has an ethnicity and the issues being referred to relate to minority groups in a UK context and any discrimination and barriers they may face. This term does not infer that the participants in the research are an homogenous group and specific reference to their country of birth (Bangladesh, Iraq, Sierra Leone, Somalia, UK) and their cultural heritage (2nd and 3rd generation British) reflect the individual meanings they gave to describe their ethnic or cultural background.

1.7 The structure of the thesis

With a global demand for knowledge and understanding of autism there has been a steady rise in internationally published case studies of families' experiences of having an autistic child (Kim, 2012; Grinker and Cho, 2013; Manor-Binyamini and Shoshana, 2018). It was therefore pertinent throughout this research to incorporate literature that represents a global narrative about autism to eschew the White ethnocentric focus that has been dominant (Ennis-Cole, Durodoye and Harris, 2013). Chapter 2 discusses how the global literature on autism has been conceptualised and influenced minority ethnic families' experiences of the diagnostic process. Engaging with the extant literature on family-focused autism research with minority ethnic families and parent-professional interactions, it argues why there is a need for a shift towards a transcultural understanding of families' experiences and the development of professional practices. Chapter 3 presents a discussion on the methodological approach to address the research questions and gives prominence to process of data collection and methods used to analyse the families' narratives about parenting an autistic child. This also required an understanding of the ethical nature of researching across 'difference' and my role as a reflexive researcher from the data collection through to the interpretive and analytical stage of the research. The findings are presented in Chapters 4 and 5. Firstly, Chapter 4 provides pen portraits of the

individual case studies with interpretive summaries to explore patterns of meaning within the parents interviews and inductively and deductively evaluates the ways in which their storying of specific events represented their family's transcultural lives. Chapter 5 then presents a cross-case analysis of the parents interviews and provides a collective narrative about the similarities and differences in parenting an autistic child across multiple cultural contexts. Chapter 6 provides a summary of the findings and a discussion on the implications of the research on educational practices and the development of culturally responsive pedagogy in autism education. Chapter 7 concludes the thesis by considering the limitations of the research and how I would take it forward and disseminate the findings.

1.8 Conclusion

Evidence from family-focused autism research to date has recognised that engaging minority ethnic families in research has not been extensive (Munroe, Hammond and Cole, 2016) and as consequence, the diverse perspectives of autistic individuals and their families from minority ethnic backgrounds, has been largely under-represented. I sought to address this by undertaking research with families to develop a transcultural understanding of autism and create opportunities for shared cultural understanding between families and professional practices in education. The following chapter will critically appraise the current literature on the global concept of autism, the justification for the development of a transcultural perspective on autism and the factors affecting the subjective experiences of minority ethnic families who have a child diagnosed with autism.

Chapter 2: Literature Review

2.1 Introduction

This review of the literature presents a theoretical discussion on autism and family-focused research that supports the research questions and provides a deeper understanding of what transculturalism brings to the knowledge about minority ethnic families' responses to an autism diagnosis, how they access services of support and seek an appropriate education for their children. Key to establishing why a transcultural approach to the research was adopted, the discussion begins with an understanding of how autism, diagnosis and assessment has been historically and culturally positioned within Euro-American medical science research and had a global influence on families and institutional practices world-wide. Pellicano and Stears (2011) have affirmed how medical research has dominated the developments in knowledge about autism symptomology, research and practices and seeking sociocultural explanations for autism have not been prevalent. As a consequence, what has emerged is a global debate on the disparities in global prevalence rates and the reasons why the diagnostic tools that are currently available have continued to challenge how autism as a global phenomenon, has come to be defined.

Through the literature cited, I will argue how transculturalism offers an approach to researching with families that goes beyond the need for cultural comparisons to avoid what Manor-Binyamini and Shoshana (2018) suggests, is a continual refinement of the differences between cultural and ethnic groups and the need to adopt more focus on clarifying the similarities between them. A transcultural paradigm removes the need to emphasise difference between 'cultures' by focusing instead on how families develop a transcultural identity, how their lives are transformed through significant events, how professionals engage with them through intercultural dialogue and how they seek a sense of belonging to their community and networks of support. This distinction critically underpins the concept of transculturalism in autism and family functioning and provides an opportunity to theorise how families are interacting across multiple cultural contexts when they have a child diagnosed with autism.

The availability of research on autism in families from countries other than those in the Global North, has in more recent years, made it possible to evaluate representations

of autism and families' experiences through global literature, as well as studies that are pertinent to immigrant and minority ethnic populations in the UK. Crucial to this debate will be a focus on family-focused research that will provide an understanding of the dynamic nature of families' lived experiences and the individual coping strategies that families adopt in response to having a child diagnosed with autism.

2.2 A cultural narrative of autism

This section discusses the historical conceptualisation of autism and how the global narrative on autism has been influenced by a culturally dominant Global North perspective. This is critical to understanding how minority ethnic families have developed their own transcultural narratives about the nature of autism and the cultural influences that impact on their individual responses to having a child diagnosed with autism.

The autism narrative that is ontologically grounded in psychiatric and psychotherapeutic theories emanating from Euro-American scientific research over the last century, has been largely responsible for the conceptualisation of autism. The term 'autistic' was first used in 1911 by Bleuler, a German psychiatrist to describe the mental disturbance in adults with schizophrenia. It was Kanner, an Austrian-American who in 1943 then used the term 'autistic' as a diagnostic construct to refer to a group of children who he identified as emotionally and intellectually impaired and showing an extreme 'aloneness', which he later wrote about in his seminal paper *Autistic Disturbances of Affective Contact* (Kanner, 1943). The treatments which followed were predominantly based on psychiatric interventions aimed at reintegrating adverse ways of thinking and behaving. By the 1970s the concept of autism as a psychotic disorder was being re-conceptualised as a behavioural disorder and with the development of cognitive neuroscience in the 1980s, interest in neurobiological damage as a causal explanation of autism began to emerge. Interestingly, this was a return to Kanner's original view that it was biological damage that resulted in the 'autistic behaviours' he observed (Boucher, 2009).

Wing and Gould's (1979) study of 35,000 children in Camberwell, London who had intellectual, social, communication and behavioural impairments took the 'cognitive deficit' view of autism a step further. They theorised that autism symptomology could

exist as a multi-dimensional condition, not necessarily in a distinct form but sharing a 'triad' of behavioural features that included impairments of social interaction, social communication and social imagination and flexibility. The term 'autism spectrum disorder' is now widely used both by professionals and practitioners and this seminal research has been largely responsible for the development of autism diagnostic assessment tools which have international recognition. The international classification of autism as a spectrum disorder in both DSM-5 (APA, 2013) and ICD-11 (WHO, 2017) define the heterogeneity of 'autism spectrum disorder' as a complex phenomenon that includes those with severe intellectual and communication difficulties and those with no intellectual or language impairment. Exponentially this has led to challenges in establishing a global understanding of autism, assessments and diagnosis.

2.3 Autism: a global perspective

Constructing a concept of autism that is fundamentally culturally and historically grounded in scientific research is useful for highlighting how autism research into the aetiology, genetic variations and cognitive deficits has continued to pathologise autism and positioned it firmly within the deficit-focused disability discourse (Grinker, 2008; World Health Organisation, 2013; O'Dell et al., 2016). This precedence for scientific research is key to understanding how the generalisation and acquisition of knowledge about autism in the UK and globally, has come to dominate treatment and intervention programmes in healthcare and educational provision and influenced families' access to diagnostic assessment and networks of support. It has led several authors (Daley, Singhal and Krishnamurthy, 2013; El-Ghoroury and Krakow, 2012; Elsabbagh et al., 2012) to research the factors affecting under-diagnosis or symptom recognition in particular communities that has negatively affected an early diagnosis and access to treatments or educational interventions. These factors are discussed in the following sections as they go some way to understanding how the development of global knowledge about autism has influenced how families from Global South countries and minority ethnic families who are living in the Global North respond to an autism diagnosis and the decisions they make about their child's education and care needs.

2.4 The problem with autism assessments and diagnosis

The *Autism Diagnostic Observation Schedule* (ADOS) and the *Autism Diagnostic Interview* (ADI) were devised by Lord et al. (1989) to identify individuals on the autism

spectrum as distinct from individuals with other developmental delays. The ADOS is a behaviour observational tool that involves administering several tasks for individuals to carry out to identify strengths and needs and together with the ADI-Revised aims to determine the mildness or severity in an autism diagnosis. Although widely used across many countries, there continues to be a significant gap in considering other cultural variables within the ADOS and ADI such as child-rearing practices, birth country, factors influencing immigration, language(s) spoken, physical and mental wellbeing and economic status (Grinker et al., 2011; Daley et al., 2013).

Meekosha (2004) has also highlighted the need for caution in positioning families from Global South countries as the recipients of 'Western' psychological theories that impose cultural views about disability and how it impacts on a child's developmental potential. By defaulting to the White Euro-American view of disability and neurological differences it has been argued that the dominance of psychological theories on autism has paid insufficient attention to cultural and environmental factors affecting individual responses to an autism diagnosis, with the intersections of ethnicity, culture and identity within the autism discourse being largely ignored in research (Cascio, 2015; Daley, 2002) to the extent that explanations about autism have perpetuated cultural disparities in how it is perceived. This has led researchers to question the efficacy of the autism diagnostic assessment tools currently in circulation that conceptually presuppose that the heterogeneity of autism can be determined without reference to the influence of cultural and linguistic diversity (Dyches, et al., 2004; Trembath, Balandin and Rossi, 2005).

In a US study Harrison et al. (2017) posited that increased global access to ADOS through translation did not sufficiently provide linguistic or cultural adaptation to some of the measures presented in the test. To examine bias for 'race', ethnicity and gender majority White, Black African-American, Black African, Hispanic and Asian participants were included in their study. After analysing the algorithm scores from the items within the 'Social Affect' and 'Restricted and Repetitive Behavior' domains they found significance for a White ethnicity/race bias in *Unusual Eyecontact*, *Stereotyped/Idiosyncratic Use of Words or Phrases,* and *Immediate Echolalia*. The authors suggested that a more in-depth investigation would benefit from further

unpacking of cultural variables influenced by socio-economic status, birth country, immigration history, language spoken and acculturation.

To overcome this issue of determining 'ethnic difference' as an 'cultural difference' Perepa's (2014) UK-based study, explored the cultural basis for social 'deficits' in autism from the perspective of families from different ethnic backgrounds (White British, Somali, South Asian, African and Caribbean). Semi-structured interviews were carried out to ask the parents about the importance they gave to different social behaviours and those commonly associated with social 'deficits' in autism. There was no consensus across the interviews with some parents recognising the importance of teaching their children social skills that would help them to 'fit in' better into British society while others placed more value on reducing the social 'deficits' associated with autism. Among the themes that had influenced their responses, he found that the length of time parents had been living in the UK, their acculturation experience and the parent's gender, to be significant in which social behaviours they considered important to teach their autistic children. In concluding this study he questioned the extent to which the diagnostic criteria for autism is culturally biased towards a 'Westernised' perspective on social behaviour and cautioned against making cultural assumptions about families based on ethnicity.

The cultural disparities in the autism assessment and diagnostic tools are now widely recognised (Wilford, 2012; Durkin et al., 2015; Tomlinson et al., 2014; Elsabbagh, 2014) implying that a global understanding of autism remains incomplete and potentially biased towards White families in high-income Global North countries. Consequently, questions have been raised about the efficacy of a global assessment tool that is based on White, middle class Euro-American behavioural categorisations that may not translate as 'autism' in another society or culture (Zeliadt, 2017).

2.5 Autism prevalence in minority ethnic families

Another debate within autism studies that is relevant to researching minority ethnic families, is whether a global increase in autism diagnoses is due to the broadening of the autism criteria and a greater awareness of the symptoms of autism by migrant families living in Global North countries (Daley, Singhal and Krishnamurthy, 2013; Elsabbagh et al., 2012). In Sweden, research into an increased prevalence of autism

diagnoses amongst the immigrant Somali community (Barnevik–Olsson, Gillberg, and Fernell, 2008; Magnusson et al., 2012) has sought a biomedical explanation linked to dietary changes, lack of vitamin D as a result of moving from an African country to a country in the northern hemisphere, coming from conflict situations in their home country that have been very stressful, or previously unidentified diseases specific to their African country of origin. Barnevik–Olsson, Gillberg, and Fernell (2008) concluded that environmental factors associated with migration may contribute to the development of autism presenting with 'comorbid intellectual disability' (p.12) that was higher among the Somali migrant population than the general population, but affirmed that the data on the aetiology across the autism spectrum of disorders remained inconclusive. Similar studies on prevalence rates amongst minority ethnic populations in the UK have not been undertaken on a national scale, except where they have been included in local authority statistics for autism in different ethnic groups (Hassan, 2012). While studies are beginning to identify high ratios of autism diagnoses among certain ethnic populations in the UK, Tromans et al. (2020), in their systematic review of literature on autism identification across ethnic groups, suggest caution is needed to attribute the causes, implying that further research with minority ethnic families is required.

Likewise, Elsabbagh (2014) has expressed concern about the recent studies on the increased prevalence for autism amongst migrant populations to Canada, Europe and the US, and that too much emphasis is being placed on health disparities in autism being attributed to racial differences in biology. Families' self-reporting that autism was rare, or not part of the family history in their country of origin are, according to Elsabbagh (2014), not a sufficient explanation for increases in autism diagnoses within a particular ethnic group, but more likely associated with a 'catch up' in diagnoses being recognised that would previous have been un- or under- diagnosed.

2.6 An under-diagnosis of autism

Studies involving immigrants to Canada, Europe and the US have identified that minority ethnic families tend to seek an autism diagnosis for their child at an older age than majority White families (Barnevik–Olsson, 2010; Dealberto, 2011; Kediye, et al., 2009; Kuenzli, 2012; Miller-Gairy and Mofya, 2015). Miller-Gairy and Mofya's (2015) research with eight immigrant Somali mothers whose autistic children were born in the

US, strongly suggested that cultural attitudes and beliefs about disability influenced parents' decision not to seek an early autism diagnosis and cited a lack of understanding within the Somali community about autism as a key reason for the delay. They also referred to other reasons for a delay in seeking a diagnosis which related to concerns about the cost of accessing healthcare and professionals making cultural assumptions about the Somali mothers' attitudes towards seeking advice outside of their extended family and Somali community. Researching the under-diagnosis of autistic children in minority ethnic families living in Global North countries, Begeer et al. (2009) cited how access to diagnostic assessments in terms of the cost of medical assessments, the economic consideration of needing to take time off work or to travel to attend regular assessments, were also factors affecting the delay in diagnosis. This link to healthcare costs and access to diagnostic assessments has been related to the socio-economic status of minority ethnic families in Global North countries where many families remain in lower paid employment (Emerson and Hatton, 2007). However, it is important from a socio-economic perspective, to recognise that this is not specific to minority ethnic families.

Despite the cost of healthcare in the UK being markedly different, similar findings were noted in the UK-based National Autistic Society (NAS) report, *Missing Out?* (Corbett and Perepa, 2007) on minority ethnic families' experiences of gaining an autism diagnosis for their child. Parents reported that the social stigma associated with certain behaviours and cultural differences in developmental expectations, had influenced their decision not to seek an earlier diagnosis. They took longer to consider asking for further information about their child's development but also wanted recognition that they had knowledge and expertise about their child and did not want to be treated in a way that suggested they lacked the capacity to do so due to language and cultural differences. What this study involving immigrant families and British-born minority ethnic families advocated, was the need for increased knowledge and understanding by professionals about family traditions in child-rearing and extended family support, recognition of the increased stress experienced in families, the challenges of bringing up a child with a disability and engaging with professionals in an unfamiliar system. The findings also suggest that there needs to be some caution in linking a lack of engagement or delay in seeking diagnosis to a 'cultural' or 'ethnic' difference.

It would appear that a reshaping of the science of autism has not kept pace with the increased global movement of people and the cultural diversity which characterises many societies in the Global North (Mandell et al., 2009). Reducing the hegemony of scientific approaches to autism and moving from a medical model of autism has been evolving in recent years with an emerging social reconstruction of autism taking place (Happé and Frith, 2020). It is on this premise that most families will seek a biomedical explanation for their child's social communication difficulties as they personally re-configure how autism and disability has been socially and culturally constructed within the family and wider community (Seligman and Darling, 2007). For most parents, they are choosing a route to diagnosis that reflects their personal journey towards acknowledgement of their child's developmental differences, which includes positive explanations for their child's uniqueness regardless of a diagnosis or any labelling of a cognitive or behavioural impairment (Runswick-Cole, 2016).

The following sections of this review will discuss how transculturalism opens up a different way of thinking about the nature of experience that is pertinent to researching with minority ethnic families. It establishes a conceptual framework for understanding how immigrant and British-born minority ethnic families negotiate their identities across different social and cultural contexts, how having an autistic child transforms their lives and influences their interactions with professionals and sense of belonging to the community. Robson (2011) has highlighted how a conceptual framework forces the researcher to be explicit about the focus of the research, to be selective about the features of the framework and how they show a relationship with the data collection and analysis. Essential to this process is the need to consider what is meant by transculturalism and how it has come to be applied across different disciplines that make it relevant for thinking transculturally about autism and family functioning.

2.7 The concept of transculturalism
The development of a transcultural framework for researching minority ethnic families' experiences of having an autistic child requires both an understanding of transculturalism and an exploration into how disability, culture and identity come to be redefined. Riddell and Watson (2014) recognise how each of these facets of human experience have created ideological challenges in how they have been applied within sociological, psychological and political spheres of research. Similarly, with the

concept of transculturalism being developed in many different disciplines, a wealth of literature exists, but not all will be relevant to researching families' transcultural experiences of having an autistic child. Although not entirely rejected, articles on transcultural arts and literature have not been scrutinised to the same extent as those related to cultural and migration studies, transcultural psychology and healthcare education.

A marked increase in the global movement of people has resulted in the recognition that in every society, there are multiple cultures and practices which co-exist. However as Giffard (2016) argues, what this means is that although most countries can no longer be defined as monocultural, they have retained a dominant social identity with a set of cultural beliefs and values that can reinforce differences and create imbalances of power between the dominant culture and minoritised groups. Where multiculturalism has been widely viewed as a recognition of ethnocultural diversity, it is now a contested concept (Epstein, 2009). Guillerme and Dietz (2015) suggest that the concept of multiculturalism, which has advocated a mutual understanding of different cultures within one society, has continued to categorise certain communities by ethnicity, religion and language who remain separated from the dominant culture. While making such groups visible, Guillerme and Dietz (2015) argue that this has resulted in heightening 'otherness' and discrimination towards minoritised groups, that has indirectly promoted an essentialist view of culture and identity.

Transculturalism has emerged as an approach to breaking down cultural boundaries rather than reinforcing them and makes it possible for different ways of thinking about multiple identities and shared cultural practices which are overlapping and yet distinctive (Grosu-Rădulescu, 2012). Slimbach (2005) also refers to the development of transculturalism as a move away from local knowledge that privileges dominant discourses on a range of social and political issues, to the recognition that there are multiple truths about the nature of experience and cultural values that give meaning to individuals' lives. Slimbach (2005) contends that transculturalism is not an ideological concept but a process through which societies realise that, 'amidst the diversity of cultural expression, we share common potential experience from where we discover the ways others make sense of their world' (p.205). Welsch's (1999) concept of transculturalism is that it aims to create societies that are multi-faceted, inclusive and

not separatist. This is not the same as minority ethnic families acculturating or responding to the way in which the dominant culture imposes its social and cultural ideologies on others from a different cultural background, but recognising that individuals will move between the cultures they are exposed to and have experience of.

Using a transcultural lens enables researchers to explore the dynamics of intercultural interactions, so that rather than imposing one set of culture beliefs onto another, there is the potential to create a different dialogue around 'difference', particularly where it relates to concepts of ethnicity and disability (Atkins and Hussain, 2003). Dossa's (2008) US-based narrative research with an immigrant South Asian mother from East Africa who had two autistic children, highlights how there is the need to create alternative and de-medicalised spaces around disability and culture in Global North countries. The mother describes how she adopted multiple identities to bridge the divide between the institutionalised systems that saw her as 'other' and her role as 'a citizen, a mother, a waged worker, an advocate and a Muslim' (p.95). Dossa (2008) describes the mother as becoming a protagonist in her actions to care for her children. Firstly by validating the cultural and historical traditions that she felt part of, but also in the way she transformed her ideals for herself and her family when confronted with the socio-political hierarchies of healthcare and education that positioned her on the margins of what was otherwise available for the majority White families. This example from research highlights a crucial element required for culturally-situated research, namely that research which does not enable those with direct experience to 'voice' their realities, perpetuates a static view of culture that is bounded within ethnic groups (Arzubiaga et al., 2008).

Nie and Fitzgerald (2011) recognise that the main features of transculturalism needed to overcome cultural stereotyping begin with appreciating the complexity in cultural differences and that internal plurality and diversity exists within every culture. By engaging in deeper dialogues about cultural beliefs and practices, there is the potential to focus not just on the differences but also the transcultural similarities and commonalities. In this way it reduces the 'tyranny of dominant cultural practices' (p.228) and puts more emphasis on connectedness and relational thinking.

König and Rakow (2016) suggest that the development of a transcultural paradigm rests on the way in which 'culture' is used as an analytical tool. In the following sections the discussion focuses on four key themes that are considered essential to the development of a conceptual framework for learning more about transculturalism in autism and family functioning. The first theme explores the notion of a *transcultural identity* that develops as a consequence of migration, where families find themselves culturally positioned by discourses of disability within the dominant culture and cultural inherited beliefs from other members of the family and the community. The next theme explores how families undergo a process of *transcultural adaptation* and *transformation*, not only as part of the acculturation process but in their affective responses to having a child diagnosed with autism. Not only are responses to diagnosis characterised by complexity and ambiguity they also induce a sense of agency as families adopt different approaches to cope with the impact of having an autistic child on family functioning. The theme of *transcultural interactions* highlights some of the issues that minority ethnic families have experienced in their interactions with professionals and accessing information and support from professional services. In overcoming some of the challenges that families experience, a solution-focused approach is presented that shows how culturally responsive professional practices have been developed to reduce discriminatory practices and families' experiences of marginalisation. The fourth theme discusses how families develop a sense of *transcultural belonging* and advocate for themselves and their autistic child to overcome some of the challenges they experience in navigating institutional policies and practices and accessing community networks of support through the different relationships they encounter. In summary, the development of a transcultural paradigm makes it possible to recognise how the processes of identity construction, transformation, interaction and belonging are uniquely experienced and interconnecting features of families' lives.

2.8 Multiple identities across different cultural contexts

A *transcultural identity* is one which Mahadevan and Mayer (2015) assert represents how individuals and groups draw on their simultaneous identities and are using multiple cultural frames of reference to attach meaning to their lived experiences. As they navigate across cultural boundaries they are also undergoing a process of cultural adaption and transformation that is adding another dimension to their sense of identity

(De Fina, 2018). In other words, identities are not 'lost' in the process of acculturation and minoritisation but are redefined as the life course is re-examined. Like 'culture', identity is a dynamic process which is constructed through a synthesis of different cultural experiences that are allied to personal, contextual and historical circumstances (Bhabha, 2004) and as such it is relevant to refer to the construction of 'identities' rather than 'identity' (De Fina, ibid).

It is in relation to migration that the concept of transculturalism in minority ethnic families' experiences of caring for an autistic child, establishes the link between culture and identity. In the UK, research with minority ethnic families has tended to focus on the cultural and cognitive dissonance they have experienced due to the knowledge they have gained about autism and the understanding about autism in their 'home' countries (Fox et al., 2017; Gilligan, 2013; Munroe et al., 2016) and emphasised the challenges in navigating unfamiliar health and education systems as a result of their immigrant status (Crozier and Davies, 2007; Rizvi, 2017). These studies focusing on Somali, South Asian and Black African and Caribbean immigrant families have highlighted how, as a consequence of learning that their child is autistic, they are having to adopt different identities as they respond to their own and others' cultural attitudes and beliefs about disability and engage with professionals to access support and information in healthcare and education.

Falicov's (2012) multidimensional ecosystemic comparative approach (MECA) for working systemically with immigrant families (see Appendix 1) was developed to assist practitioners working with immigrant families to gain a deeper understanding of how families maintain cultural values, identity and relationships while living in different contexts and adopting different patterns of behaviour, interactions and beliefs. The rationale for the framework was to remove universalist assumptions about ethnicity and family lifestyles and offer an ecosystemic view of culture and identity that emphasises the interaction between the individual or family and larger social contexts. The multidimensional aspect of the framework aligns with a transcultural approach in that it uses a critical cultural lens to understand how immigrant families are not just living *between* cultures but drawing on multiple cultural practices and contexts depending on their individual circumstances and choices. These influences can be compounded when having a disabled child requires families to reconfigure many

aspects of their family identity including factors such as the internalisation of the migration experience, changes in family relationships, child-rearing practices and socio - economic status. Migration, like disability disrupts family stability and it can be a struggle to regain family continuity while being presented with new challenges and opportunities in an unfamiliar context.

Sametband and Strong (2017) suggest how the reasons for the migration will also affect the psychological process of acculturation and the ways in which families negotiate their identities and orient themselves towards inclusion in their adoptive country. They discuss how reasons for the migration will also be associated with how families make sense of the challenges they face and the help-seeking strategies they adopt when learning about their child's developmental difficulties. Many individuals and families move to another country as refugees or asylum seekers having had traumatic experiences in their 'home country' prior to coming to the UK, while others may be joining family members, arriving as an economic migrant, or for education and healthcare reasons. Sametband and Strong (2017) also noted how families may also experience more than one migration, which can heighten family separations and a sense of connectedness to cultural rituals as well as a lack of access to familiar support systems. Puppa and King (2018) undertook a study of Italian-Bangladeshis' onward migration to the UK which was prompted by economic stagnation in Europe and a desire by parents for their children to be educated in the UK. In their interviews with 20 families, the research revealed how the reality was that most families remained in poorly paid, often part-time employment and inadequate housing conditions, which were of a lower standard than they had experienced in Italy.

The economic burden of care which families of disabled children can experience compared to those who do not have a disabled child, is widely acknowledged (Shahtahmasebi et al., 2011; UNICEF, 2013). Immigrant families can find it much harder to achieve higher paid employment and there may be economic considerations in terms of needing to take time off work to care for their child or to travel to attend assessments (Emerson and Hatton, 2010). These social and economic factors will add a further dimension to how individual family members construct their transcultural identities as they move between the traditionally inherited beliefs about their caregiving and provider roles and their agentic responsibilities towards the needs of

their family. Narratives of migration and identity can play a key role in understanding how families, when they have a child diagnosed with autism, interweave the cultural and personal dimensions of their lives to construct new identities, while simultaneously strengthening their psychological responses to living in a different cultural context (Kang-Yi et al, 2018). In the next section I expand on this by discussing how the transcultural influences on families' responses to an autism diagnosis are multi-layered and transformative. This transformative process represents the ways that families will find psychologically adaptive resources and seek out practical supports that enable them to respond to a different life course than the one that they were expecting.

2.9 How families' lives are transformed

When a family experiences a significant life event such as migration or learning that a child has a disability, there will be profound psychological adaptations which will affect individual family members in different ways and at different times within that process (Seligman and Darling, 2007). This systemic approach is seen as valuable tool for researching the *transformative nature of families' transcultural lives* that are bound within a complex and interactive social system in which all family members' needs and experiences affect each other. This section continues with the discussion on the use of systemic family approaches for working transculturally with minority ethnic families.

Family systems approaches are based on family systems theories which were derived from therapeutic work with families in the 1950's (Cridland et al., 2014). Family systems theory shifted the focus on pathologising the difficulties families were experiencing and instead emphasised 'the centrality of interpersonal relationships, communication and interaction for the development of identity and experience' (Dallos and Draper, 2005:23). Systemic theories recognise how these characteristics are emergent and always evolving to the extent that when a unique event occurs, it will impact differently on individual family members and the roles and relationships within the system as well as those outside the family system with whom they may also share common identities and experiences.

As Cridland et al. (2014) point out, applying family systems approaches to understanding the impact that having a child diagnosed with autism has on the family,

practitioners can gain insights into the ways that families interact and develop coping repertoires to overcome the challenges they are facing. This personalised approach has the potential to open up the dialogue about the transcultural similarities in how families' respond to having an autistic child that goes beyond the need to make cultural comparisons.

