Exploring the Experiences of Bangladeshi Parents Whose Children Have Been Diagnosed with Autism

Rasna Begum

University of East London

A thesis submitted in partial fulfillment of requirements of the School of Psychology, University of East London for the degree of Doctorate in Educational and Child Psychology

April 2022

Abstract

This research sought to explore the subjective experiences of Bangladeshi parents of a child with a diagnosis of autism. The study was underpinned by a social constructivist research perspective, an exploratory design and a narrative methodology. Unstructured interviews were used with five Bangladeshi participants who were asked to share their experiences and perceptions. Participants' interviews were 'restoryed' using Clandinin & Connelly's (2000) Three-Dimensional Framework. This offered a rich and in-depth insight into parental experiences. In the second phase of analysis, narrative themes and sub-themes that featured across parental stories were discussed.

The findings indicate that participants are not only navigating and making sense of their child's diagnosis themselves but also facilitating the understanding of extended family members. Participants employed multiple and varied explanatory models that suited their context. Not having a word in Bengali for autism was a barrier to sharing the diagnosis with Bengali speaking family members; in addition, the variation in the presentation of autism also created mistrust in the label. The lack of intergenerational understanding was identified by participants as a key barrier, however, all participants expressed a desire for raising awareness in the Bengali community and saw this as a way to address perceived difficulties. Having a child with a diagnosis of autism required all participants to advocate for their child in the domestic sphere, sometimes challenging culturally expected roles in the wider family and school context.

The research illustrates the complexity of experiences associated with being a Bangladeshi parent of a child with autism. The thesis concludes by discussing the implications for Educational Psychology practice.

Key words: Bangladeshi parents, children with autism, narrative

Declaration

University of East London

School of Psychology

I declare that while registered as a research degree student at UEL, I have not been a registered or enrolled student for any other award of this university or of any other academic or professional institution.

I declare that no material contained in the thesis formed part of a submission for an award for an academic award.

I declare that my research required ethical approval from the University Ethics Committee (UREC) and confirmation of approval is embedded within the thesis.

Signed: R Begum

Student Number: 1524390

Date: 22nd April 2022

Acknowledgement

My utmost gratitude and appreciation go to the parents that gave up their precious time to share their parenting journey with me. Without you, this research would have remained a vague, unrealised idea.

Dr Mary Robinson, for your listening ear, support, guidance and encouragement. Your confidence in me eventually became my own. Thank you.

The days spent completing this thesis would have passed more slowly without the support of my fellow trainees; you know who you are, as do I.

The friends who have waited patiently on the sidelines, cheering on their never present friend. I hope you will allow me to slot back in with a brew and cake.

As I near the end of this journey, I want to express my love and appreciation to my parents, Abdul Masabbir and Guljahan Begum. You have overcome so many obstacles and taught me to do the same. I hope I have made you proud.

To my siblings Shabna, Shamle, Abdul Hafez, Zinath, Ayesha and Abdul Salam, whose unwavering support and belief in me has always propelled me to strive for better.

Finally, Alhamdulillah for my two children, Suraiya and Sufyan. Without your steadfast love, patience and encouragement I would never have pushed myself and stepped outside the box.

Table of Contents

List of Figures

List of Tables

List of Abbreviations

APA	American Psychiatric Association
ASC	Autistic Spectrum Condition
ASD	Autism Spectrum Disorder
BPS	British Psychological Society
CASP	Critical Appraisal Skills Programme
CYP	Children and Young People
DECP	Division of Education and Psychology
DfE	Department for Education
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, 4th edition
DSM V	Diagnostic and Statistical Manual of Mental Disorders, 5th edition
EP(s)	Educational Psychologist(s)
EPS(s)	Educational Psychologist(s)
HCPC	Health and Care Professions Council
LA(s)	Local Authorities(s)
SEND	Special Educational Needs and Disability
SENDIASS	The Special Educational Needs and Disabilities Information Advice and Support Services
TEP	Trainee Educational Psychologist
UK	United Kingdom

Chapter One: Introduction

1.1 Aim of the Research

The purpose of this research is to gain an in-depth understanding of Bangladeshi experiences of parenting a child with a diagnosis of autism. The number of children and young people (CYP) being diagnosed with autism has increased in recent years (Department of Education, 2012). For some time, authors (Dyches et al., 2004; Welterlin & LaRue, 2007) have drawn attention to the need for further research on the cultural issues relating to the understanding and awareness of autism. Therefore, the rationale for this study was to explore the experiences of Bangladeshi parents (a minoritised group that are underrepresented in autism research). This study aims to look closely at individual parents' subjective meaning-making constructed through their experiences and perceptions.

1.2 Overview of the Chapter

This chapter will outline the current study aims; it will present a brief definition of autism and an overview of the contemporary discourses around the label. Later in the chapter, consideration will be given to the paucity of autism research with minority ethnic groups, in particular Bangladeshi parents. The background and motivation of the researcher will be shared as well as the implications for professional practice. It ends with the theoretical underpinnings of the research and the distinctive contribution of the research is outlined with a summary of the chapter.

1.3 Autism

“Autism is a life-long development disability” (National Autistic Society, 2013) that is considered to “impact an individual’s ability to communicate and interact with others” (Perepa, 2019, p. 11). The term ‘autism’ originates from the Greek word ‘autos’, which means ‘self’ and conceptualises the individual as “being locked in” (Neilson & Heffernan, 2013, p.8, as cited in Habib et al., 2018, p.2). The DSM-IV (American Psychiatry Association, 2000) classification system describes the typical behavioural manifestations in autism as a triad of impairment: social interaction, communication and restricted imagination, which often manifests as inflexible thinking, repetitive behaviours and interests. DSM-5 (2013) saw the addition of sensory perception differences that some individuals may experience. The developments in conceptualisation of autism can also be found in the terminology used to describe an overarching set of behaviours for example, high functioning autism, severe autism, Asperger’s syndrome. The APA

(2013) sought to include these various descriptors in one umbrella term, ‘autistic spectrum disorder’ (ASD).

1.3.1 Current Discourse around Autism

Perepa (2019) describes an increasing scepticism around the usefulness or accuracy of having a label for such a wide-ranging set of behaviours. In recent times there has been a shift in how people understand and talk about autism (Autism Education Trust, terminology guide, 2021). Section 1.6.1 outlines the researcher's position in relation to the contemporary debate around 'spectrum' or 'condition'. In recognition of this debate and for the purposes of this study, this researcher will adopt the position as set out by the AET (2021) and refer to autism as a set of ‘differences’ rather than a 'disorder'.

1.3.2 Lack of Autism Research with Minority Ethnic Groups

Autism has the potential to be viewed differently depending on cultural context and this necessitates the need for a better understanding of how autism is constructed in communities from diverse backgrounds. There is a dearth of research looking at culturally and linguistically diverse families with children who have a diagnosis of autism (Perepa, 2014). Our current understanding of autism is based on research with white participants (Hoekstra et al., 2018). There are gaps in the knowledge of how the culture and beliefs of culturally diverse children diagnosed with autism impact their health and educational needs (Davenport et al., 2018). This suggests a gap in the literature, where people with multiple and marginalised identities are underrepresented.

1.4 The Bangladeshi Community in England and Wales

Office of National Statistics (ONS) data indicates that there are around 451,000 Bangladeshi people living in England and Wales (ONS, 2011); over an eight-year period, these figures were estimated to increase to 617,000 (ONS, 2019). Whether we utilise the census data of 2011 or the 2019 ONS estimates, nearly half of the Bangladeshi population living in the UK, reside in London, making it 3.8% of the total population of London. Based on ONS (estimate data, 2019), nearly one-third of the Bangladeshi population is between 0-19 years of age. The figures in England show that pupils from India, Pakistan, and Bangladesh are a growing population who will need access to education and training.

Child poverty is a growing issue in the UK. Children's wellbeing, educational outcomes, employment and earning opportunities will be impacted by growing up in poverty (HM Government, 2014, as cited in Child poverty and education outcomes by ethnicity, ONS 2020). In relation to other ethnic groups, children growing up in Bangladeshi and Pakistani households are the most likely to live in low income and material deprivation

(ONS, 2020). Figures between the year 2018-2019 show that Bangladeshi pupils eligible for free school meals (FSM) is 12% higher than the national average.

However, the picture is varied; despite national trends to the contrary, educational outcomes for Bangladeshi pupils who were eligible for FSMs achieve higher Progress 8 (the rating for English secondary schools which indicates how well a child has progressed whilst attending the school) scores than the national average, despite higher poverty indicators than other ethnic groups (ONS, 2020). This data suggests no clear, consistent relationship between child poverty and progress from Key Stage 2 to Key Stage 4 in the Bangladeshi community. Other variables in relation to educational resilience will need to be considered.

1.5 The Bangladeshi Community and Autism in England and Wales

The Better Communication Research Programme (BCRP) was commissioned by the Department for Education Report (DfE, 2012) in light of the Bercow Review. Ethnic disproportionality in the identification of Special Educational Needs (SEN) was one of the four thematic reviews produced. The data produced is based on the national School Census collected every two years between 2005-2011 about each pupil attending a state school in England. ASD as a primary need increased over the period 2005-2011, from 0.48% to 0.87%. A similar trend has been observed in the US. Fombonne (2009) explains the increase in the following ways: “broadening of the definition of ASD, the expansion of diagnostic criteria, and improved awareness of the condition” (Fombonne, 2009, p. 591).

The figures in England show that pupils from India, Pakistan, Bangladesh and Other Asian pupils are underrepresented compared with White British Pupils with ASD. Corbett and Perapa (2007) considered some potential causes for the disproportionality in the identification of ASD. These included linguistic and cultural barriers, which may explain the lower levels of awareness and access to relevant support services in these communities or that services on offer did not meet the needs of these groups. Strand and Lindsay’s (DfE, 2012) study commissioned five years later highlights a need to raise awareness of ASD in the Asian communities and review relevant services to ensure they meet the need of minority ethnic groups. Perhaps, most importantly, for this current study, the report highlights a 166% increase in Bangladeshi pupils being identified with ASD between 2005-2011 (DfE, 2012). These figures indicate that Bangladeshi pupils were previously underrepresented in the identification of ASD, however the picture is changing and warrants further exploration.

1.6 Background and Motivation of the Researcher

This section will explore the researcher’s personal reflections and the discussion will be written in first person. This will also happen in sections of Chapter Three and Five for similar reasons.

My professional background includes teaching in mainstream schools for over 15 years, particularly in Early Years (EYs) and KS1. I was able to see first-hand how parents' initial sense-making changed and grew as their children developed. As a class teacher, I relied on parents' knowledge of their child's autism; these relationships were integral to my daily practice. For some parents, the diagnosis provided an 'explanation' for unwanted or unexplained behaviours; for others, it did not correspond with their conceptualisation of autism; it was to some degree 'rejected.'

As a trainee educational psychologist (TEP), I have worked with several Bangladeshi families as they navigate the diagnosis process. When engaging in consultation with parents and family members who have a child diagnosed with autism, I was always curious to learn more about their experiences. Working directly with CYP and their families led me to consider the challenges faced by parents who received a diagnosis of autism.

The term 'minoritised ethnic' is used throughout this study. It recognises that individuals have been minoritised through social processes of power and domination, rather than existing in distinct statistical minorities" (Law Society, 2022).