What practitioners working with family systems approaches have identified, is that there is an emotional language that is shared by families when they have a disabled child, that is not fixed to one set of cultural beliefs and attitudes about disability (Dunst and Trivette, 2009). Rather it is an intensely human experience that legitimates families' responses, how they construct their experiences and decide on courses of action (Vetere and Dowling, 2005). For example, acceptance, resilience and coping strategies due to families needing to take a different life course are features that can be found in the acculturation experiences of immigrant families moving to a different country (Falicov, 2012) and doubly experienced when a family has an autistic child (Çelik and Ekşi, 2018). The focus of the thesis lies in illuminating these experiences and the courses of action taken by minority ethnic families whose experiences have not been widely represented in autism research.

Stages of acceptance have been discussed as part of a grieving process, an adjustment to different family circumstances and as an ongoing process across the family life span, but as Seligman and Darling (2007) point out, it is important to recognise that 'stages' can be conceptually misleading due to the unpredictable and transformative nature of families' experiences. An illustration of this process is highlighted in Desai et al.'s (2012) research in Goa, investigated parents' experiences of caring for an autistic child and the meanings that parents gave to the realisation of their child's autism, prior to and following a diagnosis. They interviewed twelve families to gain a more in-depth understanding of the different phases in parents' awareness of autism and acceptance of the diagnosis.

The outcome of the study highlighted how a response to diagnosis translated as a global feature of parenting a disabled child, where recognising differences in a child's development included the same paradoxical tensions experienced by White Euro-American families in Global North countries. Desai et al. (2012) describe how in the

initial phase, parents explained their child's behaviours in terms of normal development and child-caring practices and were not initially seen as symptomatic of autism until the problems persisted. It was in the next phase that parents began to experience divergent views from others in the community as the child seemed to function well in many areas but not all. In the last phase the parents aim was to accept their child's limitations as a consequence of not making the same developmental progress as other children. Crucially, the age at which this occurred depended on the families' experiences of engaging with professionals and the ways in which the diagnosis impacted on the psychological and economic wellbeing of family. In this phase parents were also learning more professional and scientific knowledge about autism and as a consequence their understanding of autism changed, leading them to have a more open-ended view of their, and their child's future. This specifically related to families reaching a point of acceptance while also pursuing solutions to their ongoing challenges, one which the parents felt, was a responsibility to change others' beliefs and attitudes towards autism.

Cridland et al. (2014) suggest that a comprehensive understanding of the challenges experienced by families caring for an autistic child using family systems approaches, should also include an investigation into the positive coping and support strategies which families utilise that enable them to manage stressful situations, show resilience and respond to diverse and unpredictable situations. Bayat's (2007) qualitative analysis of resilience in families from different ethnicities highlighted the positive experiences reported by many families who found that having a child with a disability had strengthened family dynamics, confidence and assertiveness without the need to seek out interventions from service providers. Bayat identified that making meaning out of adversity, changing their world view by becoming more understanding and patient towards others, being more compassionate and having a spiritual experience or belief system, were all significant factors in families' adaptation and experiences of having a child with autism.

Utilising a family systems approach to develop an understanding of the ways in which family members' lives are transformed in the intersections of their migration and minoritised status and having an autistic child in the family, is fundamental to understanding their transcultural experiences. From a transcultural perspective,

undertaking research which illuminates the processes of adaptation and psychological transformation that minority ethnic families experience as they navigate across different social and cultural contexts to seek access to information and assessments related to a diagnosis for autism, was seen as crucial to the thesis. The next section explores how professional practices have been developed to provide more culturally responsive interactions with minority ethnic families and how they can be applied to special education for autistic children.

2.11 The nature of family and professional interactions

Transcultural interactions are foremost about establishing a dialogue between families and professionals that involve an empathetic understanding of the social and cultural influences on a family's response to their child's autism diagnosis. Numerous studies have sought to evaluate the components of family-professional partnerships that are aimed at improving outcomes for families and individuals within the families (Swain and French, 2001; Prezant and Marshak, 2006; Hsiao, 2013; Hodgetts et al., 2015). One of the challenges which have been cited by Hodge and Runswick-Cole (2008) is that the term 'partnership' that is frequently used to describe how parents and professionals should work together, is too loosely defined and invariably a source of tension and frustration rather than an idealised state of mutual respect and complementary expertise. Hodge and Runswick-Cole (ibid) identified that a further concern in establishing positive interactions with professionals is a legacy of problematising families' engagement with professionals that continues to position parents as recipients of expert knowledge about their child. Overcoming this power imbalance is particularly relevant for parents of disabled children but also for families who continue to be marginalised as a result of more than one characteristic of 'difference'.

Maitra and Rawala (2015) recognised that whilst there is a need for increased professional awareness of autism in minority ethnic communities and strategies for support, there is still a tendency to blame the families who are not wanting to access services, or who have a problem with gaining relevant information due to language differences. Different approaches to communication may be required and communication and interaction styles can also be different within and between families (McGoldrick et al. 2005). For many minority ethnic families, particularly those who are

British-born or who came from British post-colonial countries, it can be the case that language is not a barrier to accessing information. In Heer et al.'s (2012) UK study involving in-depth interviews with South Asian mothers caring for a child with a developmental delay, cultural misunderstandings and inaccessible healthcare services were identified. The parents highlighted how the coexistence of British and South Asian cultures impacted on their caregiving experiences and that the exposure to 'Western' medical explanations of autism, their family and the local community had resulted in significant cultural and emotional dissonance. They expressed how difficulties with navigating the health and education services often left them vulnerable and at risk of isolation because of the difficulties in understanding what the professionals were offering. While this may be a feature for many White British families who have an autistic child, there is a culturally dominant expectation that they should seek scientific explanations for their child's developmental differences and that engagement in this process is paramount (McKeever and Miller, 2004).

Research by Keen (2007) has shown that where there is shared decision-making and goal-setting between professionals and families, there is a greater sense of empowerment and confidence in families when they achieve the outcomes for the child or young person with a disability. This was also more effective when it involved an understanding of the within-family processes and the sociocultural context of the family (Murray, 2000; Carpenter, 2000; Morrow and Malin, 2004). The provision of transcultural models of professional practice has been stimulated by countries in the Global North responding to the need for equitable provision and accessibility for minority ethnic families in multicultural societies (Culley, 2006; Crotty and Doody, 2016). This has come about as a consequence of the inequalities in access to treatment based on ethnic and cultural differences which, according to O'Hara (2003) have been perpetuated by stereotypical assumptions and prejudicial attitudes, particularly in professional communications with families who have a disabled child.

A further challenge highlighted in the literature on transculturalism in clinical practice (Wright and van der Watt, 2010) has recognised that even where professionals are providing culturally sensitive care, the institutions they represent continue to promote diversity policies and anti-discriminatory practices based on the legacy of a multiculturalism that has a tendency to homogenise ethnic and cultural perspectives

on disability. This has resulted in families continuing to feel marginalised and separated from the dominant culture (Goodley et al., 2013; Hussain, 2014). Concerns have also been expressed about the tendency for professionals to perpetuate essentialist views about families cultural responses to diagnosis and lack of access to available services of support which has led to a reduced engagement with minority ethnic families who have a child with autism (Begeer et al., 2009; Rizvi, 2017). For professionals, working transculturally means gaining more understanding of the cultural and contextual influences on families to reduce essentialising differences *between* ethnic groups and recognising the diversity *within* them. While this has become paramount to improving transcultural healthcare practices in the UK (Papadopoulos et al., 2016), it has only recently been identified as an area for concern for educational practitioners (Wearmouth, 2017). Putting forward an argument for the development of a transcultural model for teachers working in special education, based on previous work undertaken by health and social care professionals, has the potential to change the ways in which teachers engage with culturally sensitivity in their interactions with minority ethnic families.

Culturally responsive professional practice

In the US where the over representation of minority ethnic pupils in special education has been a considerable cause for concern, the development of culturally responsive pedagogy has been at the fore in educational research and led to the development of numerous practice-based models for teachers to utilise (Gay, 2006; Kim and Slapac, 2015; Kozleski and Handy, 2017). In the UK the trend has been substantially different, with very little research carried out that focuses on pedagogies to support ethnic minority pupils who have special educational needs (Tan et al., 2017; Wearmouth, 2017; Papoudi et al., 2020).

Sue's (2002) multidimensional transcultural model recognises that an essential component of culturally responsive professional practice is the need to identify the intra-ethnic and cultural variations within social groups, the need to be flexible in service provision and acknowledge the similarities as well as the differences in how families function. This demands that professionals need to gain an understanding of those variables which are common to all cultures, the sociocultural and contextual influences on the family, how the family is organised and how specific events affect

the family life cycle. Models of transcultural care (Papadopoulos et al.,1998; Leinenger, 2001; Campinha-Bacote, 2002; Sue, 2002) have emphasised how *cultural awareness* begins with professionals examining their own cultural beliefs and biases to provide a base on which to understand the professional practices being adopted. By constructing an awareness of a personal identity there is the potential to achieve *cultural sensitivity* towards others. While cultural sensitivity is strongly rooted in caring and respecting others, having *cultural knowledge* acquired through intercultural communication can help to bring about a greater sense of partnership and trust and better reflect how families establish a sense of belonging to a community (Crotty and Doody, 2016).

As a key component in families' transcultural narratives about autism, a sense of belonging is the focus of the last section of this literature review. It draws the discussion together by focusing on the transcultural realities for families as they find their own capital resources to seek networks of support both within institutions and their communities to overcome the challenges they face in caring for an autistic child.

2.12 Belonging to a community and networks of support

A key component in the development of a transcultural identity is achieving a sense of belonging to the community and society in which families are living. As a process, *transcultural belonging* 'develops out of the necessity to process multiple cultural experiences and to engage in meaning-making of different cultural forms as well as possible cultural conflicts and inconsistencies' (Vauclair et al., 2014:12). Too simplistic is the idea that place-related acculturation will enable a sense of belonging to a community, whereas in reality individuals will draw on their life experiences to create new associations while maintaining connections and meaningful relationships with family members they are no longer living close to.

It is also important to recognise that there is an affective component involved in transcultural belonging as families, in seeking to belong to a particular group can experience both a sense of connectedness as well as separation (Lee and Canagarajah, 2015). Begeer et al. (2009) found that the impact that having a child with autism has on interfamilial relationships and access to the local community for information and support, can heighten a family's sense of belonging as well as a sense

of separation. Separation can be experienced not only in relation to changes in the familiar aspects of family functioning and traditionally held cultural beliefs about disability, but also in accessing support services and deciding on the most appropriate educational provision.

The psychological impact of belonging and separation have increasingly been explored in research involving minority ethnic families who have a disabled child. Hubert's (2006) study in a south London borough involving 30 mothers, sought their views of caring for a disabled child, the appropriateness of services they received and what they felt they needed following diagnosis. All the mothers were immigrants from the Caribbean and India or were Indian, having lived in East Africa prior to coming to the UK. Several of them stated that despite the difficulties in caring for their child, they did not seek or want their child to be looked after by someone else as they did not see that asking for help was something their family would do. The mothers highlighted how they experienced prejudice and stigmatisation from others in their country of origin because of beliefs about punishment for having a disabled child. As a consequence, the families felt more isolated and frequently sought their own solutions to enable their child's inclusion in society.

Ritcher and Nollert (2014) suggest that a further dimension of transcultural belonging and having a sense of community comprises 'feelings' of belonging, the fulfilment of need and having a shared emotional and social connection to others. Belonging to a community and faith groups has been highlighted as providing families with a support network but as studies have shown (Jegatheesan et al., 2010a; Slade, 2014) they can also be a source of stigma towards families who have an autistic child. Hussain (2014) has expressed concern about the way in which religious beliefs are referred to as having an influence on minority ethnic families' views of having a disabled child as less attention is made of this amongst White British families. For example, in the NAS report *Diverse Perspectives* (Slade, 2014) minority ethnic parents and autistic people were asked to consider whether their ethnicity, faith and religious beliefs, had impacted on the difficulties they experienced in getting the help they needed when they sought a diagnosis. One section of the report focused on how families struggled with accepting a diagnosis and informing other family members due to 'shame and blame' within the community (p.9). 'Shame' was seen as something which reflected badly on

the family whereas 'blame' was felt to be related to the reasons others gave for why they had a disabled child. Another key point which Hussain (2014) expresses is the tendency to assume that these particular emotional reactions are observed in 'other' cultures when in fact they are experiences that White British families may also have, but do not get 'voiced' as part of the White ethnicity disability discourse.

Overcoming stigma and negative attitudes towards parents of disabled children relies on parents' acquisition and use of their social and cultural capital (Trainor, 2010). Using Bourdieusian 'capital' theory (Bourdieu, 1986), Trainor (2010) was interested in the types of cultural and social resources that parents perceive to be necessary to advocate for their children's inclusion in education and the community. She found that when parents actively sought a range of formal and informal knowledge as well as social relationships and networks, that families had more confidence in their capacity to gain the provision they wanted. Families use of their social and cultural capital was identified in a recent study researching Pakistani mothers' experiences of special education in the UK (Rizvi, 2017). Rizvi's (2017) study involving interviews with five parents in a special secondary school in the north of England, highlighted how they initially had difficulties understanding their children's need for special education provision. Explanations by professionals about their child's learning disability and a lack of choice in how their children were educated made them feel inferior in their knowledge about their child and the goals they wanted for their child's future. As Rizvi's (2007) research found, while this sense of disconnection cannot be generalised, neither did it remain permanent as families gained more understanding about what they wanted for their children's future.

In creating opportunities to enhance their social capital, it can also become a motivating factor for families to develop an affective sense of belonging, with families who share a common understanding about caring for an autistic child, to affirm their identity and need to belong to the community. Why many parents become activists as a consequence of having an autistic child has been a relatively under researched area (Ryan and Runswick-Cole, 2009) and even more so in relation to minority ethnic families' engagement in community support networks, faith organisations and schools. Hence why addressing minority ethnic families' engagement in support networks is key, not only for families' sense of belonging but also to break down barriers about

autism within the wider community (Kandeh et al., 2020). Place-related identity and belonging are aspects of families' transcultural lives that occur through their lived experiences, with family members in their 'home country' and through participation in different organisations and institutions within the local community. What transculturalism offers is an opportunity to understand how families are interacting across these different spaces, which cultural values and practices they choose to draw on in response to having an autistic child and in determining their own, and their children's future.

2.13 Conclusion

The one-directional knowledge base from Global North countries that has characterised the global literature on autism has been responsible for perpetuating the biomedical and psychogenic determinants for an autism diagnosis and promoting superiority in the development of autism specific treatments and educational interventions. Research has also shown that the scientific construction of autism has been an example of globalisation's reach for diagnostic homogeneity that has not fully explained cultural variations and attitudes towards autism (Kang-Yi et al., 2018). In this discussion it has been theorised how transculturalism could contribute to a global understanding of autism and the social, cultural and psychological factors which give meaning to families experiences of caring for an autistic child. Approaching this in research requires the researcher to adopt a particular methodological standpoint that is culturally situated and experience-centred to reflect different ways of knowing about families' transcultural experiences. This is the focus of the discussion in the next chapter of this thesis.

Chapter 3: Methodology

3.1 Introduction

The aim of this research was to combine the concept of transculturalism with a narrative approach to explore minority ethnic families' personal stories about autism, what their views were about the education provision for their autistic children and the nature of the interactions they had with professionals who worked with them. Transculturalism provided the theoretical framework for analysing the parents interviews by focusing on how they conceptualised autism within the cultural contexts of their family's lives. The objective was to undertake research that was culturally informed and gave prominence to the social, psychological and cultural influences on families as they navigated systems of support and information in caring for their autistic child. The research questions were designed to achieve this aim and attention was given to the methodological approach which sought to gain unique access to the personal, cultural and ideological dimensions of their lived experiences. These are discussed in the following sections.

As the researcher, I needed to maintain an ethic of responsibility in all phases of the research process from inception to dissemination, not only towards the participants' involvement in the research, but also in the later phase of analysing and interpreting the findings. Ethical appraisal underpinned all aspects of the research process that are detailed in the following sections. In the section on ethical considerations I explore why, in undertaking qualitative research it was important to establish trustworthiness in the process of recruiting and engaging families in the research. My positionality as a researcher involved in the co-construction of knowledge is also fundamental to this discussion. Not only was this essential to the research encounter with the families but also how I approached the interpretation of their narratives.

This chapter begins by establishing the research questions which have been reviewed through the literature and inform the research methods. I then present a rationale for adopting a case study approach to research transculturalism with immigrant and British-born minority ethnic families who have an autistic child. A discussion on the narrative approach adopted is then developed, how the families were recruited and

their characteristics. This is followed by a discussion on the data collection method and how the narrative interviews were analysed using different qualitative approaches.

3.2 The research questions

Research that has focused on the perspectives of minority ethnic families in the UK who have an autistic child, has been largely under-explored. As identified in the review of the literature, this has resulted in research outcomes that have tended to focus on identifying cultural and ethnic 'difference' and problematising issues from a dominant White ethnic perspective. As Bryman (2007) suggests the role of the research question in social research is to provide a guide for the research methods and the research but it is not always a linear process. As was the case in this qualitative research, the research questions were developed through a reflexive process (Agee, 2009). I began by wanting to counter the problem of essentialising ethnic groups as cultural groups and to emphasise the cultural similarities as well as the differences in families' experiences of having an autistic child. An exploration of how this could be achieved led to the development of a transcultural paradigm and as part of the research process this developed into the specific focus of the enquiry.

I drew on the work of narrative researchers (Elliot, 2005; Clandinin and Rosiek, 2007; Riessman, 2008; Squire et al., 2013) writing about the research process, who recognise how the research question requires both a pragmatic and ethical approach. This not only relates to the collection of data but the demands of the social context in which the research interaction occurs. I needed to be mindful of the ways in which I would be acquiring knowledge about the families and the significant events in their lives that they wanted to share with me and that this would involve giving primacy to the families' personal knowledge and interpretation of specific life events. Because I wanted the research questions to be open-ended and non-directional to allow for the emergence of the families' unique and meaningful stories, this led to the following research question:

What are the transcultural experiences of minority ethnic families caring for an autistic child?

Bryman (2007) also recognises that the research question does not always have to be ideologically fixed to a particular method because the nature of the research as it

takes place can affect the interrelation between the research question and the research in practice. To provide a further focus related specifically to the educational context in which the research took place, the following sub-questions were included:

What are families' experiences of their child's education?

What are families' experiences of their interactions with professionals?

In this way the questions represented an experience-centred approach that enabled the families to choose a particular set of events to tell their story (Squire, 2013). Question 1 was seen as the central question which Creswell (2013) advocates, provides an overarching view of the research problem. Creswell (2013) then suggests, as in Questions 2 and 3 that further sub-questions help to refine the central question. Working with their narratives, these sub-questions also provided a way of examining in more depth, the implicit and explicit references to transculturalism in the families' lived experiences of caring for an autistic child.

3.3 Research design

The transcultural conceptual framework outlined in the previous chapter provided the focus for researching with minority ethnic families to gain an understanding of the personal and cultural contexts which gave meaning to their lives in caring for an autistic child. Because I was interested in gaining an in-depth understanding of the families' transcultural narratives about autism, it was important that they were regarded as individual case studies. Yin (2009) identifies that one of the features of a case study is an intense focus on a single phenomenon within its real-life context. The families invited to take part in the research, shared a common experience of having an autistic child and were from different minority ethnic groups. What was important to the research design was not their representativeness as a homogenous group, but their uniqueness as individual families. A case study method was particularly relevant for researching the transcultural lives of families because of the way their experiences were culturally situated within a particular time and place (Brannen, Elliott and Phoenix, 2016).

Creswell (2007) points out that employing both inductive and deductive approaches to the data analysis is possible in narrative research. It was relevant to this research that deductive and inductive analysis was undertaken with the aim of deconstructing notions of cultural differences in perceptions of autism and families' experiences and

identify the commonalities that are relevant to families across cultural and ethnic groups. This mixed method approach was integral to exploring the dimensions of transculturalism using a deductive approach while allowing themes, as patterns of meaning, to emerge inductively from the data within and between the case studies.

Phoenix, Brannen and Squire (2020) have also highlighted that using a mixed method approach simultaneously allows for full consideration of the family context as well as the researcher's own reflexive analysis of the research encounter. Following each interview, I used journal writing to reflect on the researched-researcher relationship and culturally situate my reactions to their emotion-saturated stories and the elements of their narratives that were linked to the transcultural concepts which underpinned my research focus. According to Jootun, McGhee and Marland (2009:45) the key to reflexivity is 'to make the relationship between and the influence of the researcher and the participants explicit'. Adopting a mixed method approach involving deductive, inductive and reflexive methods of interpretation was pertinent to this research which was aimed at adding transculturalism to the discourse on minority ethnic families' experiences of caring for an autistic child.

3.4 The narrative interviews

Riessman (2008) highlights how case studies can focus attention on the narrative details, the 'big' and 'small' stories which the narrator chooses to share with the listener as well as the way in which the events are recalled for example, through affective expression. Focusing on the participants' narratives during the interviews was the chosen approach for this research on the grounds that meeting the research aim and addressing the research questions required an understanding of families' direct knowledge and experience of having an autistic child and that this was best explored through their subjective accounts. Undertaking open-ended narrative interviews, rather than a semi-structured interview was key to researching the families transcultural experiences as this enabled them to give their own account of particular events and the meanings they assigned to those experiences. Adopting an experience-centred narrative approach (Squire, 2013) for the interviews meant that I could give primacy to their individual storying of specific events and experiences of parenting an autistic child by attending to their narratives of identity, transformation,

interaction and belonging and how they were shaped by the personal, social and cultural contexts of their past and present lives (see Fig. 3:1).

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                    ┌───────────────────┐
                    │  transculturalism │
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narratives of identity	narratives of transformation	narratives of interaction	narratives of belonging
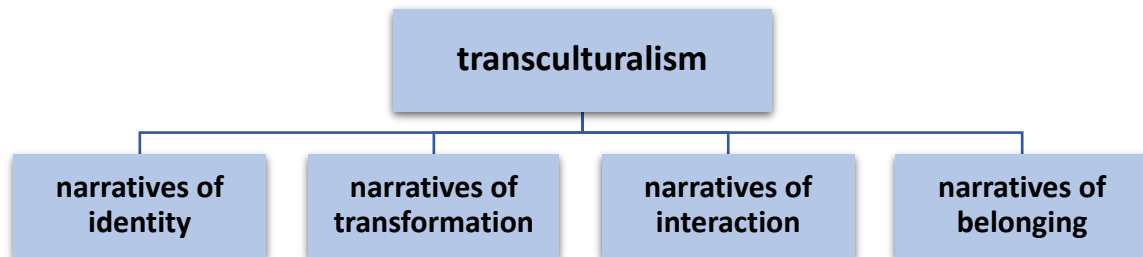
Fig. 3:1 Transculturalism as narratives of identity, transformation, interaction and belonging

How the interviews were established and maintained and how the sense of 'knowing' about autism and educational practices which we shared were both differently experienced and similarly understood, was fundamental to researching transculturalism with families. My aim was to work alongside the participants in the co-construction of the interview and to recognise the ways in which our interactions contributed to the development of their stories. Interviews involving a focus on narrative content are often referred to as being co-constructed, requiring another level of engagement in 'an embodied, connected process that works to develop an understanding of experience' (Caine et al., 2013: 582). Wengraf (2001) also suggests that co-construction enables inquirers to attend in a different way, that is not just 'knowing' the story being told but also understanding how and why the narratives are constructed in the ways that they are. This approach resonated with the therapeutic counselling approaches that I had used in my previous work with families as a systemic practitioner. Being cognisant of the dynamic and multi-faceted nature of the transcultural influences on their families' lives, my role as a reflexive researcher and the relational space in which the research took place was essential to the narrative method I adopted.

3.5 The cultural location of the researcher

Researcher positionality is an essential feature of qualitative research involving social and cultural discourses and is associated with the need to address issues such as

gender, ethnicity, age and professional identity at all phases of the research process (Milner, 2007). I adopted an approach to the research that was culturally responsive (Papadopoulos and Lee, 2002), in that I needed to recognise what I brought to the research design in terms of my own cultural assumptions, values, life experiences and social practices. For example, as a White British woman who does not have a child with autism, it was important that I reflected on my rationale for undertaking research with minority ethnic families. A key factor influencing how I approached the research was to consider how my personal and professional experience had given me insights into others' social and cultural worlds when they have a child diagnosed with autism. I drew on this knowledge to avoid essentialising cultural 'differences' and inequalities with an understanding that there will be similarities that were shared with the families I met. I also needed to recognise that my knowledge of certain cultural practices and experiences could be challenged, and that I would need to be sensitive to how the parents wanted me to understand their situation by asking them to explain, if they used terms I was not familiar with.

Deppermann (2019) has suggested that unlike more 'traditional' research methods such as formal interviews and surveys, with non-directive interviews there is greater potential for positions to be negotiated. Establishing a dialogue with the parents about the research prior to the interviews, contributed to the interviews being regarded by the parents as more of a conversation with me and that my role as the researcher was to listen to their storying of events and experiences and ask questions only to affirm aspects of their story so that it remained as intact as possible. I wanted to ensure that I approached the start of each interview with a sense of openness which shifted the power dynamic of a formal interview and positioned them as the 'tellers' and me as the 'listener' to their stories. This enable me to be reflexive in a way that was 'synonymous with ethical, responsible and culturally responsive research' (Valandra, 2012: 213). I was used to hearing traumatic and upsetting stories in my therapeutic work with families but in the research context there was a different dynamic at play. For example, when sensitive or upsetting events were recalled I checked with the parent whether they still felt comfortable in the research space and wanted to continue with the interview. Moving between subjective empathy and the need to objectify their storying of significant life events for the purpose of data gathering was also key to the reflexive process and how I established a responsibility towards the participants, by

legitimising their story during the data collection phase and treating it respectfully in the analytical phase.

3.6 Ethical considerations

In accordance with the British Education Research Association (BERA) requirements for undertaking research, I completed the UCL Institute of Education ethical application form and gained approval before the research commenced. Because conversations with the parents about the research initiated their participation in the research, informed consent began at this early stage. Informed consent has been defined as the knowing consent of an individual who is able to exercise the power of choice without undue force or coercion (Fluehr-Lobban, 2003). Duncan and Watson (2010) regard informed consent as a moral imperative, through which there is an ethical responsibility for openness, confidentiality and impartiality on the part of the researcher. Issues relating to any cultural sensitivities about engaging in the research did not arise. For example, as it was predominantly mothers who attended the parent meetings, I made no assumptions about them needing permission from the child's father to participate. It was only at the interview stage that I learnt that four of the mothers were single parents. With the two interviews which took place with both parents in their home, the fathers spoke first to their partners before consenting to my visiting their home. I did have concerns that some parents may not have wanted to consent to having the interview recorded due to having less confidence in speaking English but this did not arise. The parents' motivation for wanting to tell their stories and share their families' response to their autistic child's diagnosis, the nature of their interactions with professionals and their views about their child's educational provision was key to the parents consenting to participate in the research. The consent form (see Appendix 3) was signed by the participants before I met them for the interview, during which time they had the option to withdraw if they no longer wanted to participate in the research. At the point when the parents signed the consent form and at the start of the interview the parents were informed about the ways in which confidentiality and anonymity would be considered when the recordings were transcribed and in the writing up of the research findings. Issues of confidentiality were also considered as three of the interviews were transcribed by a professional transcriber who signed a letter of confidentiality (see Appendix 4).

3.7 Trustworthiness in research

De Fina (2015) highlights how at the heart of narrative research is the dynamics of the research encounter and that this places ethical demands on the researcher because of the way identities are negotiated in the research space and power relations, managed. A consideration for the wellbeing of the participants was paramount not only during the telling of their experiences but also in the interpretation of their storying of particular events and experiences. The basis for the ethical relationship in the research encounter is, according to Hollway and Jefferson (2013), 'to pursue the values of honesty, sympathy and respect' (p.92). Recognition that 'what is said' and 'what is interpreted' are treated with honesty and respect, are seen as key ethical principles in narrative research (Hollway and Jefferson, 2013).

Elliot (2005) and Park (2001) have also discussed how the ethical dimensions of the research encounter involving life story narratives presuppose how trust and authenticity give credibility to the method of data collection and interpretation. This shift from a positivist research approach to data with its requirement for rigour, validity and reliability, has resulted in qualitative researchers adopting a different set of attitudes towards the trustworthiness of data to emphasise *transferability* rather than generalisability, *dependability* instead of reliability and *confirmability* rather than objectivity (Lincoln and Guba, 2000). This is particularly relevant where the research involves an exploration of the subjective realities of recalled events and life experiences of others and the co-construction of meaning between the researcher and the participants (Morrow, 2005). I found this approach to trustworthiness in the production and dissemination of new knowledge involving minority ethnic families offered a way of thinking about the ethical dimensions of the research process that I had not considered in previous research. It highlighted the importance of informed consent, what they understood about their participation in the research and how, as the researcher, I took cognisance of the cultural and contextual nature of the research space.

3.8 Research context

This research was based in a special school located in one London borough which specialises in the education of pupils who have severe social communication difficulties associated with a diagnosis of autism, aged four to nineteen. In addition to

offering further education in a mainstream school setting they also have a satellite class in a mainstream primary school. The school and the school staff were not the primary focus for this research, but because most of the families who were interviewed, had children who attended this school, information about the school and the local borough is presented as it was pertinent to their feedback about the nature of support they received and their views about their children's education. The school had a multi-ethnic population which reflected the ethnic diversity of the residents in the borough. A home-school liaison officer and a member of the leadership team organised monthly parent workshops on a range of autism-related topics. These included, sharing information about education, communication and behaviour strategies, disability benefits, services of support and updates in local and national policy on the education of pupils with special education needs and disabilities (SEND). Fostering an ethos of parental engagement in their children's learning was a leadership priority within the school and it was through this culture of participation that the research was enabled.

Residents born in Bangladesh are the largest single migrant group in the borough representing over a third of the migrant population with those from African countries and the Middle East representing 3% (Corporate Research Unit, 2017). The Somali population being the second largest migrant group, has also increased since the civil war in Somalia in the 1980's, establishing a distinct community with about 6,500 living in the borough. Since 2016, there has been an increase in Italian-Bengali families in the school population in the borough. The data available indicated that there were a higher than average number of female single-parent households within the Somali community caring for dependent children, with fewer opportunities for employment and training. The borough has over 75% social, affordable (housing association) and privately rented housing mostly occupied by the minority ethnic population who have tended to remain in lower paid employment in catering, the taxi service, security and light industry (*named borough*: key facts n.d.).

An understanding of the population profile of the borough was crucial to this research as it reflects the social and economic conditions affecting the families who were interviewed. In addition, as families of a disabled child, they were entitled to further support and services available in the borough. Parents wanting an autism diagnosis

were either referred to an Autism Assessment Service where a multi-agency team of professionals were part of the assessment process, or they had access to the Child Development Centre based in the local hospital. The percentage of pupils with 'autism spectrum disorder' in the borough (32%) is higher than the national average (28%) and all pupils currently in special and mainstream schools with an autism diagnosis have an Education Health and Care Plan (EHCP) (*named borough*: key facts n.d.). Families in this borough and the local schools benefit from an outreach service based at the special school that provides autism training for school staff and regular meetings for parents. Having these established services, it was interesting to find out from families how they engaged with professionals in these services and the support they received, not only from the various institutions they came into contact with, but also their local community.

3.9 Family recruitment

I began working in the special school where the research was based in 2005 to develop an interactive play project with pupils, staff and parents. The project involved individual play sessions with pupils and staff training which contributed to a significant shift in the development of a play-based curriculum. Delivering parent workshops and ongoing consultancy ensured that the project was collaborative and parents had access to family sessions which took place in their home, if they were requested. Visits to the school have been ongoing since this project was started and this contributed to being regarded as a member of the school community by the families who wanted to be involved in this research.

A group of parents had expressed an interest in wanting to take part in research on autism within their community and I was approached by a member of the senior leadership team to lead discussions with parents about this. I was given verbal consent by the Headteacher to meet with parents at the special school where I was able to talk with them about taking part in the research. Discussions with the senior leadership team about the research meant that they were regularly updated about the interview process and the number of families who took part. Talking with the parents at their parent network meetings developed into a regular research dialogue with parents wanting to share their experiences of having an autistic child, the challenges they had in coming to terms with their child's autism diagnosis and the impact this had on their

families. This collaborative approach affirmed my rationale for wanting to undertake the research with minority ethnic families to gain more understanding of how aspects of their social and cultural lives intersect when they have an autistic child. In addition to our conversations about the research, a written introduction about the research (see Appendix 2) was also given with a consent form (see Appendix 3) if they wished to take part in the research.

A three-month timeframe was set for families to decide whether they wanted to participate although this was extended to six months as a different group of parents whose children were recently diagnosed, had been given a placement at the school and also wanted to take part. Their inclusion in the research was purposive in that all the families had an autistic child between the ages of 5 and 17 years old who was accessing educational provision at the school or in the satellite provision, or a mainstream school in the same London borough (see Table 3:2). The consent form was discussed with the parents who were then given the opportunity to decide which family members would take part in the research and where they wanted to meet me. Eleven parents from nine families self-initiated taking part in the research and although contact was made with more families who expressed an interest in taking part in the research, arranging a suitable time to meet proved difficult and no further contact was made. Some of the parents chose to contact me via email to confirm that they wanted to take part or they spoke to me following a parent meeting to arrange a convenient time for us to meet for the interview. Most of the parents, opted to meet at the school where one parent represented their family, either as a single parent or on behalf of both parents because one of them was working or at home caring for their children. One parent met at the school and then wanted me to meet his wife at their home; this meant that for this family, two interviews were carried out. I met with one family in their home where their children were present but were not part of the interview.

3.10 Family participants

The eleven parents who took part in the research were either British citizens or permanent residents from minority ethnic groups and referred to themselves as Muslim. This key information which they gave was significant for them as it reflected their expressed views about their cultural heritage and where relevant, their migration experiences. They all had a child with an autism diagnosis and two of the families had

a second child who was going through the assessment process for a formal diagnosis. Except for the two children who were not in education, all the children had an Education Health and Care Plan (EHCP). Of the nine families, six autistic children attended the special school, one was in a mainstream school waiting to start a placement at the special school, one was in a mainstream primary school with learning support and two were not in education. Seven out of the nine interviews were conducted in a quiet space in the school and two were in the families' homes. The recorded interviews took between 45 minutes and an hour although face to face or email conversations about the research had taken place prior to the interview. The study included only parents, not their children. However, analysis of their narratives showed how 'family' was interpreted by them to mean their extended family as well as their nuclear family. Two of the interviews included both parents which created a different dynamic to those with only one parent. The interview included interactions in Bengali between the husband and wife and between them and their children which meant that I became an observer of their interactions rather than a participant at this point in the interview. With both families the husband translated their conversations which maintained the conversational nature of the interview that had been established.

Table 3.2 presents information about participants including their pseudonyms, marital status, migration experience where relevant, family and the type of school that their autistic child attended. For the two interviews which took place in the family home, time was spent pre- and post- the interview to engage with the family so that the parents and the children felt comfortable with my presence in their home. All the parents were given an information sheet about the research and a consent form and agreed to their interviews being recorded so that they could be transcribed at a later stage.

Family (with pseudonyms)			Migration to UK	Children	School
Jessia	mother British Bengali 2nd generation unemployed, fulltime carer	Divorced	n/a	(M) 12 yrs (autism diagnosis) (M) 11 yrs (awaiting diagnosis)	not in school
Sahra	mother Somali unemployed, fulltime carer	Divorced	16 yrs old married in Somalia then lived in Canada for 4 yrs. Returned to UK in 2013	(F) 7 yrs (autism diagnosis) (M) 5 yrs	Special/ satellite class in Mainstream
Fatou	mother Sierra Leone part-time accountant	Divorced	16 yrs old Married a Ghanaian	(M) 19 yr (F) 17 yr (F) 6 yr (autism diagnosis)	Mainstream
Hibaq	mother Somali unemployed, fulltime carer	Married/ separated	brought up in Kenya came to UK -19 yrs old Married a Somali	(F) 8 yrs (M) 6 yrs (autism diagnosis)	Special
Nadifa	mother Somali unemployed nurse, fulltime carer	Married	brought up in Saudi Arabia came to UK 9yrs old with family Husband from Somalia	(F)12 yrs (F) 9 yrs (M) 7 yrs (autism diagnosis) (M)1 yr	Special
Arnab	father Bengali part-time taxi drive	Married	8yrs old with family Went back to Bangladesh (14 – 19 yrs) Returned to UK Wife came from Bangladesh 1999	(M)17 yrs (M)14 yrs Down's Syndrome and diabetic (autism diagnosis at 10yrs old)	Special
Manoj Madhura	father Bengali-Italian part-time security guard mother fulltime carer	Married	2014 from Italy Italian citizens, UK residents	(F) 17 yrs (premature birth, autism diagnosis and epilepsy at 5yrs old) (M)12 yrs (M)1 yr	Special
Soran	father Iraqi – Kurdish unemployed taxi driver, fulltime carer	Married	1998 Wife moved to UK in 2010	(F) 8 yrs (M) 7 yrs (autism diagnosis) (F) 5 yrs (M) 5 mths	Special
Yash Friya	father British Bengali 3rd generation employed fulltime IT systems mother Bengali fulltime carer	Married	n/a 2005 – from Bangladesh	(M) 12 yrs (SLCN diagnosis) (M) 5 yrs (autism diagnosis) (F) 3 yrs (? autism/ SLCN)	Mainstream transferring to Special Mainstream nursery

Table 3:2 Family participants

Key: n/a = parent was born in the UK; M = male, F = female; yrs = years old; SLCN = speech language and communication need

I had met with all the parents prior to the arranged interview and therefore I was not meeting them for the first time when we met for the interview. All the interviews were carried out in English as the participants spoke English either because they were UK-born, had lived in the UK since they were teenagers, or were educated in English in their home country. One of the Bengali families who were Italian citizens, were less competent in speaking English, but did not request a translator. For the two interviews with both parents, the fathers were the main narrators and either translated my comments directed to their wives in Bengali, or they translated their comments to me. The mothers understood English but preferred to express themselves in Bengali rather than English.

3.11 Data collection method

Crucial to the epistemology of the research, was the particular theoretical lens used to explore the nature of individual families' experiences that were recalled by the parents. While recognising that there are numerous qualitative and quantitative approaches to narrative interviewing, being familiar with using person-centred approaches in my therapeutic work with families, I drew on Hollway and Jefferson's (2000) free association narrative interview (FANI) method because of the way it focuses on the psychological, social and cultural factors which influence others' lives. Hollway and Jefferson (2008) combined both humanistic and post-structural theories to explore individual biographies and life history events that are socially constructed and uniquely lived and experienced. Unlike Hollway and Jefferson (2013) I did not use a psychoanalytical approach to analyse the interviews but recognised how the principles of the FANI method were relevant for exploring transculturalism in families' narratives about autism that would privilege the personal meanings which they attached to their individual stories that were 'defined by emotional motivations, rather than rational intentions' (Hollway and Jefferson, 2013:34).

The four principles for conducting FANI interviews included: using open-ended questions, eliciting a story, avoiding using 'why' questions and using the narrators ordering and phrasing of events so as not impose a structure on the narrative. In preference to using 'interview-type' questions, I wanted to focus on creating a dialogue and a co-construction of their individual experiences (Riessman, 2008) by occasionally affirming and enquiring about their storying of particular events. Rather than working

with questions to explain their experience as in 'traditional' interview methods, co-construction enabled me to explore the significance of their storying of events, the meanings they gave to what was recalled and the interactions between us during the interviews. As such, adopting a non-directive approach to their interviews meant that the research was not passively oriented towards what I, as the researcher wanted to know, but how the stories told were the ones the parents wanted to share. Explaining my approach at the beginning of each interview was one which appeared reassuring to parents and gave them an 'entitlement to talk' (Phoenix, 201:79) about aspects of their lives in ways which represented their families and their experiences of parenting an autistic child.

Eight interviews took place in a quiet room made available to me for the duration of the data collection phase of the research. As the parents were already familiar with the setting they appeared comfortable in the room as a research space. By inviting them to choose the seating configuration for the interview, could also have contributed to the parents wanting to engage with me in a context of their own choosing. I checked with the parents, as they had agreed on the consent form, that they were happy for me to record the interview and explained that it would be transcribed so that I could read through the interview and use examples from it when discussing the findings of the research. All the parents were happy for this to happen. The two interviews with both parents which took place in the family home began with a similar format but more time was taken prior to the interview to engage in conversation with the family and their children so that they were comfortable with my presence in the family home. Following the interviews with the parents, the children were then wanting to interact with me and a brief time was spent playing with them. At the end of the interviews, both in the school setting and the family home, parents were thanked for their time and for sharing their family experiences.

The interviews began by explaining to the participants that I was not going to be asking them lots of questions but wanted them to talk about their experiences of having a child diagnosed with autism and how it had impacted on their family lives, their relationships with other family members and their interactions with professionals as a consequence of having an autistic child. I also explained that I was interested in the experiences they had in accessing special education for their autistic child and how

culturally responsive the teachers had been in their interactions with them. In previous discussions at the parent workshops where I met some of the parents prior to the interview, they had given me information about their autistic child and their family, whereas for those I had not previously met, I asked them if they would like begin by telling me something about their family. It was therefore key where the parents chose to begin their story and the set of events through which to tell it. For some of the parents, beginning with their family's cultural heritage, migration to the UK and the family composition were a starting point whereas for others it was the events leading up to and following their autistic child's diagnosis which led to their emotionally-charged recall of their positive and negative reactions to learning that their child had autism.

For research involving individual narratives, it is through the sequencing of life-changing events, that the life story is given a structure and coherence to the way that experiences are re-presented (Bamberg, 2011; White and Epson, 1990). This response was something which all the parents embraced as a means of wanting to share their life stories about their family.

> While the life story partakes of socio-cultural narratives, the basic material of it is unique to each person because each individual's lived and inner experience represents a unique, interior configuration. (Smith and Sparkes, 2008:9)

Only one interview was undertaken with each family although as previously mentioned, I had an extended interview with one family, meeting first with the father at the school and then with both parents in their home. Parents agreed to my contacting them after the interview if I needed to and they also had the opportunity to contact me about any aspect of the interview after it had finished but none of them did. However, I informally met some of the parents again at parent workshops they attended after their interview with me.

3.12 Analysing the interviews

As highlighted by De Fina (2015) interpreting, analysing and representing others' lives is a complex process particularly when it involves understanding how identities are constructed and lives are reconfigured in response to significant events. Because I was interested in the families' personal stories about transculturalism as a means of

sense-making about their past, present and future lives, this required a sustained engagement with the process of interpretation across different phases of analysis. This multi-layered approach is highlighted in the following paragraphs:

Reflexive journal

Elliot (2005) and Squire et al. (2013) point out how a pragmatic and ethical approach to analysis begins at the start of the data collection process with the contextually contingent demands of the researcher encounter. After each interview I wrote down my reflections on the parents' individual stories in a research journal, to bring to the fore key aspects of our interactions and to pose reflexive questions that would enable interpretive connections to be made with the later stages of the analytical process. By capturing observations, emotional reactions and interactions this enabled me to reflect on and evaluate my role in the research process as a co-constructor and interpreter of their stories. I also needed to be aware that their personal narratives were a co-construction of the interactions between us and that my own reflexivity was part of the interpretive process. Arzubiaga et al. (2008:315) refer to this as 'highlighting the cultural work' that the research must do to support the interpretive and analytical process.

Transcribing the interviews

According to Crossley (2000) understanding the content and the complexity of meanings through a process of sustained engagement with the narrative, is crucial for presenting a coherent story at the analytic stage of research. Transcribing the interviews was essential to the interpretive process so that I could re-familiarise myself with their storying of events and experiences, the ways in which the stories were told and my involvement in the creation of their narratives. Listening to the recorded interviews provided insights into the discursive as well as the performative nature of the interview. For example, identifying a key word or phrase (discursive) that was used repeatedly showed how it had a powerful meaning for the narrator and the style (performative) in which a particular event was told, reflected the dominant emotional position that it held, for example, how and where the interview began in their telling of life story events, how emotions were expressed and their stories constructed. This was enhanced once the interviews had been transcribed as there was further opportunity to read and re-read the transcripts and begin to inductively identify

recurring patterns of meaning and their emotional engagement in their recall of events and significant experiences. At the same time, attention was paid to sections of analysis that related to the research questions. Riessman (2008: 28) emphasises this by stating that,

> In constructing a transcript, we do not stand outside in a neutrally objective position, merely presenting 'what is said'. Rather, investigators are implicated at every step along the way in constituting the narratives we then analyse.

Annotating the transcripts provided another layer of interpretation based on seeking meaning from the storying of personal events while at the same time, recognising how their narratives of identity, transformation, interaction and belonging endorsed the concept of transculturalism that was central to the research.

Thematic Analysis

Riessman (2008) points out how working thematically with narrative data provides a focus on the content of the narrators experiences and reflections which are then available for interpretation by the researcher. Similar to the research of Goddard, Lehr and Lapadat (2000) and Goodley and Tregaskis (2006) who combined a narrative interview approach with thematic analysis to illuminate the commonalities and nuanced experiences of parenting children with disabilities, this approach enabled me to focus on the significance of the events the parents were recalling. The purpose of identifying patterns of meaning deductively and inductively was to identify the connections between the families' transcultural experiences and the interpersonal and contextual influences which they drew on to make sense of their experiences of parenting an autistic child that were grounded in the data.

Thematic analysis has been defined as a qualitative research method for identifying, organising, describing and reporting themes that 'capture something important about the data in relation to the research question and represent some level of patterned response or meaning within the data set' (Braun and Clarke, 2006:10). More recently Braun and Clarke (2020) have referred to their approach as 'reflexive thematic analysis' which emphasises the importance of the researcher's subjectivity as an analytical resource. They argue that it is through reflexive engagement with theory,

data and interpretation through an iterative process of reflecting and questioning, that themes develop.

In an initial reading of the transcripts, I began a coding process by looking for recurring words and phrases used within their stories which reflected not only how they were telling the story but also their emotional response to the events they were describing. The ways in which parents sequenced events and where they positioned their experiences during the interview, also made it possible to recognise themes. For example in beginning the interview with the history of their migration to the UK or recalling events which led to the child receiving a diagnosis of autism. This allowed for themes to come to fore more readily than those which required further re-reading of the transcripts to 'identify patterns of shared meaning, united by a central idea or concept' (Braun, Clarke and Rance, 2014: 184). For example in their experiences of their interactions with professionals, a central theme, parents recalled both positive and negative experiences within and between cases. Complementary to the inductive approach used to identify themes within and across cases, I deductively analysed how they were using their narratives to express their identities, how they made adaptations to the families' lives, interacted with professionals and family members and experienced 'belonging' to their local community. This added another layer of interpretation which Geertz (2000:4) refers to this as offering a 'thick description'; an attempt to generalise within one case by critically reflecting on the association between the realities of their transcultural experiences and the ascribed meanings they gave to their storying of events. Identifying themes inductively and deductively was also part of the reflexive process of interpretation (Miles, Huberman and Saldaña, 2020).

Because I was attending to the ways that their personal experiences were shaped and enacted by the personal, cultural, and institutional narratives in which they lived through a multi-layered interpretative process (Clandinin and Raymond, 2006), I decided not to use a computer-based software package (such as Nvivo). Where Nvivo is predominantly used with larger samples, for coding and analysing qualitative data to produce patterns and themes, a small sample enabled me to focus on the individual families' narratives and identify extracts which determined personal and transcultural themes, while keeping their narratives as intact as possible.

Pen Portraits

Analysis began with pen portraits of the individual case studies which Hollway and Jefferson (2013) refer to as a way of describing the key attributes of the person that provides a holistic sense of what is meaningful in the storying of individuals' lives. Each family was described in an individual pen portrait so that the uniqueness of their transcultural experiences of caring for an autistic child could be presented with relevant details about their individual circumstances. Hollway and Jefferson (2013) suggest using a structured summary to develop the pen portrait which includes biographical information, the context of the research encounter and reference to the themes identified in the interview which are highlighted with extracts from their storying of events. The development of the pen portraits also reflected how the inductive interpretation was an evolving process of engagement and re-engagement with the transcript to explore not only the emotional significance of the events they described but to provide a reflexive account of the ways in which the stories they shared were co-constructed through the narrator-researcher relationship (Squire, 2013). In writing the pen portraits, it was important to recognise why particular narrative extracts were presented and what the reason was for their inclusion. I needed to see them, not just as 'segments of talk', but what they epitomised as the 'basis for interpretation' (Riessman, 2008, p.25) within the relational context of the interview. Maintaining the authenticity of the individual interviews by including direct quotes from the participants was crucial to ensuring that what they wanted to share about their experiences of parenting an autistic child, including any ambiguities and inconsistencies, was a representation of their reality in their transcultural lives.

Interpretive summaries

The purpose of the interpretive summary at the end of the pen portrait was to illuminate a theme which exemplified how they utilised intrapersonal and interpersonal resources to make sense of their experiences of parenting an autistic child. Listening to their individual stories became a way of knowing more about how their transcultural construction of events pre- and post- their child's autism diagnosis and how this had impacted on their sense of identity and belonging, their family and their relationships with others. Because I was interested in how the parents subjective experiences were interwoven with the social, cultural and historical contexts of their family lives, identifying an overarching theme from a psychosocial perspective enabled me to gain

a deeper insight into how the parents were making meaningful connections between the internalising of their experiences and the externalising influences on life events (Clarke and Hoggett, 2009; Schiff, 2017). Clarke and Hoggett (2009) also refer to having a psychosocial approach to narratives as a way complementing researcher reflexivity. As in Saville Young and Berry's (2016) research on maternal subjectivity in relation to childhood disability, a psychosocial interpretation enabled me to explore the ways in which their stories were told, how they were interpreting their transcultural experiences and responding to the commonalities and differences in intrafamilial and interfamilial beliefs about autism.

Cross-case analysis

Giving precedence to the interpretation of their individual life stories provided insights into the transcultural experiences of parents caring for an autistic child. Exploring the interrelations between the personal and collective narrative was essential to the iterative process of interpretation, so that by moving within and between the individual narratives I was able to add another level of interpretation and explanation to their transcultural lives. As a methodological approach, cross-case analysis has been described by Khan and van Wynsberghe (2008:2) as a way of,

> 'enhancing researchers' capacities to understand how relationships may exist among discrete cases, accumulate knowledge from the original case, refine and develop concepts and build or test theory'.

The cross-case analysis not only enabled the narratives to be located in a particular time and place but was important for identifying the commonalities and differences in their transcultural experiences of parenting an autistic child. As their narratives were also situated in professional practices and special education, the cross-case analysis provided further insights into the nature of their interactions with professionals, their experiences of their autistic child's education and how they engaged in networks of support within their community.

3.13 Conclusion

This chapter has discussed the rationale for using experience-centred narratives as an interview method to explore with minority ethnic families, the meanings they gave to their transcultural lives in their response to having a child diagnosed with autism, how they interacted with professionals and made decisions about their child's

education. The research questions derived from this 'methodological commitment' (Bryman, 2007:16) played a key role in determining the method of enquiry and the analytical process. Adopting a multi-layered interpretative approach offered a more in-depth exploration of transculturalism in autism and the families' narratives, so that by addressing the constituent elements of analysis it was possible to determine their collective meaning. The following chapter presents an analysis of the findings from the interviews that gives primacy to the personal and transcultural realities in the families' narratives about parenting an autistic child. Chapter 5 completes the analytical phase of the research with a focus on the transcultural themes which were derived from their collective narrative.

Chapter 4: Findings and analysis: family case studies

4.1 Introduction

This chapter presents the findings from the interviews with the eleven parents from nine families who participated in the research and what their narratives revealed about their transcultural experiences of caring for an autistic child which included how they interacted with professionals and their views about their children's education. As discussed in the review of the literature, developing a transcultural paradigm was intended to reduce essentialising cultural 'differences' and gain insights into parents' narratives of identity, transformation, interaction and belonging. Each family is presented below in a pen portrait with extracts from their interviews that illuminate the uniqueness of their lived experiences of parenting an autistic child. To introduce each participant, I begin with a brief introduction about their individual life stories which includes their family, their country of birth and details of their migration to the UK.

Each pen portrait provides an inductive interpretation of their individual stories and the transformative effects of parenting an autistic child, the intrapersonal and interfamilial resources and coping strategies they developed and their experiences of interacting with family and professionals to gain the services and educational provision they wanted for their autistic child and family. Using a deductive approach to analyse their narratives I also sought evidence within their narratives of identity, transformation, interaction and belonging for the development of a transcultural model of culturally-informed professional practice.

The pen portraits are concluded with an interpretive summary that added another analytical dimension to their stories as of parents of autistic children. An overarching theme was inductively derived from their individual stories which reflected both the challenges and the personal and cultural resources which they talked about during the interview. Hollway and Jefferson (2013) suggest that in summarising the pen portraits, interpretation is about making links between the participants' individual experiences and the wider significance of their stories at a social and political level. The pen portraits and the interpretive summaries enabled me to attend to the parents' narratives to highlight the significance of their transcultural experiences and the

agentic means by which families constructed the lives, and navigated across different cultural spaces in their response to their children's autism diagnoses.

As the interviews were regarded as a co-construction with the participants as the narrators and me as the listener and interpreter of their stories, the chapter concludes with my own reflexive summary of the research encounters which occurred at a particular time and place in their lives. Adding a reflexive account of the interviews following the analysis of the families' narratives acknowledged how aspects of ethnic and gender difference and narrator/researcher 'expertise' were re-imagined through the dynamics of our interactions.

4.2. Jessia: pen portrait

Jessia contacted me after one of the parent meetings she had attended at the special school. In our pre interview conversation it was clear that Jessia had a sense of urgency to share her story and have someone to listen to what she and her family were experiencing. We met for the interview at the school which was a familiar place to Jessia as she regularly attended the parent workshops. Jessia's interview lasted fifty minutes during which time I spoke only to ask questions that enabled her to continue her account of the troubling events that had happened with her children's education and their autism diagnoses.

Jessia was 2nd generation British Bengali and a single parent with two sons, aged 11 and 12 years old. Her elder son had a diagnosis of autism and she was waiting for her younger son's diagnosis to be confirmed through the assessments that had been undertaken with him. He had significant speech and language difficulties and although verbal and more able than his brother, also had behavioural difficulties. Her parents had died and she made no reference to the children's father during the interview.

When the interview took place both the children were at home without a school placement, being home tutored and looked after with help from her brother. She was now desperate to find the right school for both her children as they had been at home for two years with only support from the Pupil Referral Unit (PRU). With her children

being home tutored, she had been unable to work and had been reliant on benefits to support her family:

> *I'm a full-time carer for both my kids and it's hard to get time out for myself.*

Jessia's interactions with professionals through the diagnostic process for her older son dominated her narrative. What had happened since her eldest son had been out of school she recalled as being a very distressing, lengthy process over a two- and-a-half year period which significantly altered her cultural and personal realities. Using a deductive approach I identified transculturalism as a process of adaptation and change (Onghena, 2008) in her narratives of transformation and interaction. It was clear that Jessia was struggling with her ability to manage the uncertainty of her children's difficulties and the ambiguity this had created for her about her *identity* as a single parent and mother of two boys with significant needs. Affirming her identity as a parent of one, possibly two autistic children she said:

> *It's hard to deal with both kids and I'm a single parent. I have my brother supporting me, my sister supporting me but at the end of the day I'm still by myself dealing with two kids.*

O'Brien (2007) describes how identity ambiguity occurs particularly around the time of diagnosis for parents of autistic children due to being preoccupied with viewing their own life as independent from their child's experiences. Taking the decision to remove her children from education and experiencing difficulties in gaining a diagnosis, Jessia felt vulnerable to both health and education professionals' perceptions of her parenting:

> *You know it was really difficult and it's really overwhelming. I used to feel overwhelmed, I used to want to cry. My days were really hard, I used to cry, I used to think of it.*

With both children at home, Jessia became preoccupied with seeking professional help:

> *Cos without a diagnosis he won't even go into school, he won't get support.*

Gaining a diagnosis and getting support were fundamental to how Jessia understood the *transformation* her family had undergone and how she was recognising a different future for her family. She admitted that when the diagnostic process started:

> *I was a bit in denial. I didn't want to know my child's got that problem and any issues, I didn't wanna accept it before I found out my son's got autism, I didn't want to accept both my kids got problems.*

Although she referred to '*loosing a sense of time*' with the whole diagnostic process, she recognised how developing her self-knowledge about autism had transformed her understanding and had helped her move from denial to acceptance of her children's behaviour and developmental difficulties.