In addition, I am mindful that in seeking to look more closely at the experiences of a minoritised, under-researched group, I did not wish to perpetuate discriminatory ideas and become complicit in oppression. I talk further in Chapter 5 (section 5.13.4) about the learning journey I have undergone as part of this research. Research exists and is part of a socio-historical context. Scheurich and Young (1997) argue that the dominant white perspective has either pathologised or exoticised the minority ethnic experience. These very limiting perspectives are not ones that this research seeks to enact or perpetuate.

Lastly, and perhaps most importantly, my interest in researching parents from the Bangladeshi community stems from the fact that I am a parent from a Bangladeshi background. I was born in Bangladesh and am a child of immigrant parents whose origins are in Sylhet, a district in Bangladesh where the majority of Bangladeshis now living in the UK originate from. I was brought up embracing the Muslim faith and have experience of this community's beliefs, culture, and traditions. Furthermore, I speak fluent Sylheti (this is a dialect spoken by the majority of the Bengali community in the UK) with my parents and my extended family.

My wish to learn more about Bangladeshi families and their experiences of autism led me to pursue this study. I inhabit a very distinct position both as an insider and a researcher; however, I do not have a child with a diagnosis of autism and therefore do not navigate the circumstances related to the experiences and perceptions of being a Bangladeshi parent of a child with autism. These parental insights are central to this study. It is hoped that in sharing these, professionals supporting families will have greater awareness and understanding to enable them to enhance their culturally responsive practice.

1.6.1 Contemporary Debates about Autism

Contemporary debates about the use of the word ‘disorder’ are often divisive in the field of autism research (Perepa, 2019), with groups disagreeing over its use and implications. The argument follows that if we consider autism to be a ‘difference’, this does not necessitate the idea of it as a disability. However, others assert that whilst some people on the spectrum may not experience it as such, for some people on the spectrum, it is experienced as disabling. It is acknowledged that it is beyond the scope of this study to look at this debate in greater detail, but I think it is important that I reflect on my position in relation to the diagnosis of autism. My views are influenced by Timimi’s (2010) work, which questions the concept of autism and adopts an approach that views autism as a social construction rather than a useful and reliably discrete diagnosis. I am interested in and conscious of the role that discrimination, oppression and being part of a minority ethnic group can play in the construction of autism by professionals, parents and the CYP themselves. Even in the relatively short time I have been a TEP, I have encountered CYP and families who have found diagnosis useful and meaningful for them. So, although I may employ a critical lens to some extent, I am mindful that CYP and their families are the best sense makers of their own lives.

Throughout this research, I use ‘person first terminology, although I am aware that this is not a view adhered to by all who are interested in the subject area. However, as a researcher, it represents an important distinction around the power and positioning of language (Fox, 2015), and it highlights an acknowledgement of the power imbalances that are an inherent aspect of diagnosis. Throughout this study, I have used the term ‘autism’ to cover the multitude of meanings ascribed to this construct.

1.7 Theoretical Underpinnings of the Research

The researcher was interested in exploring the experiences of Bangladeshi parents with a child who has a diagnosis of autism. Most psychological studies centre around research in Western, industrialized, rich and democratic (WEIRD, Henrich et al., 2010) contexts and impose these understandings in varied ‘universal’ settings. There is little acknowledgement of the diverse experiences of British minoritised groups within research studies (Rizvi, 2021). Crenshaw (1989) offers an intersectional framework for exploring the lived experience of minoritised groups. It follows that Bangladeshi parents will inevitably employ hybrid intersectional identities that do not represent a singular disadvantage, e.g. ethnicity, culture, disability, gender, class, or levels of education can interplay to uniquely impact how they experience parenting a child with a diagnosis of autism.

This study will employ several theoretical understandings of experiences and how they are understood and reported. Parents in this study will come from families that have settled in the UK through naturalisation or immigration. Thus, the parents in this study will be moving between cultures which will have necessitated some degree of adaptation or acculturation (Berry,1997). It is envisaged that Bangladeshi parents in the study will be at varying stages of the acculturation process, and this will impact their understanding, perceptions and experiences shared in the study.

Parental experiences shared in the study will be based on subjective meaning-making about their child’s autism. Attributions made by a parent about their child’s autism have the potential to impact how the individual makes sense of a situation (Barrowclough & White, 1998) and how that sense-making is later shared with the researcher.

1.8 Distinct Contribution of the Research

This research offers an opportunity to gather an in-depth exploration of Bangladeshi parental experiences of raising a child with autism with a culturally sensitive researcher from the community being researched. The number of CYP being diagnosed with autism is increasing (DfE, 2012), and this study will add the experiences of a minority group to the existing literature about autism and parenting. Crucially, this research recognises that there is no single way Bangladeshi parents experience autism. Rather it acknowledges the complex and interactional experience of being a Bangladeshi parent of a child with autism. This researcher has gathered stories on an issue that is deeply impactful on the lives of the participants in this study, with the hope that EPs will utilise the stories shared to inform and enhance their skills, knowledge and understanding to improve outcomes for our increasingly diverse client population.

1.9 Conclusion of Chapter One

This chapter introduced the current study aims and the rationale in the context of our understanding and awareness of autism from a minoritised ethnic group perspective. It highlighted the paucity of autism research with parents from the Bangladeshi community. It also outlined some of the key discourses around language use and the label of autism, detailed the researcher's motivation and the unique contribution this current study hopes to make.

Chapter Two: Literature Review

2.1 Introduction

This chapter will start by discussing the initial stages of the literature search. It will then describe a systematic literature review undertaken to identify relevant literature relating to the subject matter of Bangladeshi parents of children diagnosed with autism. It details the steps undertaken and the researcher’s rationale for each step of the review process. A critical review of the studies is undertaken, exploring the key features of each study, methodology, strengths, and limitations. The chapter concludes by summarising the key findings from the literature review, identifying a gap in the literature, and highlighting implications for the current study.

2.2 Systematic Literature Review

The aim of this review is to describe, evaluate and analyse the papers identified through the systematic literature review. Furthermore, the types of data collection and analysis applied in the literature were given careful consideration, as this had the potential to impact the research design of the current study. Therefore, the researcher sought to critically evaluate the current literature and discuss the questions below:

1. What is presently known about the lived experience of Bangladeshi parents who have a child with a diagnosis of autism?
2. What is the quality and relevance of the studies identified?

2.2.1 Initial literature Search

An initial literature search was conducted in February 2021 to ascertain the availability of literature and gain an initial understanding of research in this area. This was also an opportunity for the researcher to become familiar with potential search terms and the most helpful way to use inclusion and exclusion criteria.

Table 1

Initial scoping review of the literature

Database Feb 2021	Search term	Number of identified papers	Filter	Number of articles identified for potential review
EBSCO (Academic Research Complete, Education research complete, ERIC, APA PsychINFO	"Bangladeshi" AND "parents" AND "autism"	0	2010-2021 English Language Academic journal	0

As this resulted in zero papers, this highlighted a potential gap in the research. The researcher decided to widen the search terms and extend the research timeline to studies conducted in the last 30 years. Please see Table 2 for the results.

Table 2

Second scoping review of the literature

Database Feb 2021	Search term	Number of identified articles	Filter	Number of articles identified for potential review
EBSCO (Academic Research Complete, Education research complete, ERIC, APA PsychINFO	"Bangladeshi" AND "parents" AND "caregivers" AND "fathers" AND "mothers" AND "autism"	1	1991-2021 English Language Academic journal	1

This revealed one paper Warner (1999), which looked at Bangladeshi parents' views on the special school attended by their child with severe learning difficulties (SLD). The paucity of research papers on Bangladeshi parents meant that inclusion was reviewed and expanded to include studies that potentially included Bangladeshi parents amongst the wider South Asian population. Thus, the final literature review questions became the following:

1. What is presently known about the lived experience of South Asian parents who have a child with a diagnosis of autism?
2. What is the quality and relevance of the studies identified?

2.2.2 Inclusion and Exclusion Criteria

A systematic review of the literature was carried out in February 2021 and reviewed in July 2021. The initial scoping review supported the creation of the most relevant parameters and inclusion and exclusion criteria.

Table 3

Overview of Inclusion and Exclusion Criteria

Timespan	1999-2021
Search Language Parameters	English Language Academic journal
Exclusion Criteria	Research that did not include accounts of direct lived experience from parents Parents of South Asian origin, living in their country of origin
Inclusion Criteria	Research that included direct lived experience from parents of South Asian origin, living outside their country of origin

Table 3 outlines the exclusion and inclusion criteria used for the systematic literature review. Although the researcher wanted to ensure that the research identified reflected current thinking on the subject matter, the researcher valued the need to look beyond the most recent literature in order to include potential papers that looked at the Bangladeshi community more directly. Warner (1999) had been identified through the initial scoping review, and as such, it was deemed pertinent to widen the timespan and include this relevant paper. When this paper was examined more closely, the additional insights it offered appeared worthwhile and the paper was retained as one of the papers identified through the literature review.

Papers that were published through academic journals and written in English were included to ensure accessibility and relevance to the subject area. The researcher is mindful that the papers identified lean heavily towards research that has a Western cultural focus, in relation to parental experiences and ideas about autism. The researcher reflected on this in the evaluation of the papers selected.

The implications of including studies conducted from outside of the UK were considered on several levels. The Bangladeshi diaspora is made up of several generations of immigrants. It therefore follows that the process of acculturation of this immigrant community will be multiple and varied. It is possible that this will influence or impact the research papers identified. In addition, the context of the research, with considerable differences in institutions (for example, education, health care and living conditions) will vary across cultural contexts. This may be reflected in the studies identified and their understanding of what it is to be diagnosed with autism. However, on balance this study aims to explore the lived experience of parents, and this remains central to this study.

2.2.3 Methodology of the Systematic Literature Review

Table 4 below outlines the search terms used and the number of papers identified as a result of the search.

Table 4

Search Terms and Number of Results

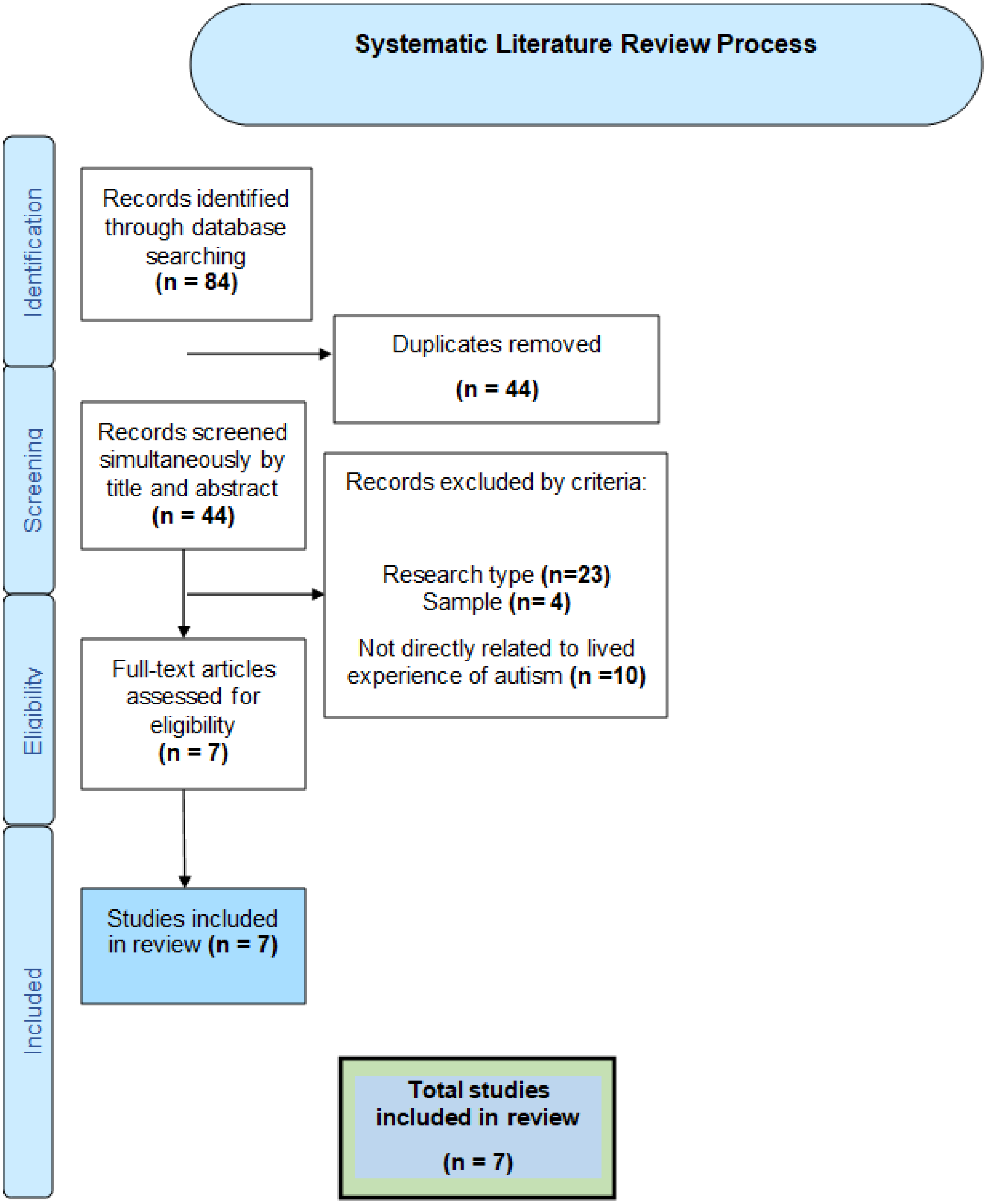
Search Terms 1	“autism” AND “ASD” AND “autism spectrum disorder” AND “aspergers” AND “aspergers syndrome” AND “autistic” AND “autistic disorder” AND “parent” AND “parents” AND “mother” AND” father” AND “caregiver” AND “Bangladeshi”		
Search Engine	No. of papers initially found after applying parameters	No of abstracts read after applying inclusion criteria	Total no. of articles selected to be read in full
EBSCO	1	1	1
SCOPUS	1	1	0
Total	1	1	1
Search Terms 2	“autism” AND “ASD” AND “autism spectrum disorder” AND “aspergers” AND “aspergers syndrome” AND “autistic” AND “autistic disorder” AND “parent” AND “parents” AND “mother” AND” father” AND “caregiver” AND “Bangladeshi” AND “South Asian” AND “Indian” AND “Pakistanii”		
Search Engine	No. of papers initially found after applying parameters	No of abstracts read after applying inclusion criteria	Total no. of articles selected to be read in full
EBSCO	48	45	7
SCOPUS	36	36	0
Total	84	44 (after removing duplicates)	7

After removing duplicates within each database, 44 papers were reviewed for their relevance to the literature review question (see section 2.2.1) by reading their titles and abstracts. The process left a total of 7 papers. Dr Perepa, an author who appeared influential during the initial scoping review, was approached through social media, and offered a video consultation. Dr Perepa confirmed and validated the references located thus far. Consultation with this expert generated an additional unpublished thesis relevant to the research area. This discussion led the researcher to search their university repository and locate a further unpublished thesis, which looked at the phenomenological experiences of Bangladeshi parents of a child with autism.

Given the limited research in this area, relying solely on peer-reviewed literature could potentially omit relevant studies. In addition, there can often be a considerable lag in the time between research being completed and published. Including these two pieces of grey literature (research that is not published in a commercial publication) means that the present review of the literature is kept both current and relevant. This also reduces publication bias and creates a more balanced picture of the available research (Paez, 2017). The inclusion of the two unpublished doctoral research papers, one identified by Dr Perepa and the other by the researcher, bought the total of identified research papers for review to 9. Figure 1 below outlines the literature review process undertaken through a PRISMA flow diagram.

Figure 1

PRISMA *Flow diagram*



A full list of the papers selected from the literature reviewed can be found in Appendix 1.

2.2.4 Weight of Evidence

This literature review aimed to answer the following questions:

1. What is presently known about the lived experience of South Asian parents who have a child with a diagnosis of autism?
2. What is the quality and relevance of the studies identified?

Gough's (2007) Weight of Evidence (WoE) framework was used to examine the relevance and quality of the papers and consider the extent to which they answer the questions posed in this systematic literature review (see Appendix 1 for the outcomes).

2.3 Critical Appraisal

The critical appraisal process is undertaken to evaluate research to ascertain its validity, methodological rigour and relevance (Hannes, 2011). Although there is no consensus on how to assess qualitative research, qualitative checklists have been identified as a suitable tool to guide the critical appraisal process (Booth et al., 2016). The CASP UK (2018) checklist for qualitative research was utilised to evaluate the papers identified; it comprises ten questions that prompt the researcher to consider the validity and reliability of research findings, research results and research value.

The overall characteristics of each study are outlined in Appendix 2, along with considerations prompted using the CASP (2018) framework.

2.3.1 Overview and Critical Appraisal of Identified Papers

Habib et al. (2017) uses a constructivist interpretative paradigm to study the parental experiences of seven Pakistani mothers who have a child with a diagnosis of ASD living in Ireland. The author describes her motivation for engaging in the research; she shares a similar cultural background with her participants and is raising a child with autism. Beyond this, the author makes little reference to her own role in the research process. This presents a potential threat to validity through researcher bias on aspects such as the formation of questions, data collection process and analysis (Guba & Lincoln, 1985). The application of the CASP (2018) framework revealed that member checking was not employed and is a limitation of the study. The author employed purposive sampling through social media but drew attention to the socio-economic status of her participants. For example, two of the participants paid privately for a diagnosis to speed up the process. This raises the possibility that the backgrounds of participants were not representative of Pakistani families living in Ireland. These factors raise questions about sample bias and transferability (Guba & Lincoln, 1985).

This study had several strengths. For example, the data collection was undertaken by a researcher who shared the ethnic, cultural, and religious background of the participants. This meant that the researcher had the potential to facilitate the sharing of cultural information between the researcher and researched and provide a degree of cultural validity to the data collected (Tilman, 2002). The use of semi-structured interviews have the advantage of exploring sensitive issues in depth to elicit individual subjective experiences. After completing a pilot study, the researcher adapted the interview question order, although no details about the questions themselves were shared. Habib et al. (2017) uses Braun and Clarke (2008) to thematically analyse each transcript transcribed by the researcher, thereby supporting the credibility of the study.

Theara and Abbott (2015) explored the experiences of nine South Asian parents living in the UK who have a child with autism. The study utilised a grounded theory (GT) approach guided by a social constructivist lens. In keeping with this approach, the researcher followed lines of inquiry that resulted from responses gained from a pilot interview. There is evidence of reflexivity and rich descriptions, which enhances the confirmability and dependability of the findings (Guba & Lincoln, 1985). The researcher acknowledges that the parents all had a son with autism, and the majority of the participants were mothers, although fathers were present during both sets of interviews. The use of purposive sampling limits the transferability of the findings to other contexts or settings (Guba & Lincoln, 1985); additionally, gender could have impacted the data collected.

The study has several strengths; it sought to recruit through a wide range of professionals who worked with parents, such as specialist teachers, special educational needs co-ordinator's (SENCo's) and educational psychologists (EPs). Participants' anonymity was maintained as they were encouraged to contact the researcher directly, and the gatekeepers were not aware of who decided to take part. The researcher is a South Asian female, but the potential effects of her presence are not acknowledged explicitly in the paper, raising concerns about the potential for researcher bias (CASP framework, 2018). The data analysis procedure is outlined in detail, and the researcher acknowledges the subjective nature of interpretation, which is an integral feature of GT. The study makes a unique contribution to the knowledge and understanding of a minority community underrepresented in the literature (CASP framework, 2018).

Jagethesan et al. (2010a), Jagetheesan et al. (2010b), and Jegatheesan (2011) produced three research papers based on the same data collected as part of a 17-month longitudinal ethnographic study looking at the experiences of three South Asian Muslim families navigating the assessment and cross-cultural conceptualisation of their child's ASD diagnosis. Both mothers and fathers from three immigrant families were interviewed; findings indicated experiences were viewed through a cultural and religious lens. A GT approach was used to analyse the data gathered. Many strengths were identified through the CASP framework (2018), including naturalistic observations, and meeting both credibility and dependability parameters (Guba & Lincoln, 1985). In addition, the interviews were open-ended, allowing the parents to share experiences that were pertinent to them rather than following the researcher's lead. The ethnographic nature of the research meant that the research procedures were customised to each family, with the intention of maintaining cultural validity. The varied interviewing techniques and the extended engagement with each family add further validity through credibility (Guba & Lincoln,1985).

Ethical considerations around anonymity are included, although ethical approval is not made explicit. Findings indicate that participants occupy a unique position navigating in and between various meaning systems. Challenges faced by families are explored, and implications for professional practice are discussed. Parents shared that it was important for their child with autism to be fully included in their wider social life (Jagetheesan et al., 2010a). Multiple language acquisition played an integral part in this (Jagetheesan, 2011). Although raising a child with autism was viewed through a particular cultural and religious lens, variations were reported across the three families (Jagetheesan et al., 2010b).

The lead researcher is a South Asian woman and drew on her insider knowledge to build rapport with the families and facilitate data collection. The researcher describes undertaking informal member checking and speaking to wider family and educational services involved with the families. This triangulation and 'rich descriptions' supported the confirmability of the data collected, which provides further confidence to the results (Guba & Lincoln, 1985). The researcher included details about how the interviews were conducted, data collected, transcribed, and checked by native speakers of the languages spoken by participants. Inductive analysis using Glaser and Strauss (1967) was utilised. Three authors cross-checked categories of phenomenon identified, confirming and disconfirming initial inferences that led to final interpretations. The features described enhance dependability and validity through description (Maxwell, 1992).

Some limitations were identified using the CASP framework (2018). The three papers with different purposes were created from the same data set. This could lead to some concerns around the selective nature of data used in each paper. However, the author was transparent about the existence of their prior work, and each paper brings with it a new perspective on the data. The very small sample size with its inherent bias means there are limitations for generalisability. However, on balance, these three studies meet all four of Guba and Lincoln's (1985) criteria of trustworthiness, and the research makes a unique contribution.

Perepa (2014) conducted an exploratory piece of research with 63 parents from four different ethnic communities. Views gathered focused on the value parents placed on the social skills of their child with a diagnosis of autism. Findings indicated that the degree of importance given to particular aspects of social skills varied according to ethnicity and to the gender of the parent. Perepa (2014) acknowledged that purposive sampling was used to recruit parents from four groups: White British, Somali, South Asian and Afro-Caribbean, but these were not presented as representative samples. Differences of opinion amongst parents in each group were attributed to cultural background, gender and individual differences.