> *After I know he's autistic, that's when my heart said, you know what I have to accept it and support my son.*

Jessia described a traumatic event related to her *interaction* with professionals which happened during the diagnostic process that had a significant impact on her confidence as a parent. She recalled how, before a diagnosis would be given, that health professionals wanted him to have an (Magnetic Resonance Imaging (MRI) scan to ascertain if there was any specific neurological cause for his challenging behaviours. She described how several attempts to get the MRI scan done with the help of a play therapist did not work out because no play therapist was available. Appointments were frequently cancelled even though she had attempted to attend everyone with her son:

> *After I done that, professionals talking about me between each other. I don't know what they were talking about and they said to me that I neglected my son. And when I found out, I said why do you say that and they told me they wanted me to get in touch with the social worker because they say I'm neglecting my son's needs, his medical needs.*

Jessia's negative experience of her interactions with professionals continued with a social work referral to the child protection team:

> *I felt that they judged me, they attacked me, it was so difficult.*

The evidence that she had always attended meetings and made a good effort to keep appointments, convinced the team that she needed professional help not only to confirm her eldest son's diagnosis but to go through the diagnostic process for her youngest son as well:

> *I was so relieved, she* [the Chair of the conference] *was the one that said there is no neglecting, "this mother has not neglected, infact yous are neglecting this mother because she's trying to support her kids by herself without any diagnosis".*

For Jessia, finally receiving the diagnosis of autism for her eldest son gave her access to support and the opportunity to talk with other parents at NAS workshops. *Belonging* to an NAS WhatsApp group and meeting with other parents at the workshops she no longer felt isolated, and she had found the confidence to advocate for her children and continue discussions with the local authority about educational placements for her children:

> *I am trying to attend the workshops and asking other parents that's going through the same thing. Cos sometimes another parent will know more than the professional cos they understand exactly what I'm going through cos they have a child with it, an autistic kid. So parents are a lot of help, they're really good help.*

Marginalised

When transcribing Jessia's storying of events, I noted how frequently 'neglect' appeared (19 times) in her narrative and how she used it as a reference to describe her interactions with professionals. Feeling judged and marginalised was a theme that was inductively derived from her storying of her experiences in trying to obtain a diagnosis for her son. Without a network of professional support to help her in making sense of her sons problems she had felt undermined, making it even more difficult for her to make sense of her situation. She felt strongly that she had been positioned as a 'neglectful' parent not only by some of the professionals but also the institutions she came into contact with:

> *I was neglected by the system, the system has failed me.*

> *There was all these people saying I've neglected his needs.*

> *and they said, "You've, neglected your son, we will put you under child protection."*

Her experiences of feeling marginalised reflected the dichotomy that many families who have a disabled child encounter when they become reliant on professional services. Hodge and Runswick-Cole (2013:643) point out that one of the reasons for this is because, 'professionals continue to adopt the exclusive position of 'expert' and by doing so remain all powerful'. Jessia had expectations of what professionals should being doing while at the same time experienced a sense of powerlessness because she was not getting the help she wanted in finding a suitable educational setting for her children.

> Jessia: *Usually when a child is diagnosed there are a lot of people that get involved and teach you strategies, but I didn't get that help, I didn't get that support.*

> Diana: *Do you know why you didn't get that support?*

> Jessia: *I think that because my son was diagnosed late and that before he got the diagnosis his behaviour was really difficult.*

For Jessia, key to achieving a diagnosis for both her children was how she expressed her identity and wanted to be identified as a competent parent:

> *I'm not on the neglect team, I'm on the disabilities team now.*

In my journal I reflected on her transformation during the interview. She began by talking about how *'the system has failed me'* with an openness to talk about her traumatic experience. By the time interview ended she had gone through a process of transition by positioning herself as knowledgeable parent, seeing herself as having a different life trajectory and wanting to advocate for her children and other Bengali families:

> *If I had the opportunity I would love to talk to other Bengali parents that don't understand English, don't understand what autism is. Even if it's autism, they are human beings, you know it's just certain behaviours they have is not normal, the same as other kids but accept it, there's ways to manage it.*

Six months after the interview I met Jessia again at a parent induction meeting at the special school. She was relaxed and very pleased to tell me that both her sons were going to be attending the school and that they would now be accessing an education. She told me that having talked to me about her experiences, *'gave me the strength to continue to fight for my children's education'.*

4.3 Sahra: pen portrait

Sahra introduced herself to me on one of my visits to the school and during our conversation said that she would like to take part in my research. We arranged to meet for the interview at the school on another occasion and the recorded interview lasted 45 minutes. Sahra was born in Somalia and came to the UK when she was 16 years old. She had an older sister who was already living in the UK and came to live with her. Soon after she arrived she went to college to learn English and do a course in Business Studies. She also started a GNVQ course in Health and Social Care but after a year she became ill and could not continue her studies. In 2006, she went back to

Somalia to marry a man who she knew from her childhood and as he was living in Canada they went to live there. She stayed in Canada for four years and they had two children, a daughter and a son. When her daughter was two years old she became more certain about the differences in her development:

> *I think it was when my son was born that she kinda showed, oh I'm not sure whether it was before, when he was born I was definitely certain… her speech had become much less and stuff.*

Because they found the referral system for a diagnostic assessment in Canada too slow, her husband thought it would be better if they came back to the UK to be with her family. They returned to live with her family in London and not long after being in the UK she and her husband divorced. Sahra explained that this was due to, '*how he was raised and his idea about a family was completely different*'. From their childhood there had been the expectation that they would have the '*ideal family life*' but as she recalled:

> *When things were real and serious things were happening, this wasn't his authentic way of being.*

When he returned to Canada, she moved from her sister's home and was now living with her daughter aged 7 and her son, aged 5 in a flat in the borough.

Sahra's transcultural journey began with her migration to the UK, then living in Canada and now permanently resident in the UK, She felt that this had adversely influenced her relationship with her family and going through the diagnostic process for her daughter, she had not found them very supportive:

> *To start, it was hard to stay with two kids with family and having their own kind of cultural background and that kind of stuff, really it was a challenge and very stressful… had to find out after a bit, what the whole process was all about. It wasn't just involving with him but kinda the whole system, that I was reasoning at the same time.*

The diagnostic process for her daughter, did not take long and she was diagnosed with autism at 3½ years old on '*30th August 2013',* a significant date for Sahra to remember. It was talking to the speech and language therapist who assessed her daughter, that Sahra began to question whether she also had autism. From her daughter's assessments she could relate to some of the sensory sensitivity issues she experienced and she decided to get a referral from the doctor.

> *I said, "doctor I think I may have autism because all my life I felt different when I was growing up". And she said to me, "even if you*

> *had autism, you know you lived with it all this long, so I don't think*
> *it's important for you to go for diagnosis".*

Her dilemma in wanting to ascertain whether she had autism also reflected her need to explore another aspect of her *identity*:

> *It set me on a path, that even if somebody is not seen as somebody*
> *with a disorder that they have that disorder and that's how diverse*
> *we are and how people need to be treated like individuals. We all*
> *have this difference.*

Sahra's ambivalence towards her family was not reflected in her *interactions* with professionals who she described as '*helping*', '*able to listen*' and understanding things from her perspective. She spoke positively about her interactions with the professionals involved in her daughter's diagnosis:

> *The team was the health team and they were really good people and*
> *they were very compassionate and um very understanding and we*
> *worked together really well. I think it depends on the people but also*
> *their experience as well. Specifically with like the speech and language*
> *therapist and the way he treated (child's name) and the way he*
> *modelled what a good, you know, caring system looks like.*

The professionals who she felt confronted by were those who challenged her sense of agency and control over her child's needs, and ultimately her need to care for her family. When her daughter started at a mainstream nursery school, Sahra's experience of the teachers and teaching assistants (TAs) was less positive:

> *The TA was very overpowering and the school weren't too helpful.*

Sahra was not happy with the arrangements the school made as her daughter was only expected to attend for half days because the TA could not be funded to be with her all day. Sahra took advice from a parent support centre and decided that her daughter should go to a special school, but she acknowledged that:

> *The decision to choose the best education for your child with special*
> *needs, or for all children for that matter, is not easy to do.*

Since moving her to the special school, Sahra had noticed a marked improvement in her daughter's progress and that it was mostly down to the teachers and how they worked with her:

> *I think the teachers make a lot of difference. You know, makes the*
> *learning a huge difference, not only the child's learning but the parent's*
> *model as well. So, it matters really, what kind of teacher the child has.*

Having positive interactions with others was clearly important to Sahra as she talked a lot about the different relationships she had with other mothers of autistic children and professionals:

> Diana: *What would you say was the most helpful way that professionals have worked with you?*
>
> Sahra: *One thing that people don't forget about is the person who is there for them when they are going through a difficulty. It means a lot, it makes a huge difference, also, to have compassion for the people who are not quite where you are.*

I reflected how Sahra had sought to re-configure her identity through her personal narrative of experiencing 'difference', in considering whether she was autistic, and the 'indifference' she experienced from her family members.   Having her child diagnosed with autism had helped her to establish a social identity and sense of *belonging* with other mothers of autistic children and both the school community and the parent network that she was part of had offered her this.

Self-Other awareness

Sahra's story was dominated by the impact that having her daughter diagnosed with autism had on her sense of identity and how this influenced her interactions with her family, professionals and others in the community. Using an inductive approach I noted in her narrative how Sahra had experienced three migrations from the age of sixteen and how she referred to 'difference' in her sense of self and relationship to others when talking about the sequence of events in her personal and family life.

In my journal I reflected on whether part of the process of re-framing the difficulties she had experienced in her relationships was in wanting others' attitudes about autism and identity to change. I wrote: *'Was there a sense of aloneness in her story that she focused on herself and her 'difference' as possibly being autistic? Was she trying to make sense of her identity by othering those who didn't understand what autism was?* Throughout our conversation, Sahra made several references to 'cultural difference' when talking about herself and her family who lived in Somalia and the UK. For Brah (1996) 'difference' is conceptualised through the modalities of, experience, social relations, subjectivity and identity. Sahra voiced all of these configurations of difference in her response to her daughter's diagnosis and focused on cultural

differences to defend her sense of 'self' while attempting to unify what she thought about her family in the context in which she was now living:

> *I think they are very conditioned in a kind of, you know they have all the stereotypical way of being, having an identity, what somebody should be like or what a woman should be like, whatever that is, if I don't kind of, it's hard for me to relate to them, to identify with them really.*

Sahra's heightened sense of cultural separation from her family is salient to Hall's (1996:17) idea that 'identities are constructed within, not outside, difference'. Hall (1996) highlights, that it is only in relation to the 'other', to what it is not or what it lacks, that a positive identity is constructed. Sahra was quite firm in her resolve for:

> *Just… people to have their kind of identity, just to be able to be what they are, to relate to who they are.*

The interplay between the cultural expectations of her family, her anxieties about her personal challenges and the ongoing concerns about her children were all key signifiers in her narratives of identity and belonging. For Sahra this was an acknowledgement that the experience of being Somali, a mother and single parent of an autistic child was:

> *Not something you do and close files, it's evolving and you learn and your learning about yourself at the same time.*

4.4 Fatou: pen portrait

Fatou initiated email contact with me to take part in the research. The interview with Fatou took place in the school and lasted fifty minutes. The interview became a series of long descriptions of events, such that my role as listener was to be a witness to her stories of anguish about her daughter's education and the redemptive strategies she employed in mothering her autistic child. Although her daughter did not attend the special school Fatou regularly attended the parent workshops where she had made friends with other parents. Fatou's transcultural narratives of identity and interaction were dominated by the events that had occurred at the first school her daughter attended and the impact that her challenging behaviours had on their family life.

She was a single parent and had three children, an 18-year old son at university, a 16-year old daughter studying A levels and a daughter, aged six who had an autism diagnosis and possibly attention deficit hyperactivity disorder (ADHD), which had not yet been confirmed through formal assessments. Fatou came from Sierra Leone when

she was 16 years old without her parents and stayed with an aunt. Before her youngest child was given a diagnosis of autism at four years old, her Ghanaian husband had left the family home and they divorced. As her aunt had gone back to Sierra Leone where her parents still lived, she had no other relatives in the UK.

Through deductive analysis it was possible to identify how the transformational nature of the diagnosis was a major shift in her thinking about *identity* as a mother and provider for her three children. Prior to her youngest daughter having a diagnosis she had worked fulltime as an accountant but with so many medical appointments to attend with her daughter, she had reduced her hours and now worked part-time:

> *So yeh, of course my wages was cut massively, but um for me I'm able to attend workshops, I'm able to be there for my child so that compensates the money I got, even though we struggle financially at home.*

For Fatou, concerns about her daughter's development were raised at nursery school where her daughter would get angry, hit out at the other children and break toys:

> *She comes across as normal child, she's verbal, and then behaviour was quite different… so she was just put in time out constantly and then when she comes out, she go and do it again and they put her on time out again. It was frustrating for me to see that.*

At home Fatou was dealing with her daughter's eating issues, poor sleep and lack of a sense of danger that she had hoped would change once she started school. On the advice of the SENCO, Fatou's daughter was referred for an autism assessment.

The diagnostic process took a year and the day of the diagnosis was particularly poignant for Fatou:

> Fatou: *I was left feeling numb because I didn't know where to put it. I asked, they said it's official your daughter got autism. They done all the referrals, now I just have to wait. For me it was like, 'what do I do now?' And I was still left lost, numb. In my mind I was asking 'how long before she grows out of it?' Yeh, because not knowing what autism is fully, but I don't know, was I lazy, not to read into it before, before the actual diagnosis? But yeh, I was left numb, confused and lost, cos I thought, after the diagnosis someone would step in and say, okay, don't worry, take a break.*

> Diana: *So when you had the initial diagnosis, did the doctors explain to you what autism was?*

> Fatou: *No, they just give me a booklet full of information and then say okay, here's everything you need, everything will make sense, just read the booklet.*

She wanted someone to explain autism to her and was hoping that someone would step in and guide her. Instead, she decided to attend parent workshops and found a sense of *belonging* with other parents, sharing their experiences and meeting professionals to find out where to go for information:

> *Cos I never read that booklet. I never.*

Fatou's daughter had been at the school for a year before she was diagnosed with autism and she was increasingly concerned that her behaviours were not understood by the teachers:

> *They don't see the signs when the signs are there like okay, is this reaching a boiling point you know and stepping in a doing something before you know.   I've explained that to them they've said 'no' that's their policy – when a child does something you know – deal with them'.*

With a recommendation from the SENCO, Fatou sought advice from the LA parent advice centre and this resulted in going through the assessment process for an EHCP. She sought advice from the autism outreach team and an educational psychologist and worked with the teachers and TAs to implement strategies to manage her daughter's physical behaviour and eating issues both at home and at school. Despite Fatou's attempt to work with teachers to find effective strategies and the involvement of the outreach team, the focus on managing her behaviour meant that her daughter was not achieving or progressing academically. Fatou decided to move her daughter to another mainstream primary school where she explained:

> *It wasn't easy at first because she met new teachers, new TAs, new staff, so it was a bit tricky…and then eventually they got in an OT for her and then they got in a speech and language therapist and then they [school] got the outreach team to train the teachers and the TA. So now they working towards helping her.*

The outreach team at the school were supporting her daughter and the staff at the mainstream school and Fatou was proactive in regularly attending meetings and discussing the strategies that had been put in place to support her learning in the mainstream classroom.

Advocacy

Inductive analysis of Fatou's interview highlighted her interactions with professionals and her overriding effort to be proactive in asking for advice and initiate contact with professionals to seek solutions to the challenges she faced in wanting the most appropriate education for her daughter. Fatou had been employed full-time and was a parent of two older children who were achieving well educationally and having an autistic child with challenging behaviour had involved a significant psychological shift in thinking about her *identity*, her parenting role and the ways she was now having to *interact* with professionals. Fatou, like many mothers of disabled children, felt socially positioned to respond to the culturally dominant narrative about mother-blame as well as self-blame (Blum, 2007; Read, 2000):

> *I lost confidence in myself completely. I was an emotional wreck. I would cry for no reason. People say comments, inappropriate comments and then that would bring me down to tears. And I say it's not my fault and I'd cry and say it's not my fault, I didn't ask for this.*

> *I used to question myself at every angle, my parenting skills. Is it something I am doing wrong?*

Fatou talked about her efforts to establish positive *interactions* with teachers at the school and a willingness to advocate for her daughter's education. She had tried to work with the teachers but it became too stressful for her:

> W*e were focusing so much on the behaviour which they don't make room for helping her and it got to a point where I couldn't handle it anymore.*

Fatou's move from advocate to activist (Ryan and Runswick-Cole, 2008) became more essential to her in her interactions with professionals when she sought a different educational placement for her daughter. Although she wanted her to attend a specialist residential school, the LA decision was that her daughter should attend a local mainstream school with support. Continuing to strive for what she wanted in place at the school to enable her daughter to make progress had made Fatou more assertive and she had received affirmation from the parent support network that her actions had brought about improvements in her daughter's behaviour:

> *Now when she comes home, she doesn't want to damage everything and throw things and but, no, now she comes home, she knows. I know what she's feeling at that point and understand what to do for her and how to help her. I have that understanding now.*

Fatou relied a lot on the parent workshops where could relate to other parents who understood what she was going through. *Belonging* to parent network had become essential to her as she had gained a lot more knowledge about strategies to manage her daughter's behaviour at home:

> F*or me, I've made it like a long-term commitment, like I have to attend these things. I found out the best way to get the information is to attend workshops.*

4.5 Hibaq: pen portrait

I met Hibaq at a parent workshop and we arranged to meet at the special school where her interview lasted one hour. Hibaq was born in Somalia and grew up in Nairobi, Kenya. She came to the UK when she was 19 years old with an uncle. She was brought up speaking Swahili and English and only learnt Somali when she came to the UK. Her uncle and his family returned to Nairobi when their children finished school. Her father lived in America and her mother and sister still lived in Nairobi. Hibaq felt that relationship with her family had changed, not only as a result of her migration experience but also in how she communicated with them about what autism was and how she had to care differently for her son because of his developmental difficulties. She met her husband, who was from Somalia, in the UK and they had a daughter aged 8 and a son aged 5 who had a diagnosis of autism. After their son was diagnosed her husband left the family home. She said it had affected her relationship with her husband and members of his family.

Hibaq, described herself as separated from her husband but they had recently reconciled because of the children and he was visiting the family home:

> *But now he's trying. He's trying, doing the school runs, being back in their lives.*

His sister lived in Manchester and had two children, one with Down's syndrome and one with autism, and they had another relative who had a child with autism, whose son attended the same special school as their son. As a child, Hibaq's sister had speech and language delay but was speaking by the time she was five years old and so it was assumed, before his diagnosis that their son was also just slow at learning to talk.

Although the children predominantly spoke English, at home both the children responded to all the languages she spoke. She reflected on this as a positive aspect of her identity and her connections with both the local Somali community and her Swahili-speaking family in Nairobi who she frequently visited. Hibaq had started studying Psychology at university in the UK but when she got married, family commitments made it difficult for her to continue and she was unable to complete the degree. Inductive analysis of her narrative showed that throughout the interview she focused on her own self-learning and the importance of education so that she did not have to rely on professionals:

> *It's better for me to equip myself, rather than asking the next person to help me.*

The story of her son's diagnosis merged with her knowledge of children's early development and her family experience:

> *I noticed when he was about 15 months and people were like, "no you are reading too much into it". When he got about 15 months I noticed like he has the traits of it - ASD. But trying to get the professionals to see, no he's too young, we can't refer him now.*

She described how neither the health visitor nor the nursery staff could '*see anything wrong with him'* so she went to the Child Development Centre where she saw a speech and language therapist who referred him to the autism assessment service:

> *He was not even two then. Then he was seen for his initial assessment, he was two and a half and they said 'no' give it six months and bring him back. Bring him back and they said yeh "he has autism".*

Hibaq's response to her son's diagnosis was to learn as much as she could about autism, attending numerous parent training workshops at the Child Development Centre, completing the NAS EarlyBird course, attending the parent workshops at the school and doing a First Aid course as well as her own internet research:

> *I find it easier cos at times, your child might have a meltdown at midnight. Who can I call at midnight to help me? - no one. So, I have to learn how to deal with it.*

Hibaq's views about her son's education came at the beginning of her story when she described how she had to *'fight long and hard for him to come here'.* The EHCP assessment process had taken longer than she wanted it to but after she told the LA,

'I'll take you to tribunal', a place at the school become available, *'which was a bonus'.* Hibaq clearly valued the collaboration with her son's teachers:

> *You feel like in partnership, your child will achieve something, but if I'm not open to it, it's not happening any way. And if we are not persistent with whatever is happening in school, at home, he won't learn. Honestly, because I'm talking from experience, I've seen it.*

Deductive analysis identified that a strong theme in Hibaq's story was how she made sense of her *identity* within her community as a Somali, Swahili and English speaker and advocating for herself as a parent of an autistic child. Hibaq had advocated for other parents in the community and her own family to develop a greater understanding of autism because she had learnt so much from specialist teachers about how to interact with her son. What she now wanted was professional help for her daughter's mental wellbeing to enable her to adjust to the demands of having an autistic sibling in the family and was keen to develop her own parent group.

Adaptation

Following the interview, I reflected on transculturalism in Hibaq's story and her narrative of *transformation* since her son was diagnosed:

> Diana: *You were telling me earlier that you went through a grieving process when you were waiting for your son to be diagnosed. What do you think now?*
>
> Hibaq: *You know sometimes you get this child, and you think oh my God, why was I given this child? Or you find some people hiding the stigma, hiding that the child's got a condition. And I'm like, for me, it was a blessing. Because my child taught me. I've learnt so much from that little boy. Like, I'm changed, like I've done a 360 transformation just because of him. I'm more empathetic, I'm more patient, yeh. I see other children, I'm less judgemental, I'm more accepting. Like, it changes you as a person, so it's a blessing.*

Hibaq found that her religious belief had helped her to come to terms with why she had a child with autism and in turn how this had resulted in her affective self-transformation and empathy for others who did not have the same understanding as she did:

> *Unless you live it, or you work with it is when you are going to understand it.*

The metaphor of her '360 transformation' was a central theme in her narrative about her personal, social and interfamilial experience since her son's autism diagnosis. Falicov (2012) refers to transformation as always involving an awareness of continuity and change, particularly when it involves a significant life experience. In terms of continuity, there were two distinct features embedded in Hibaq's life story about her religious belief and the languages she spoke. Closely aligned to her religious faith was her acceptance of the value of speaking different languages and she wanted her children to be able to do this as well:

> *My daughter, I want her to learn the religion and the Koran is in Arabic so if she learns Arabic, then she reads in Arabic, she'll understand it more. Cos when I learning the Koran we were not taught the Arabic side of it. So I find if you know the Arabic it's gonna be easier to understand it.*

> *Cos I learnt Somali in this country, I didn't speak Somali before. Cos I went to school in Kenya. So when I got here is when I learnt the Somali that I know.*

> *Before when I was doing [learning] speech and language, I would speak one language, but now what I read through research about bilingual language they say bilingual language helps. So I started doing that and he's responding to it. If I say 'give me' in Somali he will give me.*

For Hibaq, the languages she spoke were important in terms of her connectedness to her family and her sense of *belonging* to the local community and faith community. The need to communicate in different ways had also had a psychological impact on her relationship with her son:

> *Once you accept the child for who they are rather than having all these dreams or all this aspiration for them. And rather than forcing him into my world, getting into his world, I think that helps. And I found out since I was laid back (child's name) is progressing. Like I changed. I had to change in order for him to open.*

In my reflexive journal I wrote about how Hibaq and her family had experienced many transitions across the life course that had resulted in the need to adapt and find different ways to connect with her family while creating new opportunities to be part of her community. This in turn had enabled her to find the emotional resources to manage the changes she had experienced in many aspects of her life story.

4.6 Nadifa: pen portrait

I met with Nadifa after a parent workshop she had attended. The interview lasted an hour, during which time, she spoke with confidence about her son's autism and the impact of the diagnosis on her and her family. Inductive analysis of her narrative showed how she was very family-focused and she talked more about the nature of autism and treatments for her son than about his education. She had been trained as a nurse and this may have been why she had an interest in the medical aspects of her child's developmental needs. Nadifa described her transcultural journey, that her family was from Somalia and she was born in Saudi Arabia where she lived until she was 9 years old when the family came to the UK. She had married a Somali man in the UK and they had four children; two daughters aged 12 and 9 years old, a 7-year old son who had an autism diagnosis and a one year old daughter. Six months after her son was born she was diagnosed with breast cancer. After a year of treatment and recovery, when her son was seen by the health visitor for his two-year-old check, it was suggested that his social behaviour was typical of a child with autism. She expressed this with a sense of guilt:

> *Because the focus shifted on me, he was kind of put on the back burner. If I think back now about milestones for (child's name), I don't actually remember them because I was in and out of hospital with chemo and treatment, so maybe there were things that we could've picked up earlier.*

When 'autism' was first mentioned to Nadifa and her husband by the health visitor she recognised that there was '*stuff we were not aware of and were not conscious of but obviously when someone else points it out to you it's like, " Oh, I see it now".'* Although they responded by admitting that they didn't know what autism was, Nadifa talked about noticing signs of the *'illness called autism'* and started '*Googling'.* Following initial research and reading about autism, she described how:

> *It was a very quick acceptance for me personally simply because I could just connect the dots and I could just see and then it very quickly turned into a, 'Okay, so what do we do about it? How can we help?*

Using her professional knowledge, Nadifa put a lot of emphasis on the way in which she accepted her son's diagnosis, describing 'acceptance' as something in which she needed to be proactive in finding treatment solutions:

> Diana: *Do you think your acceptance came early because of your nursing background?*

> Nadifa: *Yes, it really was pretty much an acceptance from day one, but it was a proactive acceptance. It wasn't never an acceptance that said "okay, he's autistic, there's nothing I can do about it". It's a lifelong diagnosis. He will be like this for the rest of his life.*
>
> Diana: *Was it the same for your husband?*
>
> Nadifa: *My husband accepts that he is autistic, but I don't think he knows what to do with it. He's very supportive with it but he just doesn't take the lead.*

She found out about different interventions and treatments with a similar approach to how she had also dealt with her cancer and how she got on with what needed to be done for her son:

> *I then made the conscious decision to take everything onboard personally myself and deal with it, not leave it up to mum, not to dad, not to my husband, not to anybody else, and I made the decision to quit work at the same time.*

Nadifa positioned herself as knowledgeable and knowledge-seeking and proactively sought to engage other professionals, not just about his diagnosis but with early intervention from health and education professionals. The family paid for private speech and language therapy and occupational therapy and based on research that she had read, obtained a course of oxygen therapy and gave him camel milk:

> *I've done the oxygen, I've done the milk and I've done (special school) all together at the same time so I don't know, but I'd like to think that all three complement each other and at the end of the day if progress is what we're seeing, then fantastic.*

Possibly because of her professional expertise, Nadifa had no difficulty establishing positive *interactions* with health and education professionals who helped her achieve what she wanted for her son. She also recognised that when staff at the schools her son attended were supportive and took time to build a relationship with her and her family that *'it made a huge difference'.* Nadifa was pragmatic about him not managing in mainstream school and that the special school was currently the best place for him:

> *Here, actually the environment is set up for them and I think that's a lot of where parents don't understand. So this is set up for children with autism, the teachers, the set-up, everything. So actually, (child's name) just comes in and fits right in, whereas over there [mainstream school] you'd have to either force him to fit in or at best he would just be on the outside, being supervised and made*

> *sure he's safe but still really not, he'd just be on the outside…. So*
> *it was a no-brainer really.*

What she valued was that the special school her son attended was very family-oriented:

> *Not here just for the child, they're actually here for the family.*

There was a strong sense of *belonging* in Nadifa's narrative which not only included her family network of support but also what she experienced through the school and with other local Somali families who had an autistic child. Being part of the parent network at the school had given her a broader understanding that not everyone could accept their child's diagnosis in the way that she had. Within the Somali community and with members of her family, who were struggling to come to terms with what autism meant, Nadifa's transcultural approach was that she found herself prepared to campaign on their behalf and was willing to accede to their different perspectives. She accepted that there were intrafamilial differences in understanding autism even though as a family their attitude was, '*it is what it is'.*

Agency

By giving a chronological account of events leading up to, and following her son's diagnosis of autism, Nadifa's narrative revealed how her maternal self-efficacy (Al-Kandari and Al-Qashan, 2010) as a parent of an autistic child had evolved and was continuing to determine her future actions and decisions for her family. Agency was inductively identified as a key theme in Nadifa's sequencing of events because of the way she had dealt with personal adversity and took agentic responsibility for her actions towards the needs of her autistic son, her family and the wider community.