Semi-structured interviews were conducted with parents living in an inner-city in the UK. Parents were contacted through local ASD support groups, which suggests sample bias. Participants would have received support through the organisation and would have been in a different situation to those who had not benefited from accessing similar services. Homogeneity in participant groups is challenging to achieve, each participant's child will not have comparable needs, and the caring responsibilities of each parent will inevitably be situation-specific. No mention was made of how data was transcribed or if member checking was employed. In addition, Perepa (2014) acknowledges the need to simplify the language used as the study did not utilise translators; this raises a potential threat to validity through interpretation (Maxwell, 1992).

The study involves a relatively large sample. This is considered a strength; it offers insight into how a diverse group perceives social skills used to diagnose autism, which is helpful for practitioners seeking to support families through intervention.

Doig (2012) is a qualitative study that aimed to explore the subjective experiences of nine Bangladeshi parents (two fathers and seven mothers) who attended an inner-city London Child Development and Special Needs assessment clinic. The study looked to understand the experiences of Bangladeshi parents as they went through the assessment, diagnostic and intervention process of receiving an ASD diagnosis for their child. The study utilised an Interpretative Phenomenological Analysis (IPA) approach; findings indicated that parents employed a range of coping strategies and viewed their experiences of the assessment process through a cultural lens.

The strength of the research lies in its contribution to an under-researched population, limitations of the scope of the study are considered, and ways that future research could build on the research are discussed.

Nair (2015) employs a qualitative interpretative case study approach to access the lived experiences of Black and Minority Ethnic (BME) parents who have a child with autism and their experiences of education and support. In addition, interviews were conducted with stakeholders to better understand the phenomena. Eleven BME parents (six of whom were from a South Asian Background) from a range of socio-economic backgrounds were interviewed. Reliability, validity and ethical considerations are discussed (Guba & Lincoln, 1985). The researcher was reflexive in their approach and drew attention to her role as a minority ethnic (ME) researcher. Considerations about how participants might receive her and how she potentially would become part of the research process were also considered. These displays attempt to address researcher bias and would meet confirmability standards (Guba & Lincoln, 1985).

Although sample size indicates that data saturation was not achieved, the outcomes can be considered alongside studies that look at BME parental experiences and are therefore transferable and make a significant contribution to this under-researched area (CASP UK, 2018; Guba & Lincoln, 1985).

Warner (1999) was not reviewed in full as it related to SLD rather than autism. However, the findings were retained as the paper included two participants who were Bangladeshi and had children with autism.

2.4 Key Themes from the Literature Review

The researcher utilised a thematic synthesis approach to review the qualitative studies as outlined by Booth et al. (2016). A thematic synthesis approach requires the researcher to systematically code the data and assimilate identified codes into descriptive and analytical themes to create a thematic synthesis.

The steps outlined below were employed to identify patterns and themes emerging from the studies identified. In addition to noting patterns, inconsistencies and exceptions were also considered within the findings from the nine studies. These were then utilised to answer the identified literature review questions.

- Each paper was read several times to ensure the researcher was familiar with the key findings
- Themes identified by the author were tabulated for each paper individually
- These themes were coded to create overarching themes (see Appendix 3 for thematic breakdown)
- Overarching themes were used to develop a thematic matrix (see Appendix 4).

The thematic synthesis identified six superordinate themes across the studies; these are listed in the order of thematic pervasiveness.

- Parental Experiences / Parental Needs
- Variations in the way Autism is Understood / Explained
- Impact of Autism on Family Life
- The Impact of Acculturation
- Privileging the Medical Model and Implications
- Multilingualism, Perceptions and Experiences

2.4.1 Constructions of Autism

Faith and belief framed how the parents in Jegatheesan et al. (2010a, 20110b) and Jegatheesan (2011) framed their experiences and were integral to each Muslim immigrant families' understanding of their child's diagnosis. Their child with autism is considered a gift from God. Parents have been 'chosen' to raise their child because they have the necessary attributes; they are resilient, moral and view themselves as protectors of Allah’s (God’s) child. Parenting a child with autism was viewed as a ‘test’, and their efforts are expected to be rewarded. This was consistent with Doig (2012), which also looked at specifically Muslim families. Authors in both studies argue that the religious perspective offered parents a coping system, enabling them to accept their child’s diagnosis as Allah’s (God’s) will and any resulting challenges were for the greater good. Parents described engaging in prayers, hoping that there would be a positive change in their child. All of the studies with Muslim parents indicated a general trust that God (Allah) would help over professionals. This theme is echoed in Warner (1999) and Habib et al. (2018), which is a strong indicator that religious beliefs are a strong protective factor for parents raising a child with autism.

Theara and Abbott (2015) was the only study to explicitly consider the South Asian communities' conceptualisation of disability and impairment. The author found that prevailing ideas in South Asian countries have influenced how the community in the UK explains and understands disability. The dominant view expressed by parents in this study is one of fear, prejudice and stigma; disability is something to be concealed and kept hidden. This meant that acceptance and understanding of disability in the family and the wider community were limited (Theara & Abbott, 2015). Jegatheesan et al. (2010a, 2010b) and Jegatheesan (2011) sought to include their child in the wider social world. This illustrates a discrepancy that warrants further exploration.

2.4.2 Privileging the Medical Model and Implications

Understanding autism as a medical diagnosis given by a medical professional was favoured by South Asian parents (Doig, 2012; Habib et al., 2017; Theara & Abbott, 2015) here in the UK. This meant parents perceived there to be an underlying physiological cause and therefore sought information that further reinforced the medical model. The authors argue that this potentially explains the lack of parental engagement with professionals from a non-medical background.

Privileging the medical model in this way has several implications for parents. Both Doig (2012) and Nair (2015) found that mothers, rather than fathers, felt blamed by the community for bad parenting. Mothers were seen as integral to the domestic sphere, and it was their parenting or deficient parenting that contributed to their child's needs. The cultural values and beliefs associated with the medical model offer parents a non – stigmatising, physiological explanation, which increases the likelihood of acceptance for the parent and their child in the wider community (Theara & Abbott, 2015). In contrast, parents in Warner's (1999) study did not express any ideas or experiences of maternal guilt. Arguably this indicates that the picture is a varied one and could be explained in a variety of ways, for example, the use of translators in that study.

2.4.3 Not Fully Understanding their Child's Diagnosis

Parents' responses in several studies highlighted that they did not fully comprehend their child's diagnosis and its wider implications. Parents' home languages did not have the equivalent word 'autism'. Attempts made by parents to explain the condition to the wider family often resulted in the use of words that held connotations of mental retardation, cognitive delay or being less than a person (Doig, 2012). Studies discussed here highlight the implications of the negative use of language, which can hinder the conceptualisation of needs. Variability in how autism presents also contributed to some distrust of the diagnosis by parents; it is not unusual to have inconsistencies in presentation for CYP on the spectrum, which has led to some parents discrediting the term (Theara & Abbott, 2015).

One possible implication of parents not understanding their child's diagnosis is a reluctance to share the diagnosis with family (Theara & Abbott, 2015) not wishing to unduly worry grandparents and wider family and feeling responsible for worry that might result. Jegatheesan et al. (2010a) described how older family members were confused by the diagnosis as the child did not have a physical disability. A gender difference appeared in several studies; fathers sought to protect wider family members and engaged in conversations that saw the positive aspects of diagnosis (Doig, 2012; Jegatheesan et al., 2010a). Mothers displayed a sense of who to share the diagnosis with and how to describe best their child's diagnosis (Doig, 2012). Overall, parents employed explanations that protected themselves and their child from prejudice and scrutiny.

2.4.4 The Impact of Acculturation

Parents appeared to use a framework of acculturation to make sense of their child's diagnosis (Doig, 2012). In this study, parents described the difficulties in maintaining a Bengali culture whilst living in the west; defining themselves as British Muslims felt more comfortable and progressive. This worldview was seen as more accepting of their child with autism. This represents a shift away from the 'backward mentality' the parents in the study associated with Bengali culture. Parents described a process of amalgamation and undertaking cultural negotiations to make sense of their child's diagnosis. This highlights that parents' experiences and views are evolving and individual.

Parents did not expect social support from non-medical professionals (Habib et al., 2017; Jegatheesan, 2011; Jegatheesan et al., 2010b, 2010a; Nair, 2015; Theara & Abbott, 2015). Having roots in developing countries both elevated the role of the family (Theara & Abbott, 2015) and created a tendency to look inwards - 'we can manage'. Although participants in each of the studies were at different stages of acculturation, each participant displayed a strong sense of determination. Autism was viewed as a threat to their family thriving economically but something that, with determined efforts, could be reduced or overcome (Doig, 2012; Theara & Abbott, 2015)

2.4.5 Impact of Autism on Family Life

Parental responsibility was a recurring theme and manifested differently across the studies. In Theara and Abbot's (2015) study, there is a strong focus on the immigrant experience and how this informs parents' approach to effecting change through effort. This suggests that they have employed a coping mechanism that looks forward to when the situation will improve. Reports from parents indicate that they felt a duty to work hard so their child could 'overcome' autism, 'succeed' and 'get better.' This complements the medical model employed by parents wanting to support their child to manage the condition in the short term to avoid long term labelling and social stigma (Theara & Abbott, 2015).

Parents in Jegatheesan et al. (2010a, 2010b) and Jegatheesan (2011) expected their child to play a social role in their community; their interpretation of faith placed a duty on parents to ensure their child participated in wider community life. This contrasts with the disability model discussed in Theara and Abbott (2015), where impairment is something to be concealed and kept indoors.

In Doig (2012), parents expressed a wider worry about what would happen to their child when they were no longer alive. Parents felt a responsibility and duty to ensure that their child was married, fulfilling perceived community and religious goals of functioning 'normally', whilst also ensuring that their child was cared for by others. This highlights that the family would play a role in their child's long-term care rather than professional services.

2.4.6 Parental Experiences / Parental Needs

Parents in Warner's (1999) study saw attending mainstream provision as a means to ensure academic progress; more able role models were viewed as integral to developmental progress. In Jegatheesan et al.'s (2010b) study, parents spoke about the negative deficit-based discourse professionals utilised when discussing their child's needs. Parents gave this as a reason for refusing to engage meaningfully with non-medical professionals; they wanted professionals to be more holistic and less reductive about their child.

A notable contrast in the literature is that parents in Warner's (1999) study felt school was about education and learning self-help skills. Parents separated their culture and religion as something they were responsible for and would encourage at home, 'I pray with her at home, she's happy… they can't do that at school, they're English people' (Warner, 1999, p.4). Parents in Nair's (2015) study, which is notably 16 years later, described the education system as 'colour blind', disappointed that the same services were offered to all, and no consideration was shown to parents' cultural and ethnic origins (Nair, 2015).

In Nair's (2015) study, parents benefited from their local authorities and charities' respite care and parenting training. One parent in this study reported that the non-BME community understood autism better; eight out of eleven parents said they received no help from their families and communities. This contrasts with parental views described in the studies pertaining to specifically South Asian parents. Here, the lack of parental engagement with non-medical professionals was perceived to result from the elevated role of the family and an inward-looking approach characterised by 'we can manage' (Doig, 2012; Jegatheesan, 2011; Jegatheesan et al., 2010b, 2010a; Nair, 2015; Warner, 1999). This suggests that parents' support needs vary and are attributable to several factors, including the meaning-making parents have employed to understand their child's difficulties (Perepa, 2014).

Feelings of isolation were a recurring theme for parents in each of the studies. Doig (2012) and Habib et al. (2018) describe these feelings as prevalent in the diagnosis phase of their child's development. Some potential reasons for feelings of isolation are offered by Theara and Abbott (2015): parents preferring to 'mask' their difficulties, not feeling comfortable engaging with professionals, reluctance to share a diagnosis with wider family, a desire to protect the child and not wanting to concern family members. Mothers in Theara and Abbot's (2015) study expressed more feelings of isolation than fathers and a sense that their partners had emotionally distanced themselves after diagnosis. Nair's (2015) study found that parents who felt isolated withdrew from social and religious events with family, which further perpetuated the sense of isolation. A potential source of support discussed by parents was speaking with someone who had had similar experiences and seeing children with similar needs to their own (Doig, 2012).

Finally, parents described a preference for clinicians of a similar background to their own (Jegatheesan et al., 2010a). They were experienced as less formal and took time to listen to parents. Professionals who shared the family's background were perceived to understand the implications of the child's diagnosis on the family and, perhaps most importantly, parents felt heard by them.

2.4.7 Multilingualism, Perceptions, and Experiences

Being in a multilingual family and raising a child with a communication disorder brings additional challenges (Jegatheesan, 2011). Autism is considered a social communication disorder and has implications for parents who speak more than one language in the home environment. Parents in Jagatheeesan's (2011) study displayed a deep commitment to multilingualism. English was considered necessary for involvement in wider American life, such as education, employment, accessing services and communicating needs. In addition, Arabic was seen as essential for fulfilling religious responsibilities, whilst the family's home language was required for communicating with the extended family and wider community. Each of these languages represents spheres that parents expected their child to operate in.

Parents reported being advised by speech therapists to speak one language with their child. This was perceived to make language acquisition easier and more manageable for the young person. Parents did not share this perspective, nor did they feel understood by the professionals involved. Instead, parents continued to promote three languages at home, which was considered integral to maintaining normal family life. This illustrates a discrepancy between how professionals and parents view language acquisition. Parents highly value language development in the home and at school (Doig, 2012; Jegatheesan et al., 2010a; 2010b; Jegatheesan, 2011).

2.5 Summary of the Review

This review aimed to answer the following questions:

1. What is presently known about the lived experience of South Asian parents who have a child with a diagnosis of autism?
2. What is the quality and relevance of the studies identified?

The CASP UK (2018) and the WoE (Gough, 2017) were used to explore the quality and relevance of the nine papers identified to meet the criteria of the lived experience of South Asian parents who have a child with autism. The literature review highlighted that although some researchers are looking at autism specifically within minority ethnic groups such as the South Asian diaspora, there was only one unpublished paper that the researcher could locate relating to the lived experience of Bangladeshi parents and autism. The papers that did feature Bangladeshi parents explored the experiences of a wider minority ethnic group. As such, the views of these parents were considered relevant to the literature review by the researcher for the following two reasons. First, the wider South Asian diaspora group of parents will have insights relevant to Bangladeshi parents' experiences of autism. Second, the lived experience of parents from the South Asian diaspora will impact the experiences, knowledge, and understanding of Bangladeshi parents.

The themes identified suggest that parents from the South Asian diaspora applied religious and cultural models of meaning-making; however, prioritising the medical model appears to be used to counter the shame and stigma associated with disability. Nevertheless, the papers present a varied picture. Some parents sought to develop the home language and religious identities of their child with autism to keep and continue cultural and community ties.

2.5.1 Limitations of the Review

The validity and relevance of the nine papers were critically analysed in terms of their trustworthiness and relevance using both the CASP and WoE. Apart from Perepa (2014), a small sample size was a feature of all the papers. Therefore, the findings may not be representative of parental experiences more widely. Additionally, it was not always clear from the papers the gender of parents in the study; however, the voice of mothers featured more prominently in the studies reported. The implications of this disparity have not been considered in depth in this review but is something to bear in mind when considering findings from identified papers.

2.6 Gap in the Literature and current study Aims

This literature review suggests that there is currently a paucity of research on the lived experiences of Bangladeshi parents of a child with a diagnosis of autism. While some research has been conducted on South Asian parents in the diaspora, the research base on Bangladeshi parents is limited and outdated regarding the UK's contemporary context. This indicates a gap in the research for an in-depth exploration of the experiences of Bangladeshi parents of a child with a diagnosis of autism.

The researcher is a TEP of Bangladeshi heritage; the use of an insider perspective offers a contrast to the previous studies with Bangladeshi parents in the UK. The current study seeks to listen to the stories told by Bangladeshi parents who have lived experience of parenting a child with autism to answer the following research question:

> 'What are the experiences of being a Bangladeshi parent of a child with autism?'

Chapter Three: Methodology

3.1 Introduction

This chapter will explore the aims of the present study in greater detail. The philosophical assumptions of the researcher that underpin the research will first be introduced. A justification for employing a relativist perspective and social constructivist approach will be outlined. The chapter will then provide a rationale and description of the research method used for data collection. The pilot study will be discussed, including how it informed the final research study. Steps undertaken during data analysis will be outlined to answer the research question. Lastly, the researcher's understanding of reflexivity and ethical considerations of the study will be discussed.

3.2 The Theoretical Position of the Researcher

Denzin and Lincoln (2011) describe several assumptions made by qualitative researchers within an interpretive framework. These include ontology, epistemology, axiology, and methodology. Frameworks can be seen as paradigms, a basic set of beliefs a researcher holds when they set out to explore and understand a social phenomenon better (Guba & Lincoln, 1994). Theories or theoretical orientations that guide a qualitative researcher can also be considered a paradigm (Cresswell & Poth, 2018). For example, theories about social justice aim to create change or challenge social injustice, as do those related to advocacy or participatory theories.

> "We want a social science committed upfront to issues of social justice, equity, nonviolence, peace, and universal human rights." (Denzin & Lincoln, 2011. p. 11)

The researcher began this research journey by examining their own philosophical position and interest in the area of autism. According to Cresswell and Poth (2018), several viewpoints can be adopted, and the paradigm chosen will inevitably lead to the adoption of ontological and epistemological positions to their research. These will also inform decisions made about the research process. Cresswell and Poth (2018) argue that these philosophical assumptions underpin and guide the research process in several ways, including papers selected for the literature review, data collected, and the theories used to explore the data. The study will inevitably be shaped by the ontological and epistemological positions adopted by the researcher from the very outset.

3.2.1 Ontology and Epistemology

Ontology is frequently described as the study of 'being' or the nature of reality. In adopting an ontological position, one is asked to consider 'What is truth?'. Realism assumes that there is one knowable world (Braun & Clarke, 2013). In contrast, relativism, described as an interpretive paradigm, assumes that there are multiple constructed realities. Our understanding of reality is constructed through our social interactions and related experiences (Guba & Lincoln, 1994), making it essentially context dependent. The relativist approach informs most qualitative research. These opposing viewpoints represent the extreme ends of an ontological continuum (Tebes, 2005).

The researcher's ontological position will influence their epistemological assumptions. Ontology considers the nature of reality, whilst epistemology asks us to consider what knowledge consists of and how these assertions about knowledge can be justified (Cresswell & Poth, 2018).

If the researcher assumes a positivist ontological stance, the viewpoint maintains that there is one reality, and as such, it is the researcher's role to uncover that truth and, therefore, that knowledge (Robson, 2002). Post Positivist researchers acknowledge that knowledge created is subjective and socially created; the truth is partial and is never fully knowable (Braun & Clarke, 2013). Critical realism maintains an interest in understanding a 'truth,' something constructionism rejects. Social constructionism contrasts with the positivist viewpoint as it contends that there is no 'one' truth; rather, there are 'multiple truths' or knowledges. These knowledges are multiple and varied as they are produced or constructed in a particular social, cultural, historical, and political context (Burr, 2003; Gergen, 1985, 1999).

Social constructivism, like social constructionism, is also interested in meaning-making and the role of the researcher in knowledge production (Braun & Clarke, 2020). The focus shifts in social constructivism to how the individual makes sense of their subjective experience (Cresswell & Poth, 2018) as opposed to the wider collective, relational meaning-making through language associated with social constructionism (Braun & Clarke, 2020). Social constructivist research aims to make sense (get closer) to the participant's perception of their world. There is an acknowledgement that these perceptions (constructions) will be based on the participants' interactions in their world and the associated context in which they operate (Cresswell & Poth, 2018).

3.2.2 Rationale for the Researchers Position

The researcher's ontological view aligns with the relativist paradigm and supports a social constructivist epistemology. From this stance, there are multiple realities based on perceptions that individuals construct from their interactions with others (Cresswell & Poth, 2018). In this study, there was an understanding that the experiences of Bangladeshi parents raising a child with a diagnosis of autism were anticipated to be a complex multidimensional phenomenon; this awareness guided the research design process.

This research aimed to explore the individual experiences of Bangladeshi parents. Adopting a social constructionist view would necessitate a focus on the social processes and interactions that an individual is engaging in (Burr, 2015). The suggestion follows that through discourse, certain cultural norms feature to the extent that individuals, over time, come to acquire a shared or group understanding of a concept or experience (Braun & Clarke, 2013). This study sought to explore the individual experiences and stories of being Bangladeshi and parenting a child with autism. Adopting a social constructivist approach would ensure that the focus would remain on individual experiences and their subjective meanings. The researcher sought insights into how Bengali parents constructed and made sense of their experiences of parenting a child with autism. This aligned with the social constructivist view that knowledge is created by individuals through their interactions within a society (Andrews, 2012).

The social constructivist approach gives equal validity to each possible understanding and perception by asking those who have experienced the phenomenon. Therefore, it follows that the researcher's role is to understand the subjective and varied meanings participants attribute to their experiences (Cresswell & Poth, 2018).

3.3 Research Method

3.3.1 The Research Question

As set out in Chapter 2, the researcher identified a gap in the literature exploring the experiences of Bangladeshi parents who have a child with an autism diagnosis. The research sought to explore the experiences of participants who were underrepresented in autism literature. In keeping with the social constructivist approach of this research, the research question was kept open and as broad as possible; as a result, there was one overarching research question:

'What are the experiences of being a Bangladeshi parent of a child with autism?'

3.3.2 Research Aims

Creswell (2007) outlines four possible categories of research purpose: explanatory, evaluative, emancipatory, and exploratory. This research seeks to understand the experiences of an under-researched group and produce knowledge that is of benefit to a disadvantaged group (Robson & McCarten, 2017); its purpose therefore is exploratory and emancipatory.

This exploratory approach seeks to access the experiences of Bangladeshi parents with a child who has a diagnosis of autism. A secondary aim is to provide insights into a minoritised ethnic group underrepresented in literature. The researcher is conscious that the research question is both broad and open and could potentially lead to a variety of parental responses. These may not be directly related to them being Bangladeshi. The open nature of the research question aims to ensure that parents feel able to relate their subjective experiences, an element of the current study that could potentially be empowering for parents.

3.3.3 Research Design

As the research question here is exploratory and seeks to understand a particular phenomenon, not in search of casual determinations, predictions or generalisations of findings, a qualitative design was considered the most appropriate for this research (Braun & Clarke, 2013).

3.4 Approach Options

Three methodologies were considered for this research: IPA, GT and case study. A brief overview of the methodologies will be shared, and each will be considered in turn for their suitability for the current research.

3.4.1 Phenomenological Research

A phenomenological approach seeks to understand the essence of a lived experience (Cresswell & Poth, 2018). IPA seeks to explore individual subjective experiences and the meaning they make of the phenomenon (Peitkiewicz & Smith, 2014). The researcher's role is to give meaning to how people make sense of their experiences. Generally, themes are created by looking across a small homogeneous sample (Braun & Clarke, 2013). The approach focuses on individual experiences and, as such, would have enabled the analysis of the stories told by Bangladeshi parents. However, the approach requires a homogeneous group of participants. Differences between participants have the potential to impact data (Braun & Clarke, 2013). As outlined in Chapter One, parents may make sense of their experience using any number of intersections in their identity and experience. The potential for variations within the participant group meant that the IPA criteria for a broadly homogeneous sample would not be possible. Since the researcher's interest lay in individual experiences, it was appropriate to consider an alternative method.