I reflected in my journal after her interview how initially Nadifa's sense of responsibility and agency had been compounded by feelings of guilt and not being as attentive to her son when she was ill and how she admitted that sometimes she still had those feelings:

> I mean I had to go through that grieving process as well and I did
> go through it and I still go through it to be honest, I'm not going to
> lie. There are children I see sometimes that maybe a neurotypical
> around (child's name) age and I think, "This would've been (child's
> name) if he was normal," and I don't think you ever let that go but I
> don't let it ever consume me.

Rather than thinking about the diagnosis as a personal tragedy that she was resigned to coping with from a problem-focused perspective, it became her personal crusade to find out more about autism and the most effective treatments. Seligman and Darling (2007) have referred to this sense of crusadership in parents of disabled children as an attempt to achieve normalisation and endorse a new *identity*.

Brockmeier (2009) points out how agency within narrative is often contrasted with passivity and powerlessness and this was no exception in other scenarios that Nadifa shared during her interview such as how she interacted with professionals to get the treatments and education that she wanted for her son. Recalling her response to her son's diagnosis as *'Okay, so what do we do about it?',* positioned her as an active agent in decision-making with her own personal perception of what it meant for her and her family:

> *He is what he is and God intended him to be that way. There's absolutely no shame in it. I will walk down any road with him absolutely proud and that's my personal take on it.*

4.7 Arnab: pen portrait

The interview with Arnab took place following a parent workshop and lasted 55 minutes. He explained that he had been pleased to attend a workshop for the first time as he was usually working but had taken time off work while his taxi was being serviced. Arnab came to the UK from Bangladesh when he was 8 years old in 1983 and the family lived in Middlesborough. When he was 14 years old they returned to Bangladesh but came back to the UK when he was nineteen. The family then moved to London where he trained as a chef; a career he did not pursue:

> *When I came back I was young and I didn't care about education. My family and a few of my friends were telling me. Now, my mind says, why didn't I listen to them?*

He met his wife in Bangladesh and she came to live with him in 1999. They had two sons, 17 years old and 14 years old. Their younger son was born prematurely and diagnosed with Down's Syndrome at birth. In 2009 they returned to Bangladesh because his wife needed surgery which he wanted her to have there and so the family stayed there for six months.

Arnab provided a descriptive and tearful account of what he and his wife went through when their second son was born and diagnosed with Down's syndrome. There were initially no health complications for him and he received regular developmental assessments. At two years old he was seriously ill and spent a lot of time in and out of hospital where tests confirmed that he had type 1 diabetes. When he was ten years old, during a regular assessment at the hospital, the doctors agreed that their son had autism. This diagnosis did not appear to impact the family as much as the initial diagnosis of Down's syndrome and diabetes. From birth when they were told he had Down's syndrome Arnab described how he had to accept his son's diagnosis:

> *What is my son, we have to take it, what's going to happen in the future?*

and with the diagnosis of autism he described how:

> *Everything is going routine from there.*

From an inductive analysis of the transcript I interpreted Arnab's frequent use of the phrase '*we have to take it',* when responding to the diagnosis as 'accept it', not just as an emotional response but also in a practical sense in terms of dealing with the implications of caring for a child with complex needs:

> *So having a child like this, Down's syndrome, diabetes, autism, the parents gonna have lots of suffering. Taking a hard time for them. Like all the parents I appreciate for the children, stuff like this, responsibility, everyone have to take it.*

As a result of their son's health needs they had a strong dependency on their *interactions* with health professionals who supported them in managing his diabetes:

> *The diabetic nurse, the doctor, everyone coming and explain to us, now we are going to train you. So that time the diabetics nurse, we had really good service from the NHS…they explain everything.*

With professional help, Arnab and his wife became very knowledgeable and capable in managing their son's diabetes but it was also a strain for him:

> *The majority time I have to go to appointments, run for everything because my wife at that time she's back home. She's doesn't know about this country and I have to stay with him [son] and explain everything. I have so many hard time, go through.*

His son had attended a mainstream primary school and following his autism diagnosis had moved to the special school in Year 6 to be part of the secondary department.

Arnab only talked about the special school and the way in which the teachers worked with the pupils*:*

> *We are very happy… they do fantastic work.*

Arnab talked about how the special school had been really good at understanding their son's diabetic needs and had helped him to learn sign language. His wife attended classes to learn sign language and this affirmed how they were both involved in the school community:

> *Me, I don't understand that much sign, but she can understand. She has a very good relationship with (family liaison).*

Arnab mentioned how the school were helping them to think about his younger son's post-school provision but that it will be:

> *Same as now we have to care him, for how he's like. It will be the similar care.*

Because Arnab worked part-time it was not possible for him to attend many of the parent meetings at the school, which his wife usually attended, but he appreciated the opportunity to meet other parents. He also felt that the school was providing a sense of *belonging* to a community of families with similar experiences:

> *Everyone is the same, like they have lots of issues. They get lots of information from today and other parents had similar to what I had in my family, similar symptoms, it's related to them. So I feel the same.*

Post -Traumatic growth

The initial experience of his younger son's birth, supporting his wife during her illness, his work and his concern for his older son were clear themes in Arnab's narrative. In the storying of personal events, Arnab's tearful recall of the events leading to, and following the birth of their second son reflected an experience that resonated sadness for him. He also acknowledged how the stress of coping with his wife's and son's subsequent health difficulties had impacted on him and the family.

In my journal I reflected on how his narrative was centrally concerned with post-traumatic growth that gave meaning to his caregiving role, his migration experiences and seeing a better future for his children. The concept of post-traumatic growth refers to 'positive psychological change experienced as a result of the struggle with highly challenging life circumstances' (Tedeschi and Calhoun, 2004:1). In the same way that

Arnab had experienced several migrations, post-traumatic growth represented a transformative experience in the way that he found psychologically adaptive resources to seek out practical supports that enabled the family to function and respond to the different traumatic events they had experienced.

For Arnab, the importance of 'home' was a resource which he drew on frequently in the interview. The number of migration experiences he had between the UK and Bangladesh in his childhood and adulthood provided a sense of connectedness and *belonging* to his family and his cultural heritage as well as a determination to give his children the educational opportunities he wanted for them. As he referred to his lack of education and poor English as an outcome of migration, these frequent moves could be seen as negatively disruptive:

> *I went with the English. Now like I kinda speak but it's still like it's broken. Like before when I was here I was speaking with a northern accent. It takes me about one year to settle, but now I prefer London.*

Arnab saw the value of being in Bangladesh for his wife's surgery so that she could be cared for by her family. He was aware of special education provision available in Dhaka for his younger son, but was also thinking about his eldest son and wanted him to access his education in the UK:

> *Back home they can't even teach English, when you speak it's like completely different. So we stay [in Bangladesh] and then we come to the UK. I just spending much money to get one to one tutor for him and my other son's okay now, he go to college now, he doing the IT and Business.*

Arnab talked about was how he liked being self-employed as this had given him the autonomy to work when he wanted to and he could be available to help care for his younger son and support his older son's education. When Arnab spoke about his older son and his responsibilities towards his family there was a noticeable *transformation* in the way that he spoke confidently and with sensitivity. He was pleased that his eldest son was doing well at college but was concerned about the impact that having a brother with complex needs had on him:

> Arnab: *Because he have no friend at home, only at school he can be a friend. Because the other son doesn't understand… he can be friendly but he not get much help from him.*

> Diana: *Does he want to bring friends home?*

Arnab: *No, he doesn't want to bring friends home because of the condition of my other child. Because his friend is not gonna understand.*

Thinking positively about the future is also a feature of traumatic growth when parents of disabled children will utilise a positive coping strategy for the daily challenges of care by seeking future normalising activities (Wayment et al., 2019). Arnab had a plan to take his younger son on an extended holiday as this was something he enjoyed doing:

So next couple of years, my plan like, I'm just going to go somewhere, taking the time for six, seven months. So after waiting for my other child to be settled on his education, so I might take a bit off from the school for him. So that's my plan for the next few years. Do some extra work, save some money. That's my plan.

As Phelps et al. (2009) point out, caregivers' positive insights, patience and self-awareness can assist in the maintenance of a cycle of valuable growth. This sense of containment was evident in Arnab words which ended our time together:

So this is part of my life, part of my family, part of my experience of life.

4.8 Manoj and Madhura: pen portrait

Manoj introduced himself to me after a parent workshop which had focused on the changes to the disability benefit system and financial entitlements. Manoj wanted to share his family story with me and this developed over two interviews. I met with Manoj at the school for 45 minutes and in telling me about his daughter's birth, their current living conditions and their desperate need to be re-housed, he became upset. He wanted me to meet his wife and visit their home and so a second interview with Manoj and Madhura was arranged. Although I was with them for two hours, not all of our conversation was included in the recorded interview which lasted an hour and twenty minutes.

Manoj and Madhura came to the UK from Italy in 2014 where their oldest two children were born. Their daughter aged 17 had a diagnosis of autism and epilepsy and their older son was 12 years old. They had Italian citizenship and UK residency and their 13-month old son was born in the UK. Their move to the UK was prompted by an economic downturn in Europe and the need to find work using his skills as a welder.

It had also been suggested that medical care for their daughter would be better in the UK and so Manoj came to the UK for a few months prior to the family coming so that he could establish work and find somewhere to live. Manoj had not found work as a welder in the UK and was working part-time as a security guard mostly at night so that he could be available to help with the care of their daughter whose behaviour was often challenging for his wife to cope with alone.

Manoj and Madhura both spoke Italian and English but not well. Madhura joined in our conversation when I asked her a question and occasionally she would initiate comments in English. Manoj also translated in Bengali for her and in English to me when she wanted to express something in more detail. It was clear from my interactions with them, that both parents were living with the strain of caring for their daughter and the whole family in cramped and uncomfortable conditions. What they were both wanting was a change in their circumstances and to be re-housed:

> *The house is only one big room, one small room. We are five person, too much crowd, a crowd. But she's [social worker] writing, house no good, not healthy.*

Manoj tearfully described how his wife had a seizure and was taken to hospital when she was pregnant with their first child. To save their lives the doctors carried out a caesarean section and delivered the baby at six months, weighing half a kilo. She remained in hospital for three months and was allowed home when she had reached one kilo. The doctors reassured them that because of her prematurity to expect her to develop slowly:

> *When five years, after we understand, this child's problem epilepsy, autism. Taking my child doctor, specialists in Italy, checking everything, talking, playing, everything looking and check blood, eyes, brain, everything.*

Her development was severely delayed and her epilepsy still needed to be controlled with medication. Manoj described her behaviour and communication difficulties as being typical of a child with autism and severe learning difficulties but they did not refer to her as 'autistic', referring instead to her '*disability*' due to her premature birth and epilepsy:

> *After, I think I have to take my child to doctors in London, that's why I'm coming here. Only for (child's name), solve problems for my child otherwise where can any place help? Italy help, London help,*

> *everywhere, looking. But I need to help my child, I'm father no? I'm looking very well help my child.*

Deductive analysis of their family's storying of traumatic events showed how their *interactions* with health and social care professionals had been based on dependency. Health professionals had taught them how to care for their daughter's epilepsy and developmental needs and a multi-agency team at the school and social workers from the LA had spent nearly a year trying to find them suitable accommodation:

> *The papers are there, it's done. They are looking at this, they looking at something to give me another place.*

As they had been waiting for three years to move since arriving in the UK, Manoj and Madhura were now desperate:

> *I need help, but I don't know what help can come quickly.*

Manoj had a strong sense of *identity* as a father with a responsibility to care for his family and at the same time was experiencing a situation that he could not easily move away from:

> *This is a disability family, it's very hard, very, very hard now that she was nearly 18 years old…She not sleeping, I'm not sleeping, my wife, not sleeping, together we look after. Also at the same time this happening we are not going anywhere. So I am going [to work], my wife is still in the house. My wife in the house, alone, it is impossible with my children. It's very dangerous my child. Sometime the open door, looking downstairs. We are in a flat, very dangerous, fall down.*

It was not clear whether their daughter attended school in Italy as Manoj only referred to her education after they had moved to London. She attended a special school when they came to the UK but she then moved to another special school at the age of sixteen which was more appropriate for her complex learning and medical needs:

> *Here I don't know specialist, maybe have, it's important have child with epilepsy, disability and all problems, all child here. And myself, my child loves it here. It's no problem here, no problem.*

Manoj and Madhura were not able to share much about her education but knew that it was important for her to be cared for and that she was happy. Manoj understood that she was learning some life skills but *'not too much, progress a little bit, but no expect too much.'* As we were talking about this together Madhura shared how the

school took their daughter to the sports centre which she enjoyed. Recalling a positive experience was something that both Manoj and Madhura sought. I reflected on this point in the interview when their mood altered, highlighting an aspect of their family interaction. Madhura smiled as she told me:

> *(child's name) shopping, dress, shoes, jewellery. Too much like perfume.*

and Manoj talked about wanting to have some money to hire a car to take the family to *'see outside London'.* Observing Manoj playfully interacting with his infant son, had also moved the focus of our conversation about their current problem-focused situation towards a more positive trajectory for the family.

Resilience

Following my interview with Manoj and Madhura, in my journal I reflected on how their story of uncertainty and anxiety had heightened their vulnerability but also their resilience in managing the challenges they had faced and were continuing to experience:

> *It's not that families can't access help or don't want to because of their cultural beliefs. Where is the stigma? It is mostly sadness, the family who is just coping, because that's what families who have a child with autism do.* [Journal]

Although I began in the dominant position as the researcher interested in their story, the very nature of the family story and the impact it was having on Manoj and his family's life shifted this position of power. This was particularly noticeable when I went to the family home. Was he positioning me as a 'helping professional', a relationship he was used to, or was there an expectation that I could make something happen for the family? Manoj clearly wanted me to understand his reality and how it was different to mine:

> *You explain at the university but explain other things not real, but my family, my daughter is real, disability, epilepsy, is a very big problem.*

Manoj and Madhura had experienced multiple traumas and disruptions in their life as a consequence of their daughter's birth experience that had a profound impact on their well-being, psychologically, socially and economically. Manoj found meaning for their onward migration from Italy because he wanted more opportunities to work and to improve medical and educational outcomes for their daughter. Although their migration

resulted in separation from their extended family support network, who had returned to Bangladesh from Italy, they came to an area of London where they knew that they could feel part of the local community with other Bangladeshi families. The staff and families at the special school their daughter attended had been a source of support for them when they arrived in the UK and the expectation that the LA would eventually find them more suitable accommodation was also key to Manoj's determination to maintain *interaction* with professionals he knew could help the family.

Recognising resilience in Manoj and Madhura involved an understanding of how they engage in coping repertoires, manage expectations and set priorities as part of the resilience process. Manoj knew that stability was crucial for the family's wellbeing and providing a 'safe place' in which they could live more comfortably as a family was his priority. This commitment to the family was an aspect of resilience that also aligned with styles of interaction between the family members. Manoj was pleased that their eldest son was doing well in school and achieving good results:

> M*aybe in future studying as doctor or scientist.*

As Bayat (2007) discusses, these normative responses are essential for supporting resilience and understanding how families' function when they are faced with the complexities of caring for a child with autism.

Despite experiencing separation, the sense of *belonging* and the connection they had with the family in Bangladesh had helped to maintain their resilience. Manoj explained how his parents had told him how he was to care for his daughter:

> "*It's God's gift' and this is the family God has given you".*
>
> Diana: *Does that help you when your mother says, "this is the family God has given you"?*
>
> Manoj: *My father, my mother they say believe in God. I am also, my family, my wife, my child. We believe in God, God gives it all. Otherwise without God, without help, God, it's impossible to live in the world.*
>
> Diana: *Does this give you strength?*
>
> Manoj: *I try, I struggle my life. Slowly, slowly solve my problem. Maybe today, tomorrow, this year, next year, another year maybe solve my problem.*

As Jegatheesan et al. (2010a) found in their research, families' spiritual belief was not only providing them with the protective means to cope with their situation but was also a catalyst for understanding how it could change. A few months later I was able to contact Manoj via the special school, to hear that they had a new home and that their lives were more comfortable and how they were living in a safer place that was better for the family.

4.9 Soran: pen portrait

Soran had attended a parent workshop and heard about my research. He then contacted me via email and we arranged to meet at the special school where his son attended. We met for an hour and during this time he spoke mostly about the impact that his son's diagnosis had on his family and the concerns he had for his development and progress. Soran was Iraqi-Kurdish and came to the UK in 1998 after the civil war in Iraq had ended. He married a woman from Iraq in 2009 and she then came to the UK. They had four children: a daughter 8 years old, a son age 7 years old who had an autism diagnosis, a daughter 5 years old and a son, 5 months old. Soran had worked as a taxi driver but had given up this work to be a full-time carer six months ago:

> *I was working as a taxi driver and I was working in the night time and mostly, I was sleeping very less at daytime to look after… but since January, I'm not working and I had find more better time, better place, and just look at the things and start reading about him and searching all the studies and things.*

Soran made reference to his transcultural experience of autism and deductive analysis of his story showed how developing his knowledge of autism and seeking solutions to support his son's development had become a focus for Soran. He shared insights into his family life and how he wanted things to be different for them all. His extended family were living in Iraq where he explained that they knew about autism:

> *Autistic is very wide now, everyone, they heard about it, even in my country, back home, so many people are autistic.*

He had a nephew who he described as '*autistic*' but that *'even the family, they don't say'.* He had his own business running a shop and was *'doing very well, but when he's talking to the people, straightaway some people, they detect something unusual.'*

Soran recalled watching videos of his son when he was 14 months old and was starting to count and say his letters:

> *We were quite impressed by him and we didn't find anything unusual and we look at it back now, which is very sad for now and at that time, he was absolutely fine and he was good eater, he had a good relationship with me, especially with me, and with the others, the sisters and mum.*

When he was two years old they took him for his immunisations and Soran distinctly remembered:

> *One day when he was crying very hard and switching to laughing and began his unusual behaviours. That's when we remember everything's changed from that day and we were just quite worried.*

Their son stopped talking and would not respond when he was called and would not give eye contact. Soran and his wife took him to the doctor when they decided *'something is seriously wrong'.* The doctor referred them to an autism diagnostic and assessment service and before the referral Soran described how he researched and found out about autism:

> *And I found all the symptoms in my son. Spinning around, flapping finger hands, putting head like that, sitting with something for long, not looking at everybody if you call him, no answering, no eye contact, nothing. I said to my wife, "he's autistic."*

Their son was diagnosed at the age of three with autism and learning difficulties and they were concerned, not only about his lack of speech but also his limited diet. He had taken him to the GP a few times:

> *Because they're not a specialist. They couldn't help, honestly. They'll say just wait for age, maybe he'll just change in the growing up and getting better, and I had a search myself.*

Going through period of *transformation* in learning about autism, Soran's determination to find out about autism on the internet led him to request that the GP did some tests:

> *"Look, I need this test, I need this test, I need this test." I gave him like about five tests, which I heard about but I was not the professional, honestly.*

The tests did indicate low Vitamin D and iron deficiency and they started giving him supplements:

> *But thank God since we'd given him the iron supplement and vitamin, he's slightly changed. Not slightly, it's a huge change for us.*

Their son's diagnosis occurred around the same time that he was starting at a mainstream nursery school. The EHCP assessment process started and they hoped to see some improvement:

> *We just tried to just stay in the mainstream class because we thought at that time mainstream class was good for him, maybe he'd just copy the others, maybe he'd just behave a little bit better.*

After a year, with support put in place *'just like babysitting'* they decided with the teacher that *'he's gained nothing'* and they were *'advised to find a special school for him'.* Soran and his wife were very upset when they first came to the special school because of the severity of autism they observed in the pupils they saw. After much thought about what would be best for their son:

> *Eventually, we found out there's no place for us in the mainstream. Even the teachers are not happy to accept him.*

Soran continued to have concerns about his son's slow development but did feel that with the supplements and his learning in school that he was making progress.

> *The good thing is he can understand English and my own language, which is Kurdish. Two languages he can understand. If I give him direction, if I give him instruction for either languages, he can understand. Maybe picking up the English language, and he can recognise friends and families and the teachers. He's in a good relation with everyone. So I'm hoping that he's picking up with the school, numeracy and literacy, whatever they're teaching at school.*

Soran explained that since he had stopped working to help care for the children, that he rarely socialised with friends or went to the mosque. For Soran there was a strong focus on wanting to create a cohesive family unit where his son could learn to interact with his siblings and where he wanted to find positive ways to engage him:

> *So right now, say, we cannot go out, so we have to stay at home, then we have to have activities and just playing with something. So nowadays, he learned that game. We let him run and we just follow him, we just try to catch him and he likes this kind of play.*

Ambiguous loss

The story which Soran chose to share reflected how the ambiguity he was experiencing about his son's diagnosis and development had impacted on him personally and had significantly changed the patterns of family interaction. Inductive analysis of Soran's description of the changes he saw in his son's development suggested that Soran was experiencing ambiguous loss (Boss, 2004) and his need to seek explanations for his

son's autism was a response to this. According to Boss (2004) ambiguous loss is linked to the stress that affects families or individual family members when ambiguity arises from the unpredictability of caring for someone who is 'physically present but psychologically absent' (p.554).

It was significant for Soran, that his relationship with his son had changed:

> *He had a good relationship with me, especially with me, and with the others.*

Ambiguous loss may be evident during the time of diagnosis or at other transition points in the family life cycle but does not necessarily remain a permanent feature as the child develops and families adapt to a different set of expectations (O'Brien, 2007). Although O'Brien's study of ambiguous loss in families who have an autistic child, involved majority White mothers, these same issues have been identified in research as being synonymous with the transcultural experiences of minority ethnic families (Crippen and Brew, 2007).

> Parents' ability to tolerate and manage the ambiguity of their child's disability is a key factor in their experience of ambiguous loss and the related confusion over family members' identities, both of which can contribute to emotional distress'
> (Boss, 2004:135).

In an effort to gain some control through this time of change Soran proactively sought tests from the doctor to ascertain a biological cause:

> *It was not knowing exactly what's happening and there's something wrong.*

> *We look at it back now, which is very sad for now and at that time.*

> *I was worried… and everything's changed.*

Soran found meaning through his descriptions of how he now enjoyed playful engagement with his son and how he wanted the family to interact. Overcoming ambiguous loss, Soran was able to draw on the attachment patterns he had with his son and recreate these through adapting to his son's desire for playful interaction. Family gatherings in Iraq were also significant for him and for his daughters to experience interactions with the wider family. It was a place where his concerns about his son were understood and he felt supported. Grant, Ramcharan and Flynn (2007) identify how familial, social and cultural resources provide a 'holding environment' where individuals can evaluate their identities and influence how they

manage the ambiguity of the boundaries between themselves and their experiences. Observing this through a transcultural lens, for Soran, his family played an essential role in enabling him to overcome feelings of ambiguous loss and gain a sense of mastery over his situation.

O'Brien (2007) highlights another aspect of parenting a child with autism which brings about ambiguity, namely the variability of day to day caring and difficulty in predicting outcomes as the child gets older. One cause of distress for Soran was how mealtimes at home were difficult because of his son's limited diet. Eating together was a normalising activity for the family that had become a disruptive experience but where Soran had been able to adapt by teaching his son how to eat:

> *But thank God, at the moment, he's just about restarted eating. I*
> *mean that is coming back on track. If you give him a whole banana,*
> *he will eat it. Banana, apple, everything, he doesn't like slices and*
> *things like that.*

Although it was having a significant impact on the family income, Soran's decision to give up work and focus on caring for his son could also be described as achieving a sense of mastery to attend to his own wellbeing and that of his family and he felt able to manage the current family situation while having hope for a different future for his son and his family. For Soran ambiguous loss was not necessarily overcome but he was adapting and adjusting to a different future:

> *At least if he progress a little bit, still, there is hope. What we want*
> *for my son, I want him to be independent… I'm living with the hope.*
> *If there's no hope, there's no life.'*

4.10 Yash and Friya: pen portrait

I met Yash at a parent induction meeting at the special school where all the parents whose children were starting at the school in the following term had been invited for an introduction to the school and its curriculum. We arranged to meet at the family home as Yash also wanted his wife to be involved. Yash and Friya had three children, all with a learning disability. Their eldest son was 12 years old who had a diagnosis of speech and language delay. Their second son was 5 years old and had been diagnosed with autism and was due to be starting at the special school as a result of a planned move from a mainstream school. Their youngest child, a daughter, was 3 years old and they were just beginning the diagnostic process for her. They were

uncertain whether she had autism or a speech and language delay and were waiting for the assessments to be completed. Their narrative of *transformation* was about being parents of three children having a diagnostic label for their developmental difficulties:

> *So we don't know why our three children have some traits of ASD and one of them has been diagnosed with ASD, it's very difficult to pinpoint, oh this is the reason why your child has ASD or just the reason why all the three children have some special needs, it's very difficult to pinpoint that.*

Through inductive analysis I noted how Yash began the interview by establishing his identity as 3rd generation British Bengali:

> *I've been here my whole life; I was born, raised and educated in the UK.*

He gave a long account of the family and that his grandparents came to live in the UK after the second world war. His father was born in the UK and his mother came from Bangladesh. Yash then explained that Friya was born in Bangladesh and although her brothers lived *'across the globe',* her parents lived in Bangladesh. Yash and Friya were cousins and they married in Bangladesh:

> *We are part of a massive, massive family because my grandfather married twice, so I've got lots of half uncles, if you could call it that, half uncles and aunts and their children.*

Yash worked as an IT systems manager. He was also a school governor at a local mainstream primary school. All three children occupied themselves playing outside while Yash and Friya talked with me. Although I spent about two hours with the family, the recorded interview lasted 55 minutes. Yash led the conversation about their experiences and would affirm information with Friya throughout the interview. Friya did not share anything from her perspective, even when I specifically asked her a question, as Yash spoke on behalf of them both. She was also responding to the needs of the younger children, so was not able to fully participate.

Having gone through the assessment process for their first son due to a severe speech delay they were assured that he could remain in mainstream school but that his development would be slower compared to his peers:

> *But he's definitely not autistic.*

This affirmative comment by Yash seemed to provide him with a reassurance to counter the knowledge of autism in his youngest two children. With their second son

they initially thought that he was '*developing as any normal child*' and then at two years old Yash described how things began to change for them again:

> *We were seeing lots of repetitive behaviours and challenging behaviours; self-harming and lashing out because he couldn't express himself.*

Yash researched and read to discern what the problem was:

> *So we were quite certain he probably was, or would be if you look at the diagnosis, he would be autistic.*

It took over a year to receive the formal diagnosis and they were just beginning the assessments for their daughter who they described as being able to do a lot more than her brother but that she '*might be very low level on the spectrum'.* Yash explained that despite a sense of *belonging* to a large and supportive family as something they valued, they had not been able to tell family members that their son had a diagnosis of autism even though they understood his developmental differences. Their justification for this was in wanting to contain the trauma of their experiences:

> *We are still hurting inside and we don't want people's pity and to feel sorry about it.*

Inductive analysis of their storying of events leading to assessments for all their children revealed that they experienced positive *interactions* and appreciated the help and support they received from health and education professionals. Subsequent to each assessment they had gained more knowledge about the process and so for their daughter's diagnosis, there was a sense of emotional preparedness. Yash and Friya had become familiar with the process of assessments and which professionals would be involved:

> *Again we went through the motions. So going through that with our eldest child was an experience and we got to know the processes and who you'll meet then, the kind of professionals and so on.*

In the mainstream nursery school their second son attended he had received TA support but they were concerned about how much he would engage and learn as he went through the school:

> *The school's been very supportive in getting him transferred. And we're very, very happy with the service we received back and they've been absolutely fantastic. Really helpful. Very supportive.*

Yash and Friya took several months to make the decision for their son to go to the special school but had attended workshops and met other parents before making their choice:

> *It's very important and reassuring for parents to have that support, to have that network of parents and then friends who have experienced children with ASD because I think it's very, very comforting to speak to other people who have that problem.*

Transition

Interviewing Yash and Friya in their family home, I was mindful of the way in which this created a different atmosphere to those undertaken in the school setting. The parents were relaxed and comfortable talking to me while the younger children played outside and the oldest son was occupied in his bedroom. Brief insights into family functioning can add another interpretative dimension to the narrative that may not have been evident in another context (Clandinin and Rosiek, 2007). Establishing what 'family' meant to him by inviting me to their home and talking about his extended family was a stabilising force which they clearly valued. It provided a possible explanation for their emotional coping and the practical strategies they had adopted since having their first son diagnosed with speech and language difficulties.