3.4.2 Grounded Theory

GT looks to construct new theoretical perspectives from individual experiences comparatively analysed (Glaser & Strauss, 2017). The main aim of this approach is theory development, using a systematic inductive methodology to look for patterns across participants' experiences of a particular phenomenon. For this type of study, the objective would have been to generate theories about the experiences and processes that shape Bangladeshi parents who took part in this research (Cresswell, 2006). This did not align with the present research aims, which were to explore insights into individual perceptions and subjective meaning-making.

3.4.3 Case Study

A case study approach seeks to look at a particular participants’ experiences in detail, over time, using multiple sources of data such as interviews and observations (Robson & McCartan, 2017). This approach would have provided a detailed understanding of

Bangladeshi parents’ experiences in a real-world context. However, this approach would have necessitated exploration over time with access to a participant and their world in a way that was not possible during the Covid-19 pandemic.

3.5 Narrative Inquiry as the Chosen Method

All three of the above methodologies share elements that would make them appropriate for the exploration of being Bangladeshi and parenting a child with autism. Each offers the potential for rich, in-depth exploration of experience. The methodologies outlined all seek to use context and the language used by participants to make sense of a specific experience. What appeared to be missing in the approaches outlined was the opportunity to explore the participants’ accounts in detail and in their entirety (with consideration of the context in which they are told) whilst continuing to respect the unique and individual aspects of participants’ stories.

The social constructivist approach accepts that knowledge is a construct of the human mind and, therefore, the reality is perceived as subjective. This means that the methodological tools used to understand these constructions of reality will need to be sensitive to the pluralistic aspects of meaning-making employed by participants.

Narrative inquiry (NI) was considered an appropriate tool to understand how parents made meaning of their subjectively experienced realities. The section below will provide an overview of narrative methodology and the types of NI approaches and analysis selected for this research.

3.5.1 Narrative Inquiry

Narrative inquiry is a “profoundly relational form of inquiry” (Clandinin, 2007, pxv). At its core, NI is concerned with the stories we tell ourselves and each other (Murray, 2015), their purpose, organisation and content. It assumes that through sharing stories with 'others', we make sense of our own experiences, and the narratives we absorb from our interactions in the world will inevitably shape our experience of the world. Didion (1968) describes how narrative connects "what happened" to “what it means” (Didion, 1968, p.216) to the individual.

3.5.2 Defining Narrative

Defining a narrative can be problematic as there is no consensus as to what it constitutes. Its conceptualisation is often related to the field in which it is being applied (Reissman, 2008). Narrative can be both the method and the product of research (Pinnegar & Daynes, 2006).

As a method, narrative is the verbal or written expression of lived individual experiences with a chronological connection (Czarniawska, 2004). This could take a variety of forms, such as interviews, observations, or diary entries (Reissman, 2008). Narrative would then be the product, the shared narrative (Kramp, 2004). The current study is drawn to narrative as a universal practice of storytelling where subjective meaning is communicated (Reissman, 2008). This conceptualisation of narrative as deeply embedded in storytelling closely aligns with Bruner's (1991) narrative theory, which considers narratives to be a way for individuals to organise and make meaning of their lived experiences.

The terms ‘story' and ‘narrative’ are often used interchangeably and consistently across disciplines (Kramp, 2004; Reissman, 2008), but the consistent thread that appears in qualitative research is that a 'narrative' is the joining together of both events and actions through the medium of a plot (Polkinghorne, 1995). Events in themselves are not stories; arguably, it is the connecting of events over time that makes them a story (Braun & Clarke, 2013; Kamp, 2004). Squire et al. (2011) seeks to separate narratives that focus on 'events' and those that consider 'experience'. The author explains the distinction in this way:

> Event centred work assumes that these internal and individual representations are more or less constant. Experience-centred research stresses that such representations vary drastically over time and across the circumstances within one lives, so that a single phenomenon may produce very different stories, even from the same person. (Squire et al., 2008.p.5).

The temporal element of narratives is similarly echoed in Clandinin and Connelly (2000), where the meaning attributed to experience is subject to change over time and context. This builds on Dewey’s (1963) ideas around experience being an interaction between the individual and their environment, liable to change over time. Dewey (1963) posits that to understand the meaning of experience, consideration must be given to the interplay and influence of both time and context. This research is influenced by the centrality of the argument that experience is context and time dependent.

In addition, narratives are an individual's construction of reality through interactions and relationships (Kramp, 2004). This highlights the interactional and social nature of narratives (Reissman, 2008), where individual experience happens within a broader social and cultural context (Caine et al., 2013).

For the purpose of this research, the following terms will be used interchangeably and throughout the remainder of this thesis; 'narrative', 'narratives', 'story' or 'stories’.

3.5.3 Approaches to Narrative Inquiry

As explored earlier, narrative can be understood as both the product and the process (Cresswell, 2007; Kramp, 2004). The conceptualisation of narrative as the shared act of storytelling (Kramp, 2004) aligns with Bruner’s (1991) conceptualisation that narratives provide a way to make sense of our lived experiences. It is acknowledged that the connection between the conceived product and process means that the narrative approach and narrative analysis are closely intertwined, and separating them would not be beneficial (Kramp, 2004).

Bruner (1986) sets out two ways to conceptualise thinking and knowing, paradigmatic and narrative types of thinking. In the decade following, he further developed and clarified his ideas and thinking around the distinctiveness of each. Another significant author in this area, Polkinghorne (1988, 1989, 1995), further expanded these ideas and employed two of his own approaches to NI, distinguishing between “analysis of narratives” and “narrative analysis”. Central to both approaches are stories as the basic unit of analysis (Kramp, 2004). The table below outlines Polkinghorne’s (1988, 1989, 1995) approaches to NI.

Table 7

Polkinghorne’s (1988, 1989, 1995) approaches to Narrative Inquiry

"Analysis of narrative"	“Narrative analysis”
Requires the researcher to identify themes, the types of stories shared, and the characters or settings represented in the story. In this regard, the analysis of narratives shares similarities with thematic analysis (Polkinghorne, 1995; Reissman, 2008).	Engages with the data collected with an interactive 'to-ing and fro-ing between the story and its emerging themes (Kramp, 2004). The emerging themes are integrated to construct a coherent 'whole' (Polkingthorne, 1995). The resulting 'story' should not only bring order and coherence to the story (chronology) but continue to 'fit' the data initially collected (Polkingthorne, 1995). Kramp (2004) refers to this as ‘’restorying’’.

Kramp (2004) suggests that the use of analysis of narratives and narrative analysis are complementary and can be utilised together, creating a “rich analysis of the stories (shared) by participants during interviews” (Kramp, 2004, p.120).

The interaction and continuity as envisaged by Kramp (2004) is echoed in Clandinin and Connelly’s (2000) three-dimensional space approach to narrative inquiry. The ideas presented can offer a framework applicable to any narrative inquiry, where the researcher seeks a structure to develop an understanding of a lived experience. It is argued that this framework, which considers the "temporality (of experience) along one dimension, the personal and social along a second dimension, and place along the third" (Clandinin & Connelly, 2000, p.50), offers the researcher an opportunity to capture the "openness of experience" (Clandinin & Connelly, 2000, p.89). Narratives are analysed individually and subsequently “restoried" using chronological ordering (Ollerenshaw & Cresswell, 2002).

This approach considers the changing nature of narratives, where meaning is constructed through social interactions and consideration of context. The approach outlined by Clandinin and Connelly (2000) offers a NI approach that aligns closely with the research presented here.

3.5.4 Researcher's Role in Narrative Inquiry

Underpinning NI, there is an acknowledgement that experience is shaped by both the context and individuals involved (Caine et al., 2013). It therefore follows that the process of NI will recognise that the significance of the researcher and participant interaction is of some importance. In addition, there is an acceptance that the narratives shared with the researcher will depend on the context the story is shared, by whom, and to whom the story is being shared (Kramp, 2004). As a result, narratives and the meanings attributed to them are considered to be co-constructed (Riessman, 2008).

The relationship between the researcher and participant is considered a joint collaborative one (Clandinin & Connelly, 2000), with the potential to impact the richness of the story shared (Lieblich et al.,1998). NI is the storying of experience, where the role of the researcher is to interpret the experience shared (Kramp, 2004). The process requires the researcher to revisit, retell and relive the stories of experiences told (Clandinin & Connelly, 2000).

Researchers undertaking NI bring their own personal narratives, beliefs, opinions and biases (Clanidinin & Connelly, 2000). For this reason, reflexive practice is integral to NI. Reflexivity is described as critically examining the impact of one's own beliefs on the research process; researchers employ this tool to examine the impact of personal narratives on each step of the research process and the interpretation of resulting findings (Finlay, 2002).

Both social constructivism and NI share underlying assumptions that research findings will inevitably be influenced by the participant-researcher dynamic, their interactions, and personal narratives (Finlay, 2002).

3.6 Research Design

The research was planned and prepared for during the Covid-19 pandemic, with subsequent school closures and national lockdowns. The researcher set out a suggested timeline and expected timeframe to complete each stage of data recruitment, collection and analysis. When schools did reopen after the national lockdown, social distancing measures remained, and schools prioritised the recovery curriculum. This meant that each stage of the researcher's expected timeline was revised (see Appendix 5, for the timeline for each stage of the researcher's participant recruitment, data collection and analysis).

3.6.1 Selection and Recruitment of Participants

A qualitative approach was employed with an aim to consider uniqueness and subjectivity in place of representativeness, so a purposive sampling method (Robson & McCarten, 2016) was used to recruit participants. All participants were required to be a parent of a child with a diagnosis of autism and self-identify as being Bangladeshi. From the outset, the researcher was aware that the Bangladeshi parents were being asked to tell 'a specific story' influenced by their identity. Small groups of participants are anticipated in NI to allow in-depth analysis (Leiblich et al.,1998). This type of research emphasises the gathering of rich and detailed data, so five participants were sought to take part.

The initial inclusion criteria were that at least three years had elapsed since their child had received a diagnosis. This length of time was decided upon because it was likely to be an adequate time period to allow a diagnosis to have possibly ‘settled’, and the possible adjustments required at home and school would have taken place. However, due to recruitment difficulties outlined below, the inclusion criteria were adapted, and children only needed to have had a diagnosis of autism for their parent to take part.

3.6.2 Recruitment Method

There were two phases to participant recruitment in this study. Phase 1 aimed to recruit participants in an identified local authority (LA), where it was hoped that the demographic of the local population would increase the likelihood of Bangladeshi parents participating in the research. The LA required additional ethics approval before any research could be undertaken. With the support of the Educational Psychology Service in that LA, this ethical approval was granted.

Despite intensive recruitment efforts in the identified LA, using LA groups, school and EP colleagues to spread the word (See research flyer, Appendix 6a), only one parent indicated an interest in taking part. Recruitment approaches were broadened to include other London boroughs and support was sought from teacher colleagues in Special Educational Needs and Disability positions. Recognising time constraints, the researcher decided to widen the scope of the research and change one of the inclusion criteria to include:

- Participants' children needed to have received a diagnosis of autism (there was now no expectation that at least three years had elapsed since the diagnosis).
- Social media was now used to recruit, for example, Facebook and Twitter.
- Participants received a £10 voucher for their participation in the interview process.