> *As parents, we have asked why our children? You know we asked those questions but we have faith and we believe in God and we believe everything happens for a reason. And they are of course a gift to us and we have to do the best we can for them and that's what we'll do.*

Parental adjustment can be complicated by the fact that generally speaking, finding out that a child has a disability is an unanticipated event that can be experienced as traumatic (Seligman and Darling, 2007). Inductive analysis of their life story narrative also revealed the multiple transitions they had experienced as a family; Friya's migration, the diagnosis of their children's special needs and their son's impending move from a mainstream to special school, had involved a series of readjustments and a different way of thinking about the family:

> *You know we've been blessed with three children and they do have some needs, that's the way it is and we've accepted that, we just have to be strong there and do our best all the time.*

In my journal I reflected on how Yash and Friya referred to not wanting to be pitied or to have their child 'labelled' or regarded negatively, and that this was a factor in not wanting to tell the family or others in the Bangladeshi community. It was not the diagnosis that was valued but how it was viewed within their broader social context. What made the adjustment more bearable was trying not to intellectualise the event but how their affective response gave it value. With all their children they had observed a period of atypical development but recognition of the onset of their children's developmental difficulties had resulted in a significant *transformation* in their interactions with their family. Not feeling the need to be rushed into telling their extended family about his diagnosis or deciding on the special school was indicative of the coping strategy they had adopted as part of the process of transition:

> *What we realised was, transferring him to special school is the best thing for him. Ultimately, it's the best thing for us because we would know he's getting the right support in the right place.*

Despite their belief that '*everything happens for a reason*' they felt they needed to '*hold back*' the hurt they were experiencing in not wanting the family to know about their son's diagnosis of autism. At the same time, they were wanting to affirm their strength and keep a positive outlook. They seemed to adopt the same pragmatic approach in their decision for their son to transfer to the special school:

> *They considered our feelings because they know they can't force you or tell you to do something, it's entirely the parents' decision. And we felt we don't need to be rushed into making that decision because it's a big decision for us and for him, we didn't want to be rushed.*

Yash and Friya acknowledged that it was very challenging for them as parents to have three children with special needs and they were acutely aware that they would be experiencing more transitional events in the future but that for now, their mindset was to remain optimistic and have a positive outlook.

4.11 Pen portrait summary

Each of the pen portraits attended to the research questions by giving prominence to the transcultural realities of the parents' past and present lives and how they found the intrapersonal and interfamilial resources to adapt and develop family coping strategies, navigate institutional systems and interact with health and education professionals in response to having a child diagnosed with autism. Both inductive and deductive methods of analysis in the pen portraits and interpretive summaries

captured the uniqueness of their individual stories and provided a unifying narrative about their transcultural responses to parenting an autistic child and the shared reality of their experiences (see Fig.4:1). As Tartaglia (2016:1) contends, 'transculturalism is about looking for shared beliefs which cut across culturally and historically contingent boundaries while recognising that there are multiple ways to configure the world.

A focus on the families' narratives of identity, transformation, interaction and belonging in the pen portraits and interpretive summaries has gone some way to disrupting the dominant autism discourse that has had a tendency to essentialise the 'minority ethnic experience' as being fixed within cultural and ethnic boundaries. The individual family narratives highlighted how different aspects of their transcultural lives needed to be reconfigured as a consequence of significant challenges parents experienced, such as their migration experience and the impact this had on their relationships with family members. Having a child diagnosed with autism was seen as another aspect of their life story that led to a psychosocial response brought about by the need for change and adaptation. In their interviews the parents described how they needed to adapt and develop different identities since having an autistic child which had required them to rethink how they interacted with professionals, family members and those in the local community. These interactions were fundamental to how they achieved a sense of agency and drew on their own social and cultural resources to establish a sense of belonging to their community and networks of support.

TRANSCULTURALISM   **INDIVIDUAL NARRATIVES**

**identity
transformation
interaction
belonging**

**marginalised
self-other awareness
advocacy
adaptation
agency
post-traumatic growth
resilience
ambiguous loss
transition**
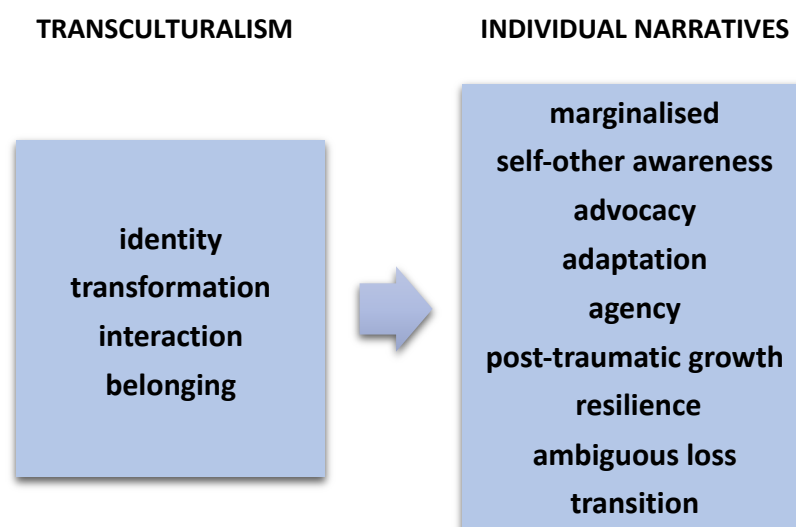
Fig. 4:1 Narratives of identity, transformation, interaction and belonging in their individual experiences

The families' narratives have also drawn attention to the ways in which minority ethnic families adopted similar psychosocial spaces across their multiple experiences of caring for an autistic child. Although these were identified as a theme in the interpretive summaries as being pertinent to individual stories, to some degree all the parents were experiencing marginalisation, ambiguous loss, post-traumatic growth and coping with transitional situations. They acknowledged that there was a cultural dimension to how they and their family responded to having an autistic child and although they actively sought a diagnosis, preferred to see autism as a developmental 'difference' and an aspect of their child's identity. This perspective appeared to positively contribute to a shift in their sense of self and family identity, advocacy, agency and resilience as they re-imagined a different trajectory for their own and their families' lives. These transformative effects of their lived experiences have further contributed to a conceptual understanding of their transcultural lives which are developed as themes in a cross-case analysis of their narratives in Chapter 5.

4.12 Reflexive summary

To conclude this chapter, I have reflected on my role as a culturally responsive researcher (Papadopoulos and Lee, 2002) and the ethical responsibility I had to locate and identify the cultural differences as well as the similarities between myself as the researcher and the researched. For me, this began with an awareness of my own cultural biases and assumptions that I brought to the interviews and whether as a White British woman, the parents would want to talk openly with me about their families. I had concerns about whether they would respond to me as the 'White expert' and only give me information they thought I wanted. I also wondered how they would regard privileging me with their personal stories. After the interviews I recorded my response to our interactions and reflected not just on what I had learnt from the parents, but also about the process of researching with minority ethnic families and the dynamic of 'difference' in relation to my ethnicity and gender, how this may have influenced the interview encounter and my interpretation of their narratives.

In my research journal I wrote:

> *Why am I anxious about interviewing the parents, isn't talking with parents about their autistic children something I am used to? Am I worried about what they will expect from me? In the parents meetings where I have shared my research proposal, they have been very vocal about wanting a medicalised understanding of why so many in their Somali community are having children diagnosed*

with autism. (They knew about Minnesota and Swedish research!). When I explained that I didn't have a medical or health background they weren't sure to begin with until I shared my professional and international background with them. They recognised how so much of the autism research focused on White ethnic families and by sharing their personal experiences of caring for an autistic child this was a way of giving them agency.

I wanted to ensure that I approached the start of each interview with a sense of openness which shifted the power dynamic of a formal interview and positioned them as the 'tellers' and me as the 'listener' of their stories. This was reminiscent of the way in which I engaged in therapeutic work with families but in the context of the research encounter it felt like a different experience because of the need to acquire data for interpretive purposes.

My first interview was with Jessia and the subsequent interviews took place in the order in which they have been presented above. Following Jessia's troubled account of gaining a diagnosis for her son I wondered about the extent to which all the parents would give me problem-saturated stories that would perpetuate stories of discriminatory and marginalised practices towards minority ethnic families. With each the interviews there was a need for a sense of preparedness in taking an empathetic researcher approach that would give meaning to their social and psychological realities (Attia and Edge, 2017). One example of this was with in the first interview with Manoj:

> Manoj: *'For 17 years, our family have this. It's very sad, explain my situation, but what will I do, it's God's gift. But very, very difficult, very difficult. It's impossible. Like this, I have to do three jobs.'*
>
> Diana: *'That makes it very difficult for you. I can see how you are caring for her, supporting your wife and wanting a better situation for your family.*

I reflected in my journal following my interview with Arnab:

> *Why am I so moved by this father story? He says his family are his life and he has not abandoned them. Despite the negativity he has received from others in the community he tells his wife, 'they are entitled to think like that but it is not the same for us, we are his family.'*

It was the interviews with the fathers where I began to reflect on the cultural assumptions I had made that I was not expecting. I felt challenged by all their stories because of the recognition of our 'difference'. As a single parent I could empathise with the mothers who talked about their struggle to cope with working, studying and caring for children but why was I surprised by the fathers' tearful responses when they talked about their family? Based on my previous knowledge of working with Muslim fathers, perhaps this was an aspect of my transcultural knowledge that needed to be challenged. This shift in my knowledge, particularly in relation to the paternal role in childcare, was a recognition of my own learning about cultural expectations and identities.

4.13 Conclusion

In this chapter I have presented an interpretive analysis of the family case studies using a transcultural paradigm to identify how parents individually responded to having a child diagnosed with autism and the impact this has had on their interactions with professionals and other family members. The nature of their interactions with professionals and how they decided on the most appropriate education for their autistic child were significant to the strategies the parents adopted to advocate for their child and family's needs which they navigated across different social and cultural contexts. Their narratives also revealed the transformative ways in which they positioned themselves with their new knowledge about autism, how they identified as parents of an autistic child and how, in turn, this impacted on their sense of belonging with their extended families and in their local communities. The following Chapter draws on the families' narratives to generate further thematic analysis and discussion about their transcultural experiences.

Chapter 5: Findings and Analysis: a collective narrative
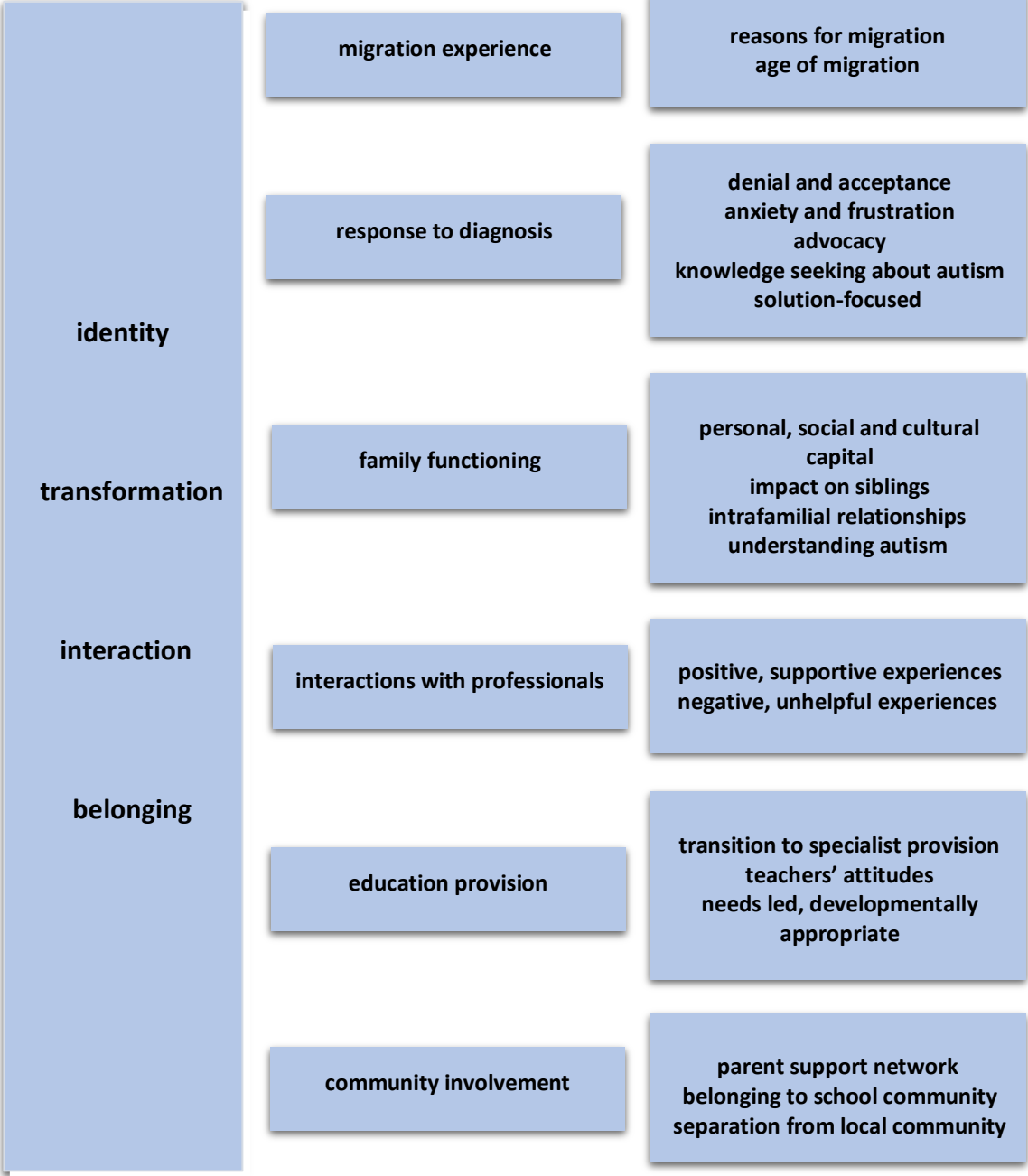
5.1 Introduction

This chapter presents a cross-case analysis of the families' narratives which aims to further articulate the multi-dimensional nature of the similarities and differences in the families' experiences of caring for an autistic child. Exploring the interrelations between the personal and collective narrative was essential to the iterative process of interpretation. Moving within and between individual narratives I was able to add another layer of interpretation and explanation to the analysis. In the previous chapter both inductive and deductive analysis was employed as I was interested in learning more about their personal experiences of caring for an autistic child and wanted to use extracts from their narratives that related to the development of a transcultural conceptual framework. In this chapter the themes, or patterns of meaning that were pertinent to all the families were also derived from inductive and deductive analysis of their individual stories which represented a nuanced approach to their personal and transcultural lives. These themes were their migration experiences, their response to diagnosis and how this impacted on family functioning, the nature of their interactions with professionals across health, education and social care, the educational provision for their child and their involvement with the community. The thematic map (Fig.5.1) presents the themes as transcultural experiences and how they were constituted from inductive coding of the families' narratives to identify sub-themes. The sub-themes helped to define the main theme and were key to offering a more detailed analysis of the patterned meanings within the data (Braun and Clarke, 2006). In the following sections, the themes are exemplified with extracts from their individual narratives of identity, transformation, interaction and belonging which gave further credibility and authenticity to the families' transcultural experiences.

As in the previous chapter, using their narratives in a co-constructed interview as the focus for interpretation required a reflexive approach to the research. To enable the themes from their collective narrative to come to the fore a reflexive summary, using extracts from my journal is presented at the end of the chapter.

TRANSCULTURALISM **TRANSCULTURAL THEMES** **SUB - THEMES**

TRANSCULTURALISM	TRANSCULTURAL THEMES	SUB - THEMES
identity	migration experience	reasons for migration age of migration
	response to diagnosis	denial and acceptance anxiety and frustration advocacy knowledge seeking about autism solution-focused
transformation	family functioning	personal, social and cultural capital impact on siblings intrafamilial relationships understanding autism
interaction	interactions with professionals	positive, supportive experiences negative, unhelpful experiences
belonging	education provision	transition to specialist provision teachers' attitudes needs led, developmentally appropriate
	community involvement	parent support network belonging to school community separation from local community

Table 5.1 A thematic map of transcultural themes and experiences

5.2 Migration experience

Deductive analysis of the parents' stories of migration to the UK affirmed how their subjective experiences shaped their identities and gave meaning to their sense of place and belonging. Similar to De Fina's (2018) research, talking about their migration experiences provided a function within their narratives by framing their responses to the life experiences they described. Although Jessia and Yash were

British born they had experienced the migration of family members to the UK and with their Bengali and British identities presented strong affiliations to their cultural positioning in the telling of their life story. Jessia's parents and Yash's mother and his wife had migrated from Bangladesh:

> *I am third generation Bangladeshi. I've been here my whole life. I was born, raised and educated in the UK. I got married in Bangladesh as my wife's from Bangladesh.* [Yash]

> *I'm Asian, I'm Bengali, British Bengali. Other's don't want to accept their child has autism, with me it was different.* [Jessia]

Making reference to their cultural heritage was a feature of all the parents' narratives that gave them a sense of continuity and identity which Falicov (2012) identified as essential for understanding the long term influences of migration on family functioning. Inductive analysis highlighted how their migration experience was defined through their unique personal histories, the reasons for their migration and the age at which they migrated. Their stories about the reasons for their migration included sanctuary from civil war, improving their education and employment opportunities, family and marriage. These aspects of migration, the languages they spoke and their education had been significant factors in how they responded to their child's autism diagnosis. Having come to the UK after the civil war in Iraq, Soran explained how he was trying to make sense of his current situation by thinking about his past:

> *We have to be thankful we are in the UK. We're very thankful. Thanks God we are much better, but still when you have a…suffering from something, you just…sometimes you've forgotten the good things because of the pressure or because at times, you're struggling with your child and sometimes, the lives become terrible for others.*

Despite the challenges they had faced in learning new languages and establishing homes for their families, the parents viewed their migration to the UK as a positive and transformational experience despite the loss of close family relationships. In addition to the educational and employment opportunities it had given them, they were accessing current knowledge and expertise in autism which they endeavoured to share with their extended family in their 'home country'. Maintaining family links both in the UK and their 'home country' they were able to draw on different cultural understandings of autism. Although the parents had sought a formal diagnosis in the

UK they appreciated that other family members did not refer to 'autism' but to the different ways their child was functioning in the family context. They recognised that while family members in their home countries did not have a medicalised understanding of autism, there was an acceptance of developmental differences:

> *My dad is in America. My dad knows, my mum knows and every time she will ask me, how is he doing? Don't worry he won't talk, blah blah blah. But she knows what autism is but I don't think they get it.* [Hibaq]

> *I don't say autism or autistic because it means nothing to them. I have to describe the behaviour, I have to describe it to them and then describe all the difficulties I'm having with her and they say, "oh, yeah, but that's okay."* [Fatou]

I reflected on how talking about their migration to the UK and their families in their 'home' country, heightened their awareness of the similarities and differences in their cultural knowledge about autism and having a transcultural perspective was more aligned to their current situation living in the UK.

5.3 Response to diagnosis

In the same way that the parents were happy to share their migration experiences, they also talked about the emotional realities of having a child diagnosed with autism. These intersectional aspects of their lives involved a continuous and dynamic process of assimilation emotionally and cognitively, as the developmental and psychological needs of the family changed. Deductive analysis identified that a dominant feature which defined the parents' response to a diagnosis was the psychological impact of the assessment and diagnostic process on their parenting role and how they identified as a parent of an autistic child. Highlighting the diversity in families' responses to seeking and receiving a diagnosis of autism was dependent upon both biomedical understanding and the unique ways in which disability was socially constructed within the family and wider community. Inductive coding of their responses to diagnosis were strongly linked to experiences of ambiguous loss and post-traumatic growth not just for Soran and Arnab but were recognised as a feature of parents' initial response to an autism diagnosis (O'Brien, 2007; Çelik and Ekşi, 2018).

Unlike previous research (Corbett and Perepa, 2007; Kuenzli, 2012) an autism diagnosis was not something which they were reluctant to seek and they were proactive in wanting to determine the nature of their child's developmental differences. Through an inductive analysis of their narratives, it was clear from the storying of events how 'acceptance' was a complex process of psychological, social and cultural adaptations to the different life cycle experiences and challenges related to caring for an autistic child.

This was Jessia's combative response:

> *Even if it's autism, they are human beings, you know. It's just certain behaviours they have is not normal, the same as other kids but accept it, there's ways to manage it. It's not a life-threatening um like problem, it's not, it's just the behaviour that you can find a way to manage.*

whereas, Arnab's response was more cautious, when he referred to his family's acceptance as having to 'take it':

> *So my son is take it as well because he gets it through the family, we are four in the family. So we have to take what's been happening. The family, the relatives, they see, they feel oh we are so sorry this, this this, like they take it but not like my family.*

In addition to describing their anxiety and frustration about the diagnostic process, deductive analysis showed how the parents' stories also revealed the positive aspects that gaining a diagnosis of autism had on them and their family and how it had given them a different understanding of their child's development. The personal and cultural resources they drew on to develop coping strategies and advocate for their child and their family were based on their overriding need to find agentic solutions to the circumstances which had positioned them as parents of an autistic child:

> *I mean we can't change it, it is what it is, as people say… so that's our mindset at the moment.* [Yash]

> *He has autism. This is what it is and this is what he struggles with. And that's just been from day one and I've always thought this is nothing to be ashamed of.* [Nadifa]

Deductive analysis of the parents' ongoing concerns about their children's future suggested that the concept of acceptance was not a fixed state. It is fundamentally a process of life-long adaption which all families who have a disabled child experience

and is manifested in different ways due to the cultural influences on the family (Ryan and Runswick-Cole, 2008).

5.4 Family functioning

Efforts to redirect problem-focused situations to find solutions and advocate for themselves and their family were key to creating a positive narrative out of the personal, social and cultural challenges the parents had faced:

> *This is a disability family. It's how I explain. It's a God gift, God has the solution.* [Manoj]

> *Once you accept the child for who they are rather than having all these dreams or all this aspiration for them. And rather than forcing him into my world, getting into his world. I think that helps*. [Hibaq]

In re-appraising their lives and how they identified themselves as a family, their stories revealed similarities with those highlighted in the dominant research on family functioning in White British families who have an autistic child (Bancroft et al., 2012) and highlighted the importance of thinking systemically about family functioning. Cross-cultural research on autism to date has tended to ignore the social aspects of family life and focused more on stereotypical views about family functioning that are bound to particular cultural and religious beliefs (Daley, 2002). Deductive analysis affirmed how taking a transcultural approach made it possible to recognise that aspects such as single parenting, the financial burden of caring, concerns for siblings and talking about autism with extended family members were also part of their narratives. Four out of the five mothers interviewed were single parents and for Hibaq, Sahra and Fatou this happened around the time of their children's diagnosis. Inductive analysis indicated how cultural differences in attitudes towards having an autistic child contributed to their current status:

> *We didn't get to each other because we are from two different parts of the world. I know it's Africa and we are both from Somalia but because of the two different backgrounds*. [Hibaq]

> *I think something to do with the way he's raised and his idea about having a family I think it was kind of completely different.* [Sahra]

> *My partner left just before the official diagnosis and it was just me and my kids and I don't have any other relatives around.* [Fatou]

Making the decision to change their work patterns or leaving work to have more involvement with their autistic child and the family was a feature of their need for agency regarding their family life:

> *So around the same time he got the diagnosis so about three and a half years I handed in my notice and I quit work and haven't gone back since. I said he needs me right now and this is where I need to be right now.* [Nadifa]

Only Yash had full-time employment, but he was able to work at home on flexible hours to help look after their three children. Soran seemed ambivalent about giving up work even though he wanted to spend more time at home helping his wife care for their four children:

> *When I used to work 12 hours or 10 hours, I wasn't so tired like these days because I would go straight into driving and dealing with the customers… but now, I have to continuously, continuously look after my son.*

In contrast, Arnab wanted to work, but due to his son's health issues needed to be available in case he became ill:

> *I have to work part-time. I don't like to give up work, because I love my work. So some days I have to care for my child, my family.*

Inductive analysis revealed that for the parents in this study, the nuclear family unit was a sustaining force that enabled them to make decisions about their child and family's future. All the parents shared concerns they had for their other children, the siblings of their autistic child:

> *There is nothing out there* [support] *for siblings.* [Hibaq]

> *They* [school] *don't really understand. My son had a hard time last year and there were specifically teachers who weren't very helpful to him.* [Sahra]

Although the needs of their autistic child dominated most of their family activities there was an expectation, a sense of hope that the siblings would have a different future:

> *I think on my mind it's playing, if you get one child normal and if you don't get any other child, a sister or brother just normal, they can affect the education, or his behaviour or your like, friends. Like, this son he's okay now, he go to college now doing IT and Business. So I support him much I can [sigh].* [Arnab]

> *Yes, my boy – good, very intelligent. Everything, results* [school], *very good. Maybe in future studying as a doctor or scientist.* [Manoj]

Through deductive analysis this research affirmed how the fathers' emotional and physical engagement with the needs of their family was equally as poignant as the mothers (Hannon et al., 2018). This research concurred with studies by Bywaters et al. (2003) and Towers (2009) which recognised how fathers took a proactive role in providing support to maintain family cohesion. Maintaining family cohesion and sharing normalising experiences such as family gatherings and family outings was also a key aspect to their lives which also challenges the dominant discourse on the stressful and burdensome nature of parenting an autistic child which has been cited in previous research (Benson, 2010; Mc Cubbin and Mc Cubbin, 2013).

5.5 Interacting with professionals

Being deductively derived, this theme relates to one of the research questions and was defined through both positive and negative experiences recalled by the parents along a continuum of ongoing interactions with professionals. Inductive analysis of their narratives identified that positive experiences of interacting with professionals were linked with an emotionally charged narrative where parents felt more in control of a situation or event related to their expectations of professionals' specialist knowledge:

> *I think what is most helpful is, the most helpful is to work with somebody who listens really, who you know, who's sympathetic to what the parents have to say or, you know, able to understand to see from the other person's perspective.* [Sahra]

> *We felt really supported and we still do.* [Nadifa]

> *The diabetic nurse, the doctor, everyone coming and explain to us, now we are going to train you to give him insulin.* [Arnab]

Conversely, negative interactions with professionals revealed how parental expectations about the supportive role of professionals impacted on their caring role:

> *I'm feeling judged by all the professionals that's working with my son.* [Jessia]

> *The doctor at the hospital didn't know much about children with autism, he was kind of, not very understanding.* [Sahra]

As previously discussed, navigating a network of professional services becomes a unique and distinguishing component of family life when a child is identified as having a developmental disability (Redmond, 2003). Moving from a state of dependency and

vulnerability when they initiated contact with professionals to becoming advocates for their children, represented a significant shift in their identity as parents of an autistic child. From a Foucauldian perspective, the dynamics of resistance came into play as the parents became more knowledgeable about their child's developmental differences and sought professionals who would affirm what they wanted for their children:

> *I went to the health visitor, they were like "there's nothing wrong with him", so I went back to the children's centre.* [Sahra]

> *I'm going to tell you what's right for my kids because if I don't talk for my kids no-one's going to talk for them.* [Jessia]

> *They considered our feelings because they know they can't force you or tell you to do something, it's entirely the parents' decision.* [Yash]

Requesting and receiving support from professionals with regards to learning about autism or their child's medical condition, was also not considered a barrier in terms of language or cultural differences, as other studies (Heer et al., 2012; Hubert, 2006) have found. For example, research on minority ethnic families' experiences of caring for a disabled child has suggested that they engage less with systems of support than the White majority population due to cultural assumptions about interfamilial support, language barriers and attitudes towards disability (Fox et al. 2016; Guldberg et al. 2019; Miller-Gairy and Mofya, 2015). Inductive analysis highlighted that for the parents who had been educated in the UK, accessing information and resources from professionals had not a problem for them.

Where other studies (O'Hara, 2003; Crotty and Doody, 2015) have considered the potential for cultural insensitivity by professionals, inductive analysis revealed that none of the parents referred explicitly to feeling discriminated because of their ethnicity, nor did they give examples of professional practice which they might have interpreted as institutionally racist. Jessia and Fatou both talked about feeling marginalised and threatened by professionals' judgements of their parenting skills but related this to a lack of professionals' understanding of their children's behaviour:

> *Because one day I said something, I don't know, I don't normally say something but I decided I had to say something back to her and then when she said to me 'why can't you control your child?" I ended up saying to her 'you control her, maybe you can do a better job than me'.* [Fatou]

> *Sitting in one room speaking to the professionals, I couldn't even speak, I couldn't get words out of my mouth cos I had a lot of anxieties…. And now I just put my foot down and tell them you need to listen to me. I want something for my son and you have to help me with that.* [Jessia]

However, as single parents, Asian and African, I reflected on the possibility of a more subtle form of cultural insensitivity which could have been at play in both these examples. This resistance was also referred to in the parents' interactions with education professionals particularly in relation to points of transition between nursery and mainstream education and between mainstream school and a planned move to specialist provision. These factors are relevant to the theme discussed in the next section.

5.6 Education provision

The importance of their child's special education and how they processed the need for their child to attend specialist rather than mainstream education was a dominant theme in the parents' narratives that inductively defined their experiences of gaining developmentally appropriate educational provision for their autistic child. For most of the parents, the internalisation of their child going through the diagnostic process, was compounded with their child beginning their Early Years education; a paradox in re-defining their own identity as well as their child's identity and learning potential:

> *And they started to say things like, it was not going to be safe for the other children. I said, I don't know what you mean cos she's not a risk to anyone.* [Sahra]

> *They couldn't change the environment to suit him. It was either a case of he has to fit into that environment or actually at best we'll just do a one-to-one for him and somebody will just supervise him and keep him safe.* [Nadifa]

With their child's inclusion in these settings being challenged by teachers and the schools, for the parents there was a heightened sense of their own exclusion from the education system even when they had other children who attended mainstream schools. 'Doing battles' with professionals and 'fighting for what's right for my child' are idiomatic expressions which many parents of disabled children have used as response to how they have been positioned when determining the most appropriate educational provision for their autistic child (autism.org.uk; Ryan and Runswick-Cole,

2008; specialneedsjungle.com) and this was no different for the parents in this research.

> *Getting a special school is a battle, getting the educational healthcare plan is a fight.* [Fatou]

> *I'm just going to do one battle at a time.* [Hibaq]

Key to the transition of their child's move to specialist education was how supported they felt by the SENCOs, teachers and advisory service. Also featured in their individual narratives was how they internalised their response to their child's need for special education. Aspects which contributed to wanting a placement for their child was that their child would *'be safe'*, where they would receive an education that met their child's developmental learning needs and where the professionals working with them had the knowledge and understanding to teach autistic children. This concurs with previous research (Corbett and Perepa, 2007; Seach, 2016) which found that minority ethnic families did have a good understanding of their autistic child's developmental needs, despite education professionals making assumptions about families not wanting their child to go to a special school due to the stigma of having a disabled child.

Soran and Yash initially had reservations about their children being educated with other autistic children but were encouraged by the SENCOs that mainstream education would not be able to meet their child's learning needs:

> *And they told us and advised us to find a specialist school and we were very unhappy… We found there's no place for him in mainstream. Even the teachers are not happy to accept him.* [Soran]

> *His needs are a lot more complex than what mainstream school can provide. The school have prompted us to consider a special school…It's a big decision for us and for him, I didn't want to be rushed. So we took our time, we took a space of six, seven months to make that decision.* [Yash]

Despite parents being given a role in decision-making about their child's special education (Special Educational Needs Code of Practice, Department for Education (DfE), 2014), many parents of disabled children continue to experience a sense of powerlessness in the process of acquiring special educational provision. Tomlinson (2017) cites an historical precedent for parents obtaining specialist education that

continues to be influenced by 'class' and 'race'. For Jessia this was a traumatic experience, whereas Fatou's crusadership in wanting a better educational setting for her daughter was that she remained in mainstream education in a setting where her daughter could make progress and was taught by staff who were supported by the autism outreach team:

> *So now they working towards helping her. They know her limitations, they know how much she can take…So when they notice that she's getting bored, just take her away somewhere else…And they realise she's very good at maths. Even though she copies so many things, but she takes in a lot as well.* [Fatou]

As Ryan and Runswick-Cole (2008) point out there is a motivational aspect to parenting an autistic child that draws out an aspect of their individual personality and influences the extent to which they take on a campaigning role to gain the support and resources they want for their children. Through inductive analysis there was a recognition that through the training workshops and the internet, the parents had developed an understanding of different autism interventions which the schools used but they were also pragmatic in their responses to how their children were progressing and developing communication skills. Although the children were all at different stages in their education, the parents' trajectories for their children's development and skills and their hopes for their future learning potential were linked to present realities:

> *I want him to be independent, I want him to brush his teeth, I want him to go to the bathroom, I want him to do all these things by himself rather than me doing it with him.* [Hibaq]

> *At least if you progress a little bit, still, there is hope. What we want for my son, I want him to be independent. I want him to be able to say, "I've got pain in my teeth." "I've got a headache." "I need some water to drink." So this is painful.* [Soran]

While achieving independence is an aspect of family life that is no different for families who do not have an autistic child, for Soran, a lack of progress was a discomforting realisation of his son's long-term diagnosis. Inductive analysis identified that gaining more knowledge and understanding of autism through the outreach service and parent information workshops had translated into the parents developing more positive interactions with education professionals:

> *Like I think everyone have first experience from my son, with the diabetes. Now most of the teachers get used to it. Everyone is done*

> *a very great job. I appreciate from the headteacher and the teacher.*
> [Arnab]

Nadifa was also very positive about her experience which was also expressed in similar ways by the other parents:

> *So in this school I think you feel the support that actually, they're not here just for the child, they're actually here for the family, and I think that's fantastic and that's demonstrated in all the courses that they do and all the parents they're having (staff name) as a contact person.*

In these extracts I was able to reflect on how this sense of belonging to a school community was in part due to the ways in which they had actively engaged in the parent meetings and training workshops provided by the school and the NAS but also how the school was supporting the needs of families within the local community.

5.7 Community involvement

The extent to which the parents felt a sense of belonging to the school community was no different for Jessia, Fatou, Yash and Friya whose children did not attend the special school, or who were waiting for a placement there. Inductive analysis of the narratives identified how access both to the parent meetings and NAS training held at the school had enhanced their sense of belonging to an autism community of parents with whom they could share their parenting experiences. Drawing on their identity as parents of an autistic child, they had positioned themselves as autism advocates, knowledge seekers and providers within their family and their local community. This was experienced as a dichotomy for Yash who explained:

> *We were so reluctant to sort of discuss it and tell others was about the reaction that we might get from others. You know, often you're getting that stigma behind like, oh you have a disabled child and it's sort of regarded in a very negative way and the people often look down upon you and your child.*

Nadifa also talked about this even though she acknowledged the prevalence of autism in the Somali community and in her own family:

> *There is a lot of stigma within the Somali community about being labelled as, "Oh, that family's got a disabled child".*

Recognising how their own views about disability had changed since having an autistic child had transformed their interactions with people in the community. Similar to

previous research by Hubert (2004) and Slade (2014), it heightened their feelings about having a 'different' family which had impacted on their access to community activities. In accordance with research by Kandeh et al. (2020) on cultural perceptions and insensitivities towards autism, although they lived in a London borough where the majority population were Muslim, Bengali and Somali where they found it easy to access community resources and sources of information, they also found those in their local community and faith community less supportive and lacking in understanding about autism. These personal and emotional responses reflect how many families of disabled children continue to be positioned as a consequence of 'difference':

> *When he go to the mosque he get like nervous or get scream, or if he just hold it like this* [hands over ears]. *You know when the people come in the mosque, other people thinking it's not the same. They might feel different or they might say like, this child is disabled, this child can't speak. The way they are speaking in our language is getting really pained to the heart.* [Arnab]

And Manoj shared how it was not possible for the family to go to a community party:

> *My child out of control and everyone looking.*

The parents' efforts to overcome negative experiences of being 'othered' were countered by their connectedness to an autism community which was in part because of the role the school played, but also the way that parents initiated and maintained friendships with other parents who had an autistic child. This had lessened the sense of isolation they had felt from their local community:

> *One thing that people don't forget about is the person who is there for them when they are going through a difficulty. It means a lot, it makes a huge difference, to have that person say 'I understand this is difficult'. Not necessarily giving you stuff or doing things for you but just saying, 'you know what, I get it, it's really hard, I understand'.* [Sahra]

 I reflected on the ways in which wanting to project the need for a positive change in their interactions with others in their community they shared a capacity to overcome feelings of 'otherness' by developing an empathetic dialogue where others could alter their thinking and behaviour towards them and their families:

> *I want the information to be spread out a lot more, cos so many people don't understand what autism is….and I think the more people have knowledge, the less judgement they will pass around.* [Fatou]

So I'd like to get involved more and to be part of their journey and try to support them as I can. Be a parent advocate, be a parent practitioner, whatever. [Yash]

Inductive analysis made it possible to recognise how taking part in this research afforded parents the opportunity to reflect on how their past and present experiences, their interactions with professionals and their views about their children's education were informed by their sense of belonging to a community of people with whom they felt both separated from and connected to. For the families in this research it highlighted how their individual response to their child's developmental difference had created cultural dissonance with others in their community but also how they used their transcultural knowledge to engage with others in dialogues about autism and the stigma of disability.

5.8 Reflexive summary

Reflecting on the themes within their collective narrative there was an initial apprehension that I could be perpetuating research *on* a minoritised group of parents that would result in the objectification of the families' experiences and the maintenance of cultural differences in the disability discourse. I found Gunaratnam's (2003) perspective on researching across difference particularly relevant to my research. Gunaratnam argues that rather than looking at the binary categories of differences and similarities between the researched and the researcher, *connectivity* serves as a 'powerful methodological device for attending to, and making explicit, power relations and social and subjective locations' (p.91). It became clear after the first interview with Jessia that I was regarded by all the families as a member of the school community *('you understand autism, yes?')* and   I was not treated as an 'outsider' during the interview and nor was my rationale for undertaking the research seen as 'othering' their lived experiences. Given that the interviews took place in a setting where they had already established trusting relationships with staff at the school and health professionals who worked there, it was possible that they regarded sharing personal and sensitive information with me, in a similar way.

One of facets of undertaking transcultural research with the families was the way in which it created an opportunity for reciprocity. Reflecting on the impact that the families' migration experiences had on the family system I was able to recall my own

migration experience, having lived in South Africa and travelled to many countries where I had been positioned as 'other' in relation to ethnic, cultural, religious and economic differences. Throughout the thesis I have considered my own position as a transcultural researcher and the extent to which my past experiences have influenced my approach to researching with families.

After my interview with Sahra I wrote in my journal:

> *Am I getting the information I want about their transcultural experiences? By not giving them questions to answer and letting them just talk about their autistic child and their family, will I be able to recognise their experiences as transcultural?*

As Brannen (2013) points out, it is often what is not explicit in the narrative that makes it worthy of interpretation and deeper analysis. Reflecting on the research encounter and reading and re-reading the transcripts I became more aware of their narratives of identity and transformation, the nature of their interactions and their sense of belonging (and separation) from their community. Was I not initially identifying transculturalism because I was looking more for the similarities in their experiences of parenting and autistic child, to avoid focusing on the differences?

I found evidence to counter this in the literature that refers to the cultural stigmatisation experienced by minority ethnic families who have an autistic child (Slade, 2014; Selman et al., 2017). In the transcripts I noted that when the parents talked about how they felt about being positioned by professionals and those in their community because they had an autistic child, the word 'stigma' was only used twice across all the interviews. Instead families referred to a 'lack of understanding' by those in their community who expressed negative and discriminatory attitudes towards them.

I often reflected on this in my journal as a concept I needed to explore further:

> *Why is the disability discourse on stigma linked to 'other' cultures and ethnic groups and not the White British ethnic group?*

> *Has stigma become a word that is culturally **in**sensitive, preventing the experiences of White British families from 'going deeper' and exploring a cultural discourse about 'difference'?*

> *Does stigma need to be talked about more in the experiences of White British families to help with the cultural acceptance of autism as difference rather than disorder?*

I found that my questions about 'stigma' and 'difference' were resolved through the parents' solution-focused responses to the challenges they had faced and in the their collective narratives the families' transcultural lives became more evident. Contextualising their experiences within the UK and their 'home' country represented an 'acceptance' and 'sameness' in their personal, social and cultural worlds as parents of an autistic child and when the interviews were completed, I wrote in my journal *'they are living transcultural lives!'*. This was also reflected in their willingness to participate and co-construct knowledge about autism that commanded from me, a deeper understanding of their transcultural experiences and a significant shift in thinking about how to engage minority ethnic families in research.

5.9 Conclusion

By undertaking a multi-layered analysis it has revealed how transculturalism, which seeks to make relevant the universal and personal aspects of an individual's life, was contained within their narratives of experience. The multi-faceted nature of the analytical process also revealed some of the paradoxical ways in which they sought an early diagnosis that were generated by different ways of thinking about their individual circumstances, such as Nadifa's response following her cancer treatment. Each parent described their own transcultural experiences and their response to their child's autism diagnosis as a process of realisation rather than a specific event. As these statements attest, this will have an ongoing emotional impact on the family:

> *I thought once they got the diagnosis, it'll open doors, but it's like one door shut and then it's a different world. I feel like I've entered a whole new different world.* [Fatou]

> *You have to go through a journey where you have to evolve.* [Sahra]

> *It's been a rollercoaster.* [Yash]

The aim of these two chapters has been to demonstrate how a transcultural approach to autism and the lived experiences of minority ethnic families takes into account their interactions with professionals and what they valued in their autistic child's education. In the discussion that follows, my intention is to critically reflect on how transculturalism can inform debates within the global autism discourse that removes cultural assumptions about autism to explore the similarities as well as the differences in families' experiences. Also discussed is how the pen portraits, interpretive summaries

and the thematic map have contributed to the development of a transcultural model which aims to support culturally responsive professional practices in autism education.

Chapter 6: Discussion

6.1 Introduction

In the discussion which follows I will be considering the wider implications of this research and its contribution towards a different way of thinking about autism in immigrant and British-born minority ethnic families. As stated in the Introduction, the research questions sought to gain more understanding of the transcultural experiences of families, their views on their children's educational provision and how they wanted professionals to interact with them. The findings have shown that by adopting a transcultural approach, there was greater potential for understanding the realities for minority ethnic families living in the UK who have an autistic child by removing the focus on cultural differences. At the analytical stage of the research this also meant that although there were individual differences in how they responded to having an autistic child I was able to explore the similarities in the cultural meanings they assigned to their understanding of autism. To achieve this, attention was paid during their interviews to their narratives of identity, transformation, interaction and belonging. The participants highlighted that there were multiple cultural and contextual factors that impacted on their response to the autism diagnosis and their decisions about their child's education. They also acknowledged that they had positive and negative experiences in their interactions with professionals who they relied on for support and information.   While they wanted professionals, particularly those in mainstream educational settings, to have an increased understanding and knowledge about autism, they also expressed the need for greater awareness of autism within their local communities.

In the following sections I will discuss the contribution that this research could make towards understanding families' transcultural experiences of caring for an autistic child with a focus on four main areas that are deemed relevant to the findings and further research in the field. It begins with an evaluation of the ways in which the families' narratives enabled closer attention to how they configured their transcultural identities and transformed their lives through a series of life changing events. Where previous studies have identified families lack of engagement in accessing service of support and information due to cultural attitudes about having an autistic child, (Begeer et al., 2009; Jegatheesan et al., 2010; Miller-Gairy and Mofya, 2015; Fox et al., 2016), this

research has enabled me to recognise the key components that could contribute to establishing more effective professional interactions with minority ethnic families. Conceptualising a transcultural model using a systemic approach could not only enhance professionals' knowledge and practice at an organisational level but also contribute to developments in inclusive pedagogy in autism education.

The final section of this discussion emphasises how the parents in this research developed an advocacy role, not only for their autistic child and their extended family but also in wanting to engage members of their communities to think differently about autism. In trying to reconfigure their sense of belonging to their local community and faith community, what they had experienced had clearly impacted their personal as well as their family wellbeing.

The findings from this research have challenged assumptions about engaging minority ethnic families in research and this has determined directions for further research. In discussing the findings, it will be important to consider the implications of this research for individual families and how it can be utilised within communities. One recommendation would be that such research is led by parents and family members as a community-based project that engages families and professionals in knowledge sharing through the implementation of community-based participatory research.

6.2 Transcultural families

A key finding in this research that has implications for professional engagement with families was recognising how the intersections of individual experience, cultural and contextual circumstances impacted on caring for an autistic child. Although this concurs with previous research undertaken with minority ethnic families (Kim, 2012; Munroe et al., 2016), using a narrative interview approach enabled close attention to be paid to the construction of their transcultural identities and the internal and external influences on family functioning. In choosing to place their migration experiences and country of birth at the beginning of their storying of life events it showed how they wanted to establish their ethnic identity and represent themselves, culturally and linguistically. For example, all the parents referred to their cultural heritage and extended family living in their 'home country' or in the UK. They also talked about acquiring or speaking multiple languages that in addition to maintaining family

connections, they saw as an asset for their autistic child. Research on bilingualism in children with autism (Kremer-Sadlik, 2005; Hambly and Fombonne, 2012; Park, 2014) has highlighted how the prevailing view of professionals has been to promote English-only approaches to language learning and teaching for autistic children. While the medium of teaching in schools is English, the assumption that bi- or multi- lingual language learning is too complex has led some researchers (Peterson et al., 2012; Yu, 2009) to express concerns about the impact this has on minority ethnic families where dual language speaking is essential for facilitating communication and interaction between family members and in the community. The parents in this research supported the view that speaking more than one language was not only helping their autistic child to develop a larger vocabulary but key to maintaining their family's transcultural identity.

As the parents' narratives about autism attested, their lives were constantly shifting between the cultural aspects of their past and present lives that gave meaning to their experiences of caring for their autistic children. Having multiple frames of cultural reference within a family to explain autism did not appear to distract Sahra, Fatou or Nadifa from seeking a medical understanding about the nature of autism and wanting to find interventions that would make a difference to their children's development. There was greater recognition for Jessia, Soran and Yash that the diversity of within-family responses to a diagnosis of autism was an acceptance of 'difference' rather than 'deficit'. As a contribution to global knowledge about autism in families, the research showed that cultural beliefs about autism are not fixed and nor were explanations of autism solely determined through the diagnostic assessments. A focus on transculturalism has shown how responses to an autism diagnosis are multi-layered and internalised at a personal and cultural level, affecting changes in family functioning, child-rearing practices, religious beliefs, socioeconomic status and acculturation.

The tendency to problematise minority ethnic families' experiences of having a child with autism by emphasising the challenges experienced in interacting with professionals and accessing services was also contested in this research. As McCubbin and McCubbin (2013) found in their research, emotional responses to the diagnosis of a life-long disabling condition in minority ethnic families were no different

to the majority population and that denial, anxiety, frustration and acceptance are fundamental to the process of life-long adaptation which all families experience. This knowledge would be key to professionals wanting to develop more culturally responsive interactions with families by focusing on the family's capacity to solve the issues they are faced with, not just the barriers they face.

Resilience and agency influenced how families engaged in coping repertoires, managed expectations and set priorities as part of the process of accessing health services and deciding on the best educational provision for their autistic child. Crippen and Brew (2007) recognised this as a feature of transculturalism in their research with minority ethnic families who had disabled children. They found that resilience was associated with having broader and stronger social skill sets in terms of cultural adaptation, intercultural effectiveness, interpersonal flexibility and less ethnocentric attitudes. Within the family system Crippen and Brew (2007) also noted a greater tolerance for diversity in problem-solving associated with a family's ability to use its inherent strengths to overcome adversity.

With similar responses revealed in the narratives of the families' who took part in this research, it suggests that a solution-focused approach to understanding family functioning is more relevant than focusing on the barriers they incur. As the families in this research tended towards seeking solutions to the difficulties they were facing in gaining the support they wanted for their autistic child and their family, it implies that greater recognition needs to be given to the capital resources (Bourdieu, 1986) which individual families utilise to overcome the challenges they are experiencing. One solution-focused approach towards increased opportunities for developing intercultural communication is to consider how families and professionals collaborate in community-based participatory research aimed at transforming and creating new knowledge about families' lived experiences of caring for an autistic child.

6.3 A transformative experience

The families involved in this research all acknowledged that being part of a network of support and having access to outreach services at the school was key to learning more about autism, their children's education and their family entitlements to social care. They also recognised that going through the diagnostic and assessment process they

had experienced both positive and negative interactions with professionals that impacted on how they made sense of their child's diagnosis and decisions about their child's education. According to Swain and French (2001) there is general recognition that this pattern of engagement typifies the experiences of families in the UK who have a disabled child. None of the families referred to the negative interactions they had with professionals as being a result of cultural assumptions about their response to having an autistic child and nor did they refer to experiencing discrimination because of their ethnicity, although this may have been an aspect of their lives that they did not want to share with me. Instead they viewed their frustrations with professionals as having more to do with time constraints imposed by the health system, a lack of understanding about autism and teachers' attitudes towards their child's behaviour and learning difficulties in the classroom setting.

Unlike previous research on professional engagement with minority ethnic families (Keen et al, 2010), this research challenged notions of parents delaying diagnosis and not wanting to seek services of support. The parents did not only advocated strongly for their autistic child but of the nine participants, six parents mentioned that they either were, or were wanting to develop an advocacy role with other parents and professionals. In moving from a position of uncertainty about their children's development, they sought solutions to overcome challenges by becoming more positive and optimistic about their own and their family's future. Advocacy facilitated their transformational process, not only in terms of taking action to gain access to professionals but also in altruistically wanting to help other families because of the experiences they had. The parents' capacity to develop a sense of agency and empowerment suggests there is the potential to develop a culturally informed approach to research that challenges cultural assumptions and re-evaluates how families and professionals work together.

6.4 Culturally responsive autism education

All the parents valued the positive interactions they had with education professionals and it was their aim to work collaboratively with them to achieve the best outcomes for their autistic children. Situating this research in a specialised educational setting enabled valuable insights to be gained during the research about the community of those with specialist knowledge of autism that engaged parents and professionals in

regular dialogue through the network meetings attended by the parents. The families felt that there was a sensitivity to families' cultural identities and the cultural influences on caring for their autistic child by the teachers and building trusting relationships and having expectations about the parent's involvement in their children's learning was an expectation.   This meant that there was increased potential for intercultural understanding and less focus on the power difference between the parents and the educators.   Although these findings were unique to these parents whose children attended, or had access to, specialist autism provision within the same borough, it does present an opportunity for a wider debate about how to translate this approach into other settings wanting to develop culturally responsive pedagogical practice in autism education.

With the increase in children diagnosed with autism in minority ethnic families who are being educated in UK schools, there is now an imperative for teachers in special education to acknowledge autism as only one aspect of the child's identity. Broadly speaking, when a child is diagnosed with autism, interventions and approaches to teaching are 'culture and colour-blind' (Gay, 2002: 617) and as such, they ignore the role that culture plays in children's development and interactional styles. Pedagogical practices that overcome stereotypes and recognise that all families have culture-specific and individual ways of functioning are an essential response to the diversity in today's school populations across multiple contexts (Artiles, 2003).

For the parents in this research, accessing the most appropriate education for their child was a priority which led some of them to question why mainstream early years settings struggled to understand their children's behaviour and social communication difficulties and were challenged in offering their children specialist provision within mainstream settings. Wanting teachers to have training and develop their knowledge of autism was seen as essential, to overcome the difficulties they and their children had in accessing education in a mainstream school.

Key to the parents' perspectives is the historical legacy of special education provision in the UK which has remained a national debate since the Warnock Report (DES,1978) and the 1981 Education Act (DES,1981). The categorisation of special educational needs along with the expectations of specialised teacher knowledge of

autism has continued to create tensions in mainstream schools both culturally and politically. Mintz (2014) argues that in wanting to fulfil the opposing requirements of inclusivity in classroom practice, teachers experience more uncertainty about teaching pupils with an autism diagnosis due to the overriding psychological view of autism as a behavioural disorder which has pervaded educational interventions and clinical practices. A further challenge for teachers working in mainstream schools is that they can feel under pressure from outside agencies to follow autism-specific interventions that have the potential to undermine professional judgements and practice and deskill otherwise experienced practitioners who already have the skills to personalise learning for the child (Tomlinson, 2017).

Gay's (2018) core components for culturally responsive teaching in special education provide an opportunity to re-evaluate practice, which the parents also alluded to in their stories about their children's education provision. Gay (2018) refers to the ways in which the physical features, the psycho-emotional tone and the quality of interactions in the classroom, the curriculum and the learning community are fundamental for promoting a positive self-concept and individual achievement. Not only should the classroom environment enable pupils to make meaningful connections between school and other social worlds, the curriculum needs to regard their cultural heritages and multilingual skills as a valid resource for learning and teaching. While these concepts may be similar in approach to the ways autism-specific classrooms are designed to support autistic learners, it is perhaps in the curriculum and teaching approaches that there is a need to develop more cultural awareness in teachers' attitudes towards autistic learners from diverse and multi-lingual backgrounds (Lindsay et al, 2011; Kandeh et al., 2020).

In the next section the discussion will focus on how the parents' narratives have contributed to the development of a transcultural model to support professionals working with minority ethnic families in special education and specialist autism settings. A transcultural model also has potential value in training teachers to develop their skills and knowledge in developing culturally responsive pedagogy in autism education.
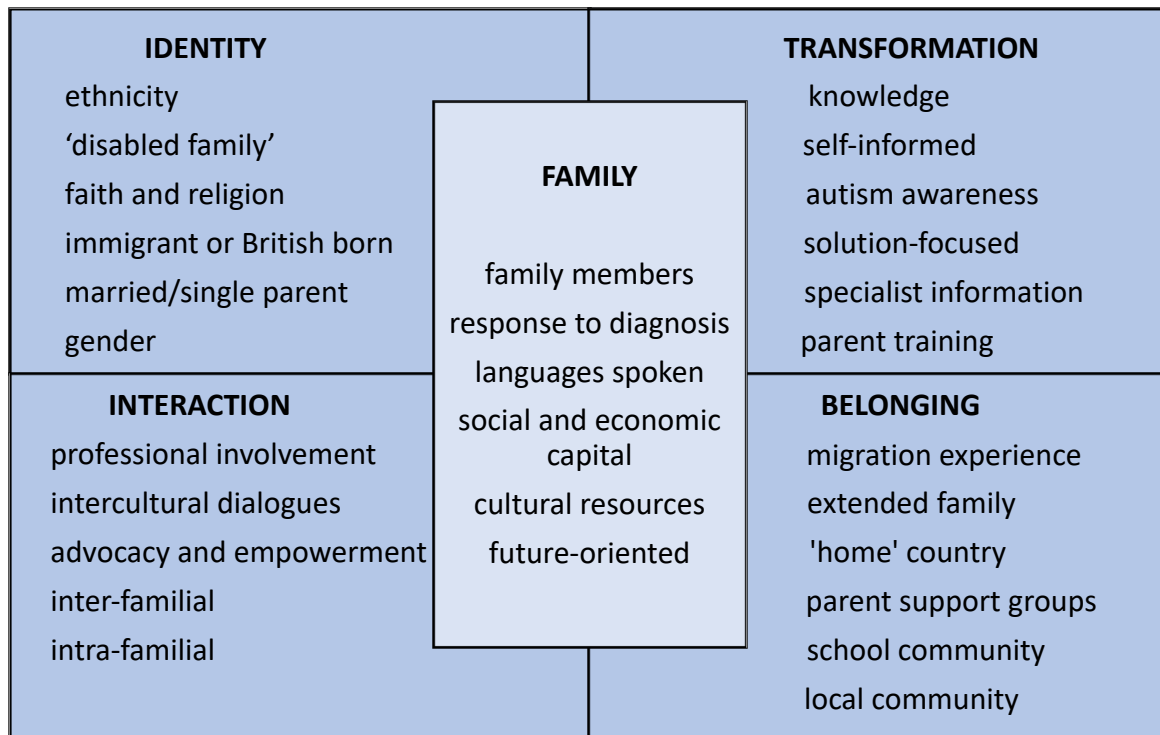
6.6 A transcultural model

Transcultural approaches have been at the forefront in establishing models of culturally responsive professional practice in health and social care, whereas inclusive education policies in the UK have continued to challenge and effectively prepare special educators to address practices that marginalise ethnically diverse learners (Shealey et al., 2011; Mintz, 2019). The rationale for developing this model was to show how a transcultural approach could be relevant for teachers working with families in special education in the UK, in the same way that Falicov's (2012) multidimensional ecosystemic comparative approach (MECA) for working systemically with immigrant families in the US (see Appendix 1) and Papadopoulos' (2014) culturally competent and compassionate healthcare model (see Appendix 6), were developed to assist practitioners in gaining a deeper understanding of families cultural values, identity and relationships. They were also intended to be used as part of training programme for professionals to remove essentialist assumptions about ethnicity and family lifestyles and develop a different understanding of 'culture' and identity in the context of dominant White ethnic institutional practices.