This second phase in recruitment resulted in five participants (see Table 6 below).

Table 6

Participant characteristics

Participant	Gender	Child's name	Year Group
Raina	Female	Taha	Y2
Mim	Female	Riz	Y8
Aliya	Female	Kabir	Y7
Tahira	Female	Sameer	Y9
Nila	Female	Musa	Reception

In keeping with the NI design, which is open and exploratory, the researcher was not required to exclude participants that had an additional diagnosis or comorbidities with other conditions. However, none of the participant's children had any comorbidities, and autism was their only diagnosed condition.

3.6.3 Pseudonyms

Research suggests that names are significant on several levels. For the researcher, it was considered to be an established and responsible part of ethical research (Allen & Wiles, 2015). Ensuring a participant's anonymity is one way we can uphold ethical principles around beneficence. Positioning theory (Harré et al., 2009) argues that we create 'story lines' about our lives, using language in social encounters to position ourselves and others (Harré et al., 2009). In research, a name has the ability to evoke or imbue a person with characteristics and impact how they are perceived and positioned by others (Hurst, 2008; Lahman et al., 2015).

Each participant was offered the opportunity to choose pseudonyms for themselves and their child after the interview and again when their storied narrative was shared with them. None of the participants wanted to choose their own names and were happy to keep the names that the researcher assigned them. Names chosen by the researcher were considered culturally appropriate and in keeping with names commonly found in the purposive sampling group. The researcher acknowledges that in taking this approach, they were undoubtedly influenced by personal interactions and experiences from their own life.

3.7 Data Collection

3.7.1 Unstructured Interviews

The social constructivist approach employed in this study focuses on individual meaning-making and constructions of what it is like to be a Bengali parent to a child with autism. The researcher sought to utilise a data collection method that allowed participants to relate their experiences in their own words. Interviews that employ minimal prompting (Robson, 2002), allowing participants to explore the phenomenon in a self-directed manner, were considered to be the most appropriate way to share their experiences. Reissman (2008) argues that narrative interviewing should ensure that the participant has opportunities to explore their own narrative paths without being restricted or controlled by the researchers' areas of interest or theoretical lens.

Therefore, it was decided that the data would be collected through unstructured interviews, providing participants with the freedom to tell their story in their own way (Clandinin & Connelly, 2000). A life story grid was shared via email prior to the interview to prompt reflection and support discussion. On the day of the interview, topics shared by each parent were self-selected.

Due to Covid-19 related social distancing regulations, all interviews were conducted online via Teams and recorded with participant permission This enabled the researcher to be fully present during the interview, and the video recording was transcribed following the interview. The use of unstructured interviews can encourage participants to tell their story without restrictions (Hiles et al., 2017).

3.7.2 Life Story Grids

Life story grids were utilised as a prompt for the interview to help participants in the sharing of their stories. They were emailed to participants before the initial meeting and were used to support participants by being an aide memoir prior to the interview and visual support for discussion and reflection during the interview (Wilson et al., 2007). Significant experiences can be placed along a horizontal line representing a duration of time. The events are placed along the line in temporal order; however, the aim is to scaffold, not restrict, the interview. The application of this prompt in a flexible way allows the participant to move between events and revisit and modify the story as it is narrated (Wilson et al., 2007).

Life grids can enable participants to pin discussions to particular times, events and places (Elliot, 2005). In the present research, it was considered that life grids provide a tool to support the unstructured nature of the interviews and facilitate discussions in a way that was meaningful for participants. Overall, it was the researcher’s view that it would make for a more relaxed encounter for the participant and researcher (Wilson et al., 2007). A script was used to explain the life story grid and its purpose during the initial meeting (Appendix 7).

3.7.3 Pilot Study

A pilot interview was completed with a volunteer known to the researcher who met the inclusion criteria. The pilot phase was valuable as it allowed the researcher to experience the unstructured interviewing processes, enabling the researcher to understand their role in the construction of the participant’s narratives. Through the use of the research journal, the researcher reflected on how the open-ended nature of a question can make for an uncomfortable experience for the interviewee. For example, at several points during the interview, the participant asked if there was “anything else that the researcher wanted to know about?”.

Subsequently, the researcher decided to prepare participants for this style of interviewing by relaying how useful it was for the researcher to display active listening skills throughout the interview. In addition, it was apparent that rapport-building was integral to the richness of the story shared. So, another outcome directly related to the pilot study was building in opportunities for 'problem-free talk' with participants before the interview commenced.

3.7.4 Method of Data Collection

An initial meeting was held with each participant online, outlining the research process. The second session involved the data collection online over Teams and was recorded (in line with the Data Management Plan, Appendix 13). The interview began with the researcher explaining that they had been emailed a life story grid to help them think about their journey as a Bangladeshi parent of a child with autism. The life story grid aimed to prompt them to consider their own experiences and prompt their recollection and memory of events they considered important to share (see Appendix 7).

Each interview began with the researcher giving the same prompt, asking the participant to tell them, “What is it like to be a Bangladeshi parent of a child with autism?”. The conversations were mainly carried out in English, with some words in Sylheti or Arabic dispersed. There was a shared understanding between the researcher and the participant that these words were common usage and would be understood by the researcher. The researcher communicated their understanding by nodding and showing attentive listening. Participants were encouraged to begin their personal narrative at any point that would help the researcher gain an understanding of their story. The researcher was aware that this might focus on the everyday aspects of their lives or the disruptions and changes that constitute a participant's experiences (Murray, 2015).

In line with the unstructured interview approach the only questions asked at this stage were to ask for clarification or more detail. The interview concluded with the researcher asking the participant if there was anything else that the participant felt was important that the researcher should know regarding their experiences of being a Bangladeshi parent of a child with autism.

As the interview drew to a close, each participant was asked to share what it felt like to talk about their child and share their story. This question allowed the researcher to check how the participant was feeling after having shared their experiences and consider if they were showing any signs of distress or discomfort that might lead to further offers of support through signposting of organisations that they could utilise for support. In addition, it encouraged the participants to reflect on their own story and perhaps offer possible insights and reflections on their own narratives. The sessions ranged between 25 – 110 minutes.

The stories shared were transcribed and organised into time or event chunks (a full description of the method employed can be found in the data analysis section below) to create a ‘story’ of their experiences.

The third and final session involved the researcher emailing each participant the 'restorying' of their experiences and requesting that we organise an appropriate time to meet online to discuss or make changes to their storied narratives. Please see section 3.8.3 below for a more detailed outline of what this involved.

3.8 Data Analysis

The data analysis approach used in this research is based on Clandinin & Connelly's (2000) Three-Dimensional Framework for analysing narrative. This builds on Dewey's (1963) ideas that individuals make sense of experience through an interplay of time and context. This approach was employed in the present research. It highlights the importance of being open to a variety of experiences whilst acknowledging the temporal nature of the narratives shared. Participants' "representations vary drastically over time and across circumstances within which one lives, so that a single phenomenon may produce very different stories, even from the same person." (Squires et al., 2008, p .5). Narrations of the past are connected to and embedded in the storytellers' present and connected to their ideas about the future.

3.8.1 Transcription of Interviews

The researcher transcribed the video recording. This enabled greater familiarity with the data and helped them gain a better understanding of the narratives. It also supported the researcher in the later phase when they storied the narrative. The researcher wanted to keep the transcript as accurate as possible and did not attempt to 'clean up' the transcript by correcting grammar. However, punctuation marks such as commas and full stops were added to support the reader and clarify the meaning.

According to Reissman (2008), there are no universal rules as to the form this written record takes, "transcriptions are by definition incomplete, partial and selective" (Riessman, 2008, p.50). The notation system advocated by Braun and Clarke (2013) was utilised; an example of transcription can be found in Appendix 14.

3.8.2 'Restorying' the Participant's Narratives

Based on Polkinghorne's (1995) narrative analysis, the first stage of the analysis involved rewriting each participant's narrative into a storied form. Ollerenshaw and Cresswell (2002) describe "restorying" as the process by which stories are gathered and analysed for features including: time, place, plot, and scene. These features are used to rewrite the participants' narratives in a chronological sequence. Configuring the participant narratives into storied accounts enabled the researcher to draw together the participants' emotions, their context, interactions and events that combined to form the participants' experience (Polkinghorne,1995). In following this approach, the researcher was able to convey the richness and detail of the participants' stories (Ollerenshaw & Cresswell, 2002).

Clandinin and Connelly's (2000) three-dimensional framework was utilised to provide a structure to the restorying process; the authors draw on the ideas put forward by Dewey (1963). Dewey argues that to understand individuals, one should consider not only subjective experience but also the interactions with those around them (Ollerenshaw & Cresswell, 2002).

Clandinin and Connelly's (2000) three-dimensional framework offers a holistic way of considering experience, drawing on factors such as emotions, thoughts, feelings, interactions and context. In addition, attention is given to continuity, enabling the researcher to gain a sense of the participant's experiences over time. This aligns closely with the life story grid shared with participants in the current research, where participants were encouraged to share their story from self-chosen points in time. Figure 2 below shows a representation of Clandinin & Connelly's (2000) three-dimensional framework as envisaged by Ollerenshaw & Cresswell (2002).

Figure 2

A representation of Clandinin & Connelly's (2000) Three-Dimensional Framework.
Adapted from Clandinin and Connelly (2000) and (Ollerenshaw and Creswell (2002)

Interaction		**Continuity**			**Situation**
Personal	Social	Past	Present	Future	Context
Look inward to internal conditions, feelings, hopes, aesthetic reactions, moral dispositions.	Look outward to existential conditions in the environment with other people and their intentions, purposes, assumptions, and points of view.	Look backwards to remembered experiences, feelings, and stories from earlier times.	Look at current experiences, feelings, and stories relating to actions of an event.	Look forward to implied and possible experiences and plot lines	Look at context, time, and place situated in a physical landscape or setting with topological and spatial boundaries with characters' intentions, purposes, and different points of view

The researcher adhered to the following six steps:

Step One:

The researcher began by familiarising themselves with the data. This involved reading and rereading the transcribed interviews and was in accordance with recommendations outlined by Clandinin and Connelly (2000).

Step Two:

The researcher grouped ideas and events together to create stanzas. A new stanza was created when the participant moved on to a new event or topic. Reissman (2008) outlines this approach as a way to organise and group transcribed speech into events or ideas (stanzas).

Step Three:

The researcher gave each stanza an overarching label using the participant's own words; the label was chosen by the researcher as it was considered to reflect the content of the stanza. This was in keeping with Clandinin and Connelly's (2000) approach, where they describe labelling sections of chronology with titles that describe the nature of that section and its meaning for the participant. Appendix 15 illustrates one stanza (Feeling empowered / wow moment) taken from the participant (Mim's) transcribed interview.

Step Four:

The transcript was colour-coded to identify the three elements outlined in the three-dimensional space framework: interaction, continuity and situation. As outlined in Figure 2 (above), the 'element' of 'interaction' was broken down further into two separate sub-sections (personal and social), the 'element' of 'continuity' was also broken down further into two additional sub-sections (past and present) and the third and final 'element' of 'situation' is referred to as 'context'. Appendix 15 is an example of a transcript colour-coded according to the features that go to make up Clandinin and Connelly's, 2000, three-dimensional framework.