The purpose of the model presented in Fig.6.1 is not for it to be used as a checklist for professionals to identify cross-cultural differences but to provide a conceptual framework for engaging with families to explore the transcultural influences on their lives and to use this knowledge to support the learning potential of the autistic children they teach. Using an inductive approach from the thematic analysis of the families' narratives, I have developed the model to exemplify how the families' transcultural experiences were key factors in their response to having an autistic child. In working systemically with families this becomes an invaluable way in which practitioners gain a deeper understanding of how immigrant and British-born minority ethnic families are drawing on multiple cultural practices and contexts depending on their individual circumstances and the choices they make in their responses to caring for an autistic child.

I will introduce the model by highlighting how the dimensions of *identity*, *transformation interaction* and *belonging* were at the core of the families' transcultural narratives about autism and their lived experiences. By placing the family rather than the disability at the centre of the model it represents how the dimensions of

transculturalism are interconnected and exemplify a dynamic, rather than a static view of the social, cultural and psychological influences on families when they have a child diagnosed with autism. Each of the dimensions include the transcultural experiences that were represented in the families' narratives.

IDENTITY	FAMILY	TRANSFORMATION
ethnicity 'disabled family' faith and religion immigrant or British born married/single parent gender	family members response to diagnosis languages spoken social and economic capital cultural resources future-oriented	knowledge self-informed autism awareness solution-focused specialist information parent training
INTERACTION professional involvement intercultural dialogues advocacy and empowerment inter-familial intra-familial		BELONGING migration experience extended family 'home' country parent support groups school community local community

Fig.6.1   A transcultural model for developing culturally-informed professional practice

A *transcultural identity* represents how parents drew on their simultaneous identities and were using multiple cultural frames of reference to attach meaning to their responses to diagnosis. For the parents, talking about their ethnicity, religious faith and migration experience represented aspects of their lives that intersected with identifying as a 'different' family due to their child's autism diagnosis. For Sahra, Fatou, Hibaq and Nadifa there was also an openness to talking about the cultural dissonances they experienced within their families and others in their community that had impacted on the maintenance of relationships, while also developing a sense of agency in determining their own and their children's future.

The model includes *transcultural transformation* as being key to how families adapt as they learn about autism both as a lived experience and through their own desire to be self-informed about autism. Becoming more knowledgeable about autism enabled them to find solutions and make decisions about their autistic child's education. This

also related to the nature of the interactions that families have as knowledge sharers with other members of their family, their community and professionals.

For the families, *transcultural interaction* involved wanting to establish dialogues with professionals where they sought an empathetic understanding of the impact that having an autistic child had on their psychological wellbeing. They also recognised how relationships between family members and those in the community had been affected by a focus on the needs of their autistic child. Through the diagnostic process they had developed an advocacy role for their children and felt more empowered to seek the information they wanted from professionals and the education they wanted for their child.

Lastly, as a process, *transcultural belonging* reflects how families are simultaneously using their different identities to navigate across different systems of support. The families in this research continued to value the views of family members about parenting their autistic child, which helped them to maintain connections with family in their 'home' country. It is also important to recognise that there is an affective component involved for families in seeking to belong to a school or parent network with others who have an autistic child.

As a contribution to knowledge in autism education, the model creates the potential for a significant shift in professional practice, moving from a deficit-focused view of autism to re-imagining how autism, identity and culture could replace the dominant White Euro-American scientific approach to interventions and treatments. With the family rather than the disability at the centre, there is an opportunity to pay more attention to the cultural, social and contextual influences on the family system, not just an individuals' behaviour, communication and learning styles, that has the potential for a different autism discourse to emerge.

A crucial factor in establishing this model within a professional development programme is an acknowledgement that transculturalism is a process that requires professionals to critically reflect on their own cultural identities and any cultural biases and assumptions which they may hold about children and families. By creating opportunities for genuine and deeper dialogues with families that focus on the family's

capacity to solve the issues they are faced with, there is the potential to develop meaningful collaborative partnerships between minority ethnic families and the educational setting to which they belong.

Lastly, it is through an inclusive ethos created by the learning community of parents, pupils and professionals that a sense of interdependence and belonging can be established. By valuing the knowledge that each can bring about the child, it removes the power imbalances that can exist when differences are emphasised. What is currently missing from the extensive literature and competency frameworks on autism education and interventions, is how to implement culturally responsive approaches to teaching autistic children when so much emphasis has been placed on creating 'autism-friendly' environments aimed at overcoming the deficits in social communication, interaction and learning for autistic children and young adults.

6.7 Autism, faith and community

The final section in this discussion draws on the parents' narratives of how they experienced being Othered within their local community and the impact this had on their sense of belonging and their interactions with members of their community. Recognising their own personal resources that they relied on to cope with negative reactions from some members of their community and the efforts they made to increase their participation in the community, has been highlighted in similar research by Hussein, Pellicano and Crane (2018) recommending the need for further community-based work to raise awareness of autism and its impact on families.

In exploring the intersections of autism and ethnicity through a transcultural lens there was a danger that a focus on cultural and religious beliefs could have risked perpetuating 'difference' and cultural assumptions about having an autistic child. However, the parents chose to talk about their religious faith and their engagement with their faith community in the context of their response to the diagnosis and the emotional impact of daily caring for their autistic child and family. Their Muslim religious beliefs also provided them with an explanation for their role as parents of children with developmental differences and as such they were drawing on their faith as a strength, a personal resource that enabled them to advocate for their child. Al-

Aoufi et al. (2012) highlight the importance of making a distinction between cultural and religious beliefs about disability as too often they are seen as being the same.

> Cultural perspectives mixed with religious values, often lead to several courses of action, which may be falsely attributed to religious faith, such as embarrassment at having a child with a disability, attempting to explain the cause of the disability, and looking for fast solutions (Al-Aoufi et al., 2012:214)

The authors also noted that social embarrassment and concerns about social exclusion which appeared to be crucial for Muslim families, are also experienced by White British families and that it is the cultural context in which they are living that will influence how they respond to having a disabled child in the family. Likewise, concerns about social stigma and protecting themselves from the negative 'gaze' of others was a feature of how the families in this research responded when they felt unable to take part in community activities that were not part of the school community or autism parent network:

> *Sometimes I feel they are not welcome. More understanding, more knowledge will help that.* [Fatou]

The cultural positioning of disability that has perpetuated discriminatory and marginalised responses to disabled people's rights to education, employment and care has remained a global challenge in all societies (Scior, 2016). However, what much of the literature on disability in Global South countries tends to focus on is the cultural dissonance between the knowledgeable and informed Global North countries and the stigmatising and discriminatory practices towards disabled people in the Global South. Attitudes toward disability stigma would appear to have been perpetuated even when families have migrated to a Global North country where they have access to a range of different explanations about autism and disability (Grech and Soldatic, 2016). Rather than assert the differences in interfamilial acceptance and social stigma towards autism as being features of a 'minority ethnic experience', it is important to recognise through a transcultural lens, how social stigma and a lack of understanding about autism continue to be experienced by White British families who have an autistic child. Where I believe that voicing concerns about social stigma, religious and interfamilial differences and cultural attitudes towards autism in minority ethnic families could be of value, is in raising awareness of these same issues and opening up debates about the social stigma and inequalities in exclusionary practices as part of the discourse on autism in the White majority.

Overcoming the adversities associated with the social stigma of having an autistic child was associated with the parents being proactive in wanting to enhance their self-knowledge about autism and to share this knowledge with others. They recognised that having a privileged understanding of autism and developmental differences had impacted on their interactions with professionals and enabled them to become advocates for their child and family's needs. In the process of developing more resilience towards stigmatising attitudes they also became more assertive and persistent in wanting others to develop greater understanding of their autistic child and their personal circumstances. Hewstone (2000) has also discussed how stigmatised individuals will draw on their multiple identities to protect their psychological wellbeing and strategically emphasise and de-emphasise identities depending on the social context.

As an example Fatou and Hibaq, who were single parents and mothers of autistic children talked about their uncertainty in attending the mosque but when they went together they realised that by being present at community events, they had a role in developing opportunities to talk with other mothers about autism. This also supports Corrigan and Watson's (2002) view that being empowered, individuals tend to engage more in efforts to remove stigma at a collective level. Likewise, for the fathers in this research, overcoming the social stigma they experienced by others in the community was countered by the emotional and physical protection they provided for their family. This protective approach was also enhanced by their religious faith and the support they received from their extended family. They had found empathetic understanding through the extended family and despite being separated from them due to migration, recognised how their shared cultural and religious beliefs had contributed to the maintenance of family cohesion.

6.8 Final reflections

A focus on researching the families' narratives gave them an 'entitlement to talk' (Phoenix, 201:79) about aspects of their lives in ways which represented their experiences as parents of an autistic child. In sharing their family's lives, the participants revealed their wish to make known what for some, may have previously been unsaid. The interviews with the participants allowed them to make their own

decisions about what to share and in the retelling of a lived experience, how they want to represent it (Shuman, 2015). Adopting a non-directive approach during the interviews was beneficial for two reasons. Firstly, it enabled me to situate the research within my own knowledge of systemic practice with families and secondly, as a methodological approach, it maintained the rigour required to gain evidence about the particular phenomenon affecting families' lives.

Key to understanding families' transcultural experiences of autism was also illustrated by the mixed methods approach to analysing their narratives. There was a risk that a focus on ethnic groups in research had the potential to maintain separatist, racialised perspectives about autism that have been a feature of much of the Global North research on autism in Global South countries (Meekosha, 2011). By paying attention to their narratives of identity, transformation, interaction and belonging, the influences on families' responses to having an autistic child was not about reifying 'culture' and objectifying cultural attitudes and beliefs about autism, but how they lived transculturally. This concurs with the need to recognise the role of subjectivity in research, as Gough and Madhill (2012) state,

> When done well, theoretically informed interpretations can enrich our understanding of phenomena and are appropriately "owned" by the researcher who takes responsibility for arguing the rationale for, and benefits of, applying a particular theoretical lens (Gough and Madgill, 2012: 8)

Using a transcultural approach has created the potential for acquiring new knowledge about autism that has recognised the transcultural realities for families and offered an alternative way of thinking about how to engage minority ethnic families in research.

Chapter 7: Conclusion

This concluding chapter summarises the key findings from the research and considers the contribution it could make towards teachers' knowledge on autism in minority ethnic families. I will discuss the potential for further research while also recognising that there were limitations within the research that could be drawn on when designing any future research involving minority ethnic families. Finally, I reflect on the research process and evaluate how, as a teacher educator in special education and disability studies, I intend to disseminate the findings and increase knowledge production in this crucial area of autism research.

7.1 Transculturalism

Throughout this research I have been aware of the potential for 'culture' to be used as an analytical tool to essentialise 'difference'. It was for this reason that I wanted to maintain the emphasis on elements of transculturalism that focus on identity, how families' lives are transformed when they have autistic child and the impact this has on their interactions with professionals and their sense of belonging to the school and local community. Using a transcultural paradigm to both situate the research and analyse the findings was fundamental to developing a dialogue about autism that was not reliant on the objectification of culture to determine 'difference' in families' experiences. Instead, interconnecting cultural and contextual meanings were embedded in their personal stories about autism which represented their own reality, rather than one determined by cultural essentialism. This was made possible through this research with families who shared how their transcultural experiences had transformed their personal and social worldview and their interactions with others as a consequence of having a child diagnosed with autism. Crucially, as Welsch (1999:7) states,

> Transculturality also contains the potential to transcend our received and supposedly determining monocultural standpoints, and we should make increasing use of these potentials.

Through their biographical narratives the families revealed the universality of their experiences as well as the unique personal, cultural and contextual capital they drew on to enable them to make sense of their lives. Having a child with an autism diagnosis heightened situations where they felt socially marginalised but also how they developed agentic ways to develop resilience and empowerment to move

towards more positive trajectories for themselves and their families. The questions posed for this research were intended to displace the dominant autism discourse about cultural and ethnic differences by capturing the multi-dimensional nature of the families' experiences. The parents who took part in this research wanted to use their life stories to accentuate their personal journey about autism, agency and advocacy, how they navigated the diagnostic and assessment systems and made decisions about their child's education. In developing their knowledge about autism, treatments and interventions they recognised the role that special education played in meeting the developmental needs of their autistic children and they were keen to maintain collaborative relationships with their children's teachers. As discussed in the previous chapter, for professionals wanting to develop knowledge about the cultural and contextual influences on families, it highlights the importance of working systemically with families. How this is achieved depends largely on how this and similar 'cultural' research is given precedence over the scientific discourse on autism within professional training programmes.

7.2 Limitations of the research

With the dominant discourse on autism studies being predominantly based on the experiences of White British families, it is only in the last two decades that research involving families from different ethnicities has come to the fore. As a consequence, understanding how minority ethnic families make sense of their experiences of having an autistic child have largely remained unheard. The tendency in research with minority ethnic families to focus on the challenges in accessing diagnostic services and special education due to language barriers and cultural attitudes towards disability was a catalyst for wanting to seek an alternative narrative about parenting autistic children that reflected their transcultural lives. While this was made possible with the families who took part in my research, there was a recognition that there were families at the school who may have felt they could not take part because they were not comfortable being interviewed in English by a White British researcher. Gunaratnam (2003) suggests that where sociocultural research has been undertaken by researchers who are ethnically and linguistically matched with the participant group, it might enable different meanings and interpretations to be revealed. However, as a counter to this Phoenix (2001) has found in research using qualitative interviewing with both White and Black interviewers, that any difference in what was shared by the

participants was not analytically discernible. A further aspect for some parents may have been that were not emotionally ready to talk about their autistic child's diagnosis and their concerns about their child's education and future development. This was a factor also highlighted by the outreach officer who ran parent workshops for those parents who had children recently diagnosed with autism. Aligned with the emotional impact of receiving the diagnosis, as Hussein et al. (2018) found in their research, parents may also have concerns about cultural attitudes towards them and their child by others in their community and preferred not to talk about it.

As a systemic family practitioner, I am interested in how significant events, such as caring for an autistic child, impacts on each member of the family. However, only parents were interviewed which would imply that a systemic view of family functioning was not fully achieved. Systemic work with families (Seligman and Darling, 2007) highlights the importance of involving all family members who will each have their own perspective on the focused issues within a family. Only one of the mothers was married and as her husband was working, they could not be interviewed together. Within Nadifa's narrative she included his 'voice' several times, highlighting where there were cultural differences in his and his family's views about autism but also how they collectively made decisions about the treatments and education they wanted for their autistic child. Soran's wife was also not able to participate, but as the importance of 'family' was central to his story, he included their shared experiences of family activities and the diagnostic process they went through together with their autistic son. All the parents made reference to the siblings of their autistic child, again placing them within their family narrative in such a way as to ensure they were represented. To date, there has a been a significant lack of research to gain the views of siblings in minority ethnic families, where their perspectives would make a significant contribution to the cultural discourse on autism in families. In Atkin and Hussain's (2003) research with Asian disabled people they did include interviews with siblings to gain a wider perspective on the social, cultural and religious influences on disability that affected their lives. As second and third generation British, the extent to which they continued to fulfil culturally gendered roles and responsibilities in caring for their autistic sibling within the family, was not explored. The cultural meanings which the siblings gave to having a disabled brother and sister reflected the same dichotomy that the parents in this research experienced in dealing with negative reactions to their disabled sibling

by people in their local community, while also being part of a supportive and close family network.

Social and contextual factors played a key role in how supported families felt by the school, the multi-professional assessment teams, outreach and family networks which were specific to this London borough where the majority of the minority ethnic population were Bangladeshi and Somali. Networks of support and access to information are likely to be very different for minority ethnic families living in provincial areas of the UK where they might incur a different set of minoritising experiences in health services and education. A broadening of the research design to include families living in different areas of the UK and involving professionals, would extend the research focus to determine the links between families' experiences and the nature of culturally responsive professional practices. Running focus groups with professionals from the different services the parents accessed, to gain their perspectives on how they work with minority ethnic families, were considered for a second phase of the research but due to the timeframe and number of parents who wanted to be involved in the research, this proposed element of the research was withdrawn.

7.3 Developments from the research

Prior to undertaking this research, I worked with Black British and Black African families in another London borough where families who participated in parent support groups were very vocal about their concerns for their autistic children, the discrimination they had experienced in schools and with the social services, and the implications this had for their children's future (Seach, 2014; Seach, 2016). There continues to be a paucity of research involving Black British and immigrant Black African families and there is an imperative to address this gap in knowledge about autism in families in the UK. Bankole (2016) suggests that because of the discriminatory practices experienced, there continues to be a need for professionals working with African families to increase their knowledge of the cultural influences on individual families, their parenting styles and attitudes to those in authority in order to establish more meaningful ways of working with them. Such possibilities for intercultural exchange have been identified as fundamental to policy change at an organisational level but are also necessary at a national level. Two recent reports by the All-Party Parliamentary Group on Autism (APPGA) (2017) and The National

Autistic Society (2019) have continued to highlight where gaps in services remain for children and their families. Despite previous NAS research (Corbett and Perepa, 2007; Slade, 2014) these latest reports make no suggestions about how professionals develop culturally responsive ways of working with minority ethnic families. It would appear that by politicising the needs of autistic people and families there is an assumption that all families, regardless of their cultural and ethnic background, will perceive autism and education, health and social care provision in the same way.

7.4 Impact of the research

This research has highlighted that any contribution to the development of a transcultural understanding of autism in minority ethnic families benefits from increased opportunities for dialogue and shared cultural knowledge about autism that is created at a community and organisational level. One contribution that this research could make would be to support the work currently being undertaken by charitable organisations for minority ethnic families who have autistic children who are lobbying for improved services and a recognition by professionals that they do have the skills and knowledge to achieve the outcomes they want for their children. As previously discussed, developing strategies to reduce essentialising practices based on characteristics of 'difference' have begun to be explored through participatory approaches that recognise families' contribution to the development of a sociocultural understanding of autism.

With the findings from this research, there is the potential to raise awareness of autism at a local level and assert the need for professional involvement with minority ethnic families who have remained at the margins of special education policy and practice. Working with minority ethnic families and teachers to pilot the transcultural model could lead to the identification of a set of core components for a professional training programme in working transculturally with families. Conceptualising how transcultural education can be embedded in inclusive pedagogical practice in autism may require a significant systemic shift from deficit-focused autism interventions to a reimagining of autism as being only one aspect of an individual's identity. As a teacher educator in special education and disability studies, working in higher education with trainee and experienced teachers, I aim to draw on this research to both inform and evaluate current practices in autism education, to develop their capacity as agents of change

in developing culturally responsive approaches for working with autistic children and young adults and their families. As a published author, I would also like to present this research in a publication for an international audience.

It would appear that there is now a greater awareness of the need to align the dominant scientific knowledge about autism with how autism has come to be defined across cultures. This study on transculturalism in autism and family narratives has highlighted how both are relevant and need to be acknowledged as having global relevance. In the Global North, cultural perspectives on autism have generally been overlooked whereas thinking transculturally provides a new way of looking at autism, how it is culturally positioned within families and hence how we can come to an increasingly informed global understanding.

> Understanding our cultural history can reveal things of value to us that others might overlook; but transcultural considerations can show us new things to value, which we might find we value more – and have good reason to. (Tartaglia, 2016:12)

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Appendices

Appendix 1

A multidimensional, ecological, comparative framework: continuities and changes in immigrant family processes

Transformations: Continuity and Change	**Migration and Acculturation**	• Type of migration (e.g., undocumented) • Composition of separations (e.g., father alone) • Trauma pre-, during, postmigration • Losses and gains • Uprooting of Meanings • Transnationalism • Psychological or virtual family • Complex acculturation (e.g., alternation) • Spontaneous rituals • Second-generation transnational exposure • Adolescent–parent biculturalism	**Social Justice**
	Ecological Context	• Poverty • Work/school • Neighborhood • Isolation • Ethnic community • Virtual community • Church and religion • Racism/anti-immigrant reception • Contextual dangers (drugs, violence, gangs) • Contextual protections (language, social network)	
	Family Life Cycle	• Cultural ideals • Meanings • Timings • Transitions • Rituals • Sociocentric childrearing practices • Developmental dilemmas (autonomy/family loyalty) • Suicide attempts and parent–adolescent conflicts • Pile-up of transitions • Absences at crucial life-cycle markers	**Cultural Diversity**

	Family Organization	• Separations and reunifications
		• Long-distance connections
		• Kin care: transnational triangles
		• Remittances
		• Relational stresses
		  ○ Gender evolutions
		  ○ Polarizations about migration
		  ○ Boundary ambiguity	

Falicov (2012) Immigrant Family Processes: A multidimensional framework, in F. Walsh (2012) Normal Family Processes (4th edition), pp297 – 323. New York: Guilford Press

Culturally Responsive Special Education

Dear Parents and Guardians,
I am writing to invite your family to take part in a research project that I am undertaking for my doctoral studies at UCL Institute of Education. I am interested in finding out about your experiences of living with a child who has autism and your views about his/her education. The aim of this research is to gain your views, to inform how you would like educational professionals to develop cultural understanding in their practice with families from different cultural and ethnic backgrounds.

What will it involve?
I will contact you to arrange a time for me to come and see you either in your home or your child's school. I will spend about an hour talking about your experiences of your child's education, what is working well and not so well, how teachers have worked with you and your child and the kinds of help and support you would like in the future I will record the interview for typing up and analysis, but you can choose whether or not you want this done. If you would like me to come and talk with you more than once , we can arrange this when we meet.

How can you be involved?
It is up to you whether or not you take part. At the end of this information sheet there is a form for you to sign if you decide that you would like to take part. Some of the issues we discuss might be quite sensitive. Please be assured that what you say will remain confidential and that we can stop and take a break at any time, if you need to. anyone who signs the consent form is still free to withdraw at any time without giving a reason. A decision to withdraw, or a decision not to take part, will not affect your access to the findings of the research.

What will happen with the information you give?
This project aims to give you the opportunity to talk about your experiences of living with a child who has autism and how you would like teachers to work with you. I will not include the names of any participants, schools or community groups in the report. The information I collect will be part of a report that I am required to write as part of my doctoral studies at UCL Institute of Education, which you would be welcome to have a copy of. I would like to use the information you give me to inform the development of a model of good practice for educating children and young people with autism from minority ethnic families.

What will happen next?
If you would like to take part in this study, please fill in the form and return it to me via email ███

██ If you would like to discuss the research with me or if you have questions please do not hesitate to get in touch.

Diana Seach
█████████████

Appendix 3
Consent form

UCL

Institute of Education

Culturally Responsive Special Education

This study has been reviewed and approved by the Institute of Education's Research and Ethics Committee.

I/We have read the information sheet about the research   ☐ **Yes**   ☐ **No**

I/ we understand that taking part is voluntary and that I/we can withdraw at any time without giving a reason and without my child's education or access to services being affected in any way.   ☐ **Yes**   ☐ **No**

I am happy for my/our comments to be recorded during the interview.   ☐ **Yes**   ☐ **No**

I would be happy to be contacted again about future research.   ☐ **Yes**   ☐ **No**

Your name(s): _____ _____ ☐ **Male** ☐ **Female**
              (forename)   (surname)

          _____ _____ ☐ **Male** ☐ **Female**
            (forename)   (surname)

Contact email: _____

Contact   **telephone:**
_____

Contact address: _____

Signature: _____ **date:** _____

Return to: Diana Seach

██
████████████████████████

Thank you

Appendix 4
Professional transcriber confidentiality letter

CONFIDENTIALITY STATEMENT – TRANSCRIBER

Research Title: Transculturalism in parents' experiences of caring for an autistic child

I understand that as a transcriber for a small scale research project conducted by the researcher Diana Seach for her doctoral studies, that I am privy to confidential information. I agree to:

1. Keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format with anyone other than the researcher.

2. Keep all research information in any format secure while in my possession

3. Return all research information in any format to the researcher when I have completed the research task.

4. After consulting with the researcher, erase or destroy all research information in any form or format regarding this research that is not returnable to the researcher (eg. information stored on a computer hard drive).

Name: Signature:
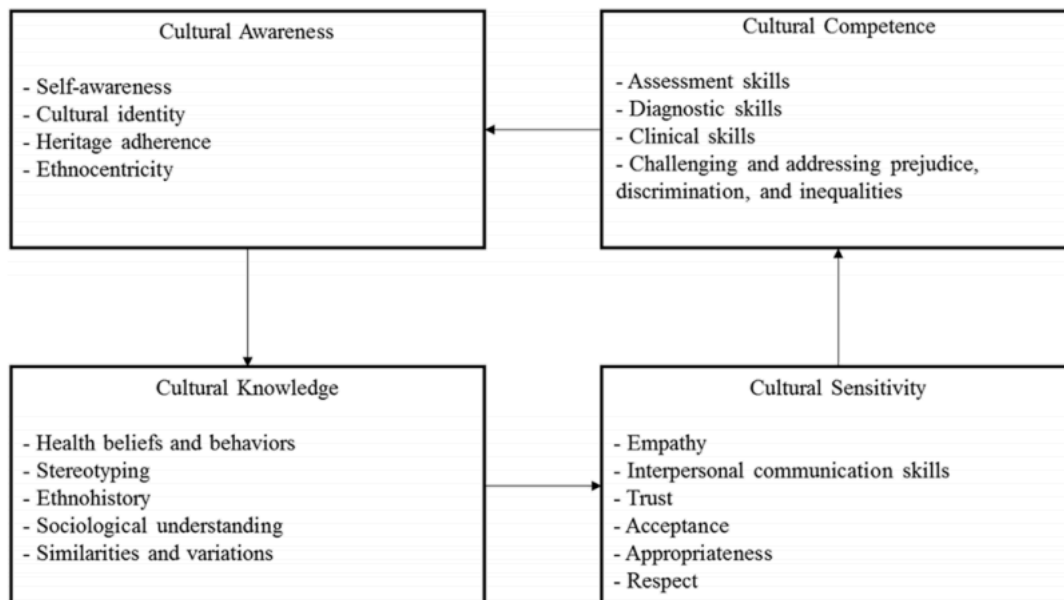

Date: Witness signature:

NB. All research procedures have been ethically approved by the doctoral school at the Institute of Education, University College London.

Diana Seach 2019

The Papadopoulos, Tilki and Taylor model for developing culturally competent healthcare professionals

Cultural Awareness	Cultural Competence
- Self-awareness - Cultural identity - Heritage adherence - Ethnocentricity	- Assessment skills - Diagnostic skills - Clinical skills - Challenging and addressing prejudice, discrimination, and inequalities
Cultural Knowledge	**Cultural Sensitivity**
- Health beliefs and behaviors - Stereotyping - Ethnohistory - Sociological understanding - Similarities and variations	- Empathy - Interpersonal communication skills - Trust - Acceptance - Appropriateness - Respect

Cultural Awareness
The degree of awareness we have about our own cultural background and cultural identity. This helps us to understand the importance of our cultural heritage and that of others, and makes us appreciate the dangers of ethnocentricity.

Cultural Knowledge
Derives from a number of disciplines such as anthropology, sociology, psychology, biology, nursing, medicine, and the arts, and can be gained in a number of ways. Meaningful contact with people from different ethnic groups can enhance knowledge around their health beliefs and behaviours as well as raise understanding around the problems they face.

Cultural Sensitivity
This entails the crucial development of appropriate interpersonal relationships with our clients. An important element in achieving cultural sensitivity is how professionals view people in their care. Unless clients are considered as true partners, culturally sensitive care is not being achieved.

Cultural Competence
The capacity to provide effective healthcare taking into consideration people's cultural beliefs, behaviours and needs. Cultural competence is both a process and an output, and results from the synthesis of knowledge and skills which we acquire during our personal and professional lives and to which we are constantly adding

Papadopoulos, I., Shea, S., Taylor, G., Pezzella, A. and Foley, L. (2016) Developing tools to promote culturally competent compassion, courage, and intercultural communication in healthcare. *Journal of Compassionate Health Care*, *3*(1).