- For interaction, this meant considering both the personal and social world of the participant as related by them in their narrative (Appendix 15, coded in blue and pink).
- For continuity, this meant noticing how they looked backwards in their narrative and remembered feelings and experiences, in addition to how they looked at present experiences and those implied by the participant about experiences in the future. (Appendix 15, coded in green, yellow and red, respectively).
- For context, this meant being aware of the time and situational context of where the narrative takes place. (Appendix 15, coded in grey).

Step Five:

The colour-coded data extracts were then taken and used to populate a grid similar to the one highlighted in Figure 2. Please see Appendix 16, p.161, for an example. Line numbers were retained so that all extracts could be retraced back to the original data.

Step Six:

The researcher then organised the stanzas (grouped ideas/events) into meaningful groups that best reflected the participant's story (direct quotes from the transcript continue to feature in each stanza). These 'interim narratives' (meaningful groups of ideas) were used as the foundations for the final 'storied narratives' (Clandinin & Connelly, 2000). (Appendix 17 illustrates the process undertaken by the researcher in configuring the data into 'final storied narratives').

To keep the storied narrative as close as possible to the participants' experiences, the participants' own words and phrases were used (Kramp, 2004). In addition, it was decided that the storied narratives be written in the third person. This acknowledges that although the researcher had endeavoured to share the story from the narrators' perspective, there is an acceptance and understanding that the final storied narratives are co-constructed.

The pseudonyms were chosen by the researcher and approved by the participants during the member checking stage. By sharing the storied narratives with the owners of the experience, it was hoped that the potential gap between the subjective experience and the storied narrative would be reduced (Ollerenshaw & Cresswell, 2002).

The researcher decided that all identified stanzas from each participant's narrative would be included in their individual storied narrative (these re-storied narratives were later shared with individual participants during the member checking stage). This approach was consistent with the researcher's ontological and epistemological position as outlined in 3.2.2, where the focus remains on individual experiences and the meanings they attribute to that experience. However, the researcher acknowledges that each participant's story was co-constructed, and a degree of interpretation would feature in the analysis process. The researcher sought to mitigate their role in the interpretative process by employing and maintaining a reflexive approach throughout the analysis procedure outlined here (please see 3.9.4 for further details).

3.8.3 Member Checking

The resulting narratives were emailed to the parents; they each had an opportunity to check the validity and authenticity of the narratives. Each parent was offered the opportunity to meet with the researcher for the third and final time online for a video call to discuss how they felt after reading their storied narratives and make any amendments that would lead to the final storied narratives. Each participant was also offered the opportunity to change the pseudonym assigned to their story. In addition, two of the parents did not use their child's name during our interview; for example, they used 'my son' or 'my child'. In the interest of making it easier to read and follow the story, a name was assigned to the child by the researcher. Only two of the parents were able to make time in their schedules to meet; the remaining three parents all emailed their responses and gave renewed consent to use the narrative as presented to them. None of the parents wished to make any changes. One of the storied narratives is presented in the following chapter: all five parent stories can be found in Appendix 20-24.

3.8.4 Identifying Participant's Shared Storylines

This phase, along with the one outlined above, combined together to answer the research question:

'What are the experiences of being a Bangladeshi parent of a child with autism?'

The second phase of analysis drew on Pokinghornes' (1995) analysis of narratives approach. In accordance with this approach, themes are inductively gathered from the stories collected. For the current research, the 'stories collected' were the storied narratives created in phase one of the analysis. The analysis process outlined below also draws on paradigmatic approaches outlined earlier, such as Reissman (2008) and Squire et al., (2008) in sections 3.5.2 and 3.5.3.

- Each stanza identified in the first phase of analysis (3.8.2) was examined in accordance with the storyline or experience it conveyed (see Appendix 18 for stanza table)
- Identified stanzas were colour-coded
- Stanzas that were found to share common or 'shared storylines' were grouped to create 'Narrative themes'
- Experiences that contributed to or shaped the identified 'Narrative theme' were grouped to create 'Sub-themes'.

(See Appendix 19, for identified Narrative themes / Sub-themes)

Although many of the 'Sub-themes' consisted of experiences shared by many participants in their narratives, others were less common across the stories and were pertinent to individual narratives. 'Sub-themes' acknowledge the very different ways some of the shared storylines are experienced by participants but come together under the broader Narrative theme. Narrative themes and their corresponding sub-themes encompassed all the stanzas from the 'restoryed' narratives. No data was excluded.

Again, the researcher was keen to ensure that in looking for commonalities across stanzas this did not detract from the subjective meaning-making as envisaged by the social constructivist approach. The shared storylines and narrative themes identified across the five participants should be considered alongside the storied narratives; both of these phases of analysis combine to answer the research question outlined above.

3.9 Ethical Considerations

As part of the research process, ethical approval was sought and gained from the University of East London, and one identified LA was chosen for purposive sampling (Appendix 10 and 11). An initial letter was shared with potential participants that outlined a general overview of the research and what participants could expect in terms of informed consent, confidentiality and anonymity (Appendix 6b). Each potential participant was offered an initial online Teams meeting so the researcher could share the purpose of the research, explain the procedure that would be followed, and the part the participants would play in the research. Each potential participant was also given the opportunity to reflect on the information shared and given up to one week to contact the researcher if they wished to participate in the research.

3.9.1 Informed Consent

Potential participants were able to use this initial meeting to ask questions and clarify their understanding. It was important to the researcher that consent be an ongoing process. Participants were emailed the invitation letter again, this time with the addition of the consent form. Participants were required to return the signed consent form before the online interview. On the day of the interview, verbal consent was again obtained before the actual interview began. This approach closely aligns with the researcher's values around promoting informed and continuing consent. All participants were reminded of their right to withdraw from the research at any time during or after the interview had taken place. The debrief letter shared with participants also reiterated the participants' right to withdraw (Appendix 7) within a three-week time frame, after which the transcription and analysis process would have begun.

One aspect of ethical consideration in the research was the particular sensitivities related to the research topic, which could require the parents to revisit some difficult experiences and trigger some potential feelings of distress. At various points in the study, there was a possibility of causing potential harm. These include during the interviews when the storied narratives were shared or as a result of the analysis of the stories. During the interviews, the researcher was mindful of ensuring that those participating in the research were not caused distress.

As a TEP, the researcher felt suitably equipped to recognise any signs that the interview caused the participant to experience distress. No participants displayed signs that suggested they felt distressed by the interview process. A debrief letter was shared with each participant, signposting specialist support services that they could approach if they experienced distress in the period after the interview (Appendix 9). The researcher was supported by their supervisor in relation to interview experiences. In addition, the researcher used the research diary to explore and reflect on the interviews after they had taken place.

3.9.2 Incentives

All participants received a £10 online voucher for their participation in the research process. This was not a feature of the original research design and ethics application, so an amendment to the original ethics approval was sought and agreed. (See Appendix 12 for revised ethical approval).

3.9.2 An Ethically Minded Custodian

The following two sections will explore the researcher's personal reflections on the research process. This discussion will be written in the first person, and the participants will be referred to as parents. This will also happen in several sections in Chapter Five, as these also pertain to the researchers' personal reflections.

Perhaps one of the most significant ethical issues for me was my role as a custodian of the stories parents shared. Although the narratives were co-constructed with the researcher, I was mindful that these narratives were the participants' lived experiences, and there was a responsibility on my part not to 'rupture' the stories that parents share about their lives that sustain or support them (Clandinin & Connelly, 2000, Reissman, 2008). Throughout the study, efforts were made to protect the identity of the participant and their families. Pseudonyms were used, and parents were asked to provide a name of their choosing or were assigned one. Despite efforts not to reveal details that might identify parents, it became clear in the 'storying' phase that the omission of specific identifying details would make some aspects of the story difficult to follow. I decided to keep these details in, and they formed part of the parents' narrative ‘‘restorying’’. Once again, parents were asked to give their continuing consent. They were emailed their narrative "restorying" and asked if this co-constructed narrative reflected the story they had shared. This was an acknowledgement on my part that the parents continued to own their story, and, in that email/online meeting, permission was sought to become a custodian of their story. This experience was something I reflected on as part of the research diary (Appendix 25).

3.9.4 Research Reflexivity and Cultural Considerations

Bolton (2009) explains that research reflexivity involves the researcher locating themselves in the study. He asks the researcher to consider their own role in relation to the research and, perhaps most importantly, the extent to which they are able to remain separate from the activities undertaken as part of the study. Bolton (2009) argues that in acknowledging and critically examining their experiences in relation to those being offered up as part of the study, researchers and participants become engaged in activity that makes them co-researchers. The insight gained from this joint effort enabled me to understand parents' many and varied views. As envisaged by Finlay (2002), the researcher's role has the power to influence the research process and create uncertainty around the researcher's own position and potential for researcher bias.

As outlined by Bolton (2009) and Finlay (2002), my position as the researcher conducting the study in relation to the research process is pertinent. I share the same background as the participants and there is a strong possibility that I became part of the research process as envisaged by Bolton (2009). The implication being that my role in the research process is significant and will play a part in my analysis and discussion of findings. Bolton (2009) encourages researchers to question their own thoughts and thinking in relation to the research process.

However, I am mindful that my ethnicity and background does not overly influence the data gathering and analysis procedure, and the findings should be meaningful relevant to the data collected.

I am from the community being researched; however, as will be explored throughout this research, the Bengali community is diverse and varied. Neither the parents nor the researcher in this study are assumed to be representative of a community; to do so would be reductive and diminish the uniqueness of each parent's story (see Appendix 27 for excerpt from research journal).

3.10 Conclusion of Chapter Three

This chapter outlined the reasoning behind the adoption of a relativist paradigm and a social constructivist epistemology. Several possible research methods were outlined, and the justification for a narrative approach was presented. The research design was presented along with the ethical considerations in relation to this study. The research findings will be presented in Chapter Four.

Chapter Four: Research Findings

4.1 Introduction

This chapter will present the research findings in relation to the two phases of analysis outlined in Chapter Three. The first section will provide the reader with one of the storied narratives, which provides a unique insight into the experiences of being a Bangladeshi parent of a child with a diagnosis of autism. The storied narrative presented below and, in the appendix (Appendix 20-24), play an essential role in answering the research question. In the second part, there is an exploration and commentary of the story themes and sub-themes present in all five shared experiences. Findings from both of these two aspects of analysis combined will seek to answer the central research question:

> 'What are the experiences of being a Bangladeshi parent of a child with autism?'

4.2 Nila's Story

Nila and her son Musa

Lack of Understanding from the Bengali Community

Nila describes having to educate a lot of people about autism; it's something she continues to do to this day, even though it has been three years since her son's diagnosis. With some people, she would say they have come a long way, but with others, they are still at the beginning of their understanding. The constant battle has made them isolated, as a family, from the wider community.

Experiences within the Family

A lot of people don't see her son as another being; he is often ignored, and people will ask about her daughters. But the questions she does get asked about her son Musa are intrusive. When it comes to getting to know Musa, they think it's best just to leave it. This is something Nila and her husband have an issue with, and now they only mix with a select few people. As a result, the family doesn't bother very much with social gatherings.

Nila has left quite a few houses and weddings crying because she can see the experience has been like torture for her son. The family doesn't bother with social gatherings anymore. Now with the isolation (for Covid-19), they just don't get invited to a lot of places because people just don't want to cater to his needs and would rather take him out of the equation altogether. This has been Nila's experience of the Bengali community.

The family went to an evening *dawat* (dinner party) not long ago; it was at her husband's aunt's house. The family live nearby, so they agreed to go. Musa found sweets everywhere, so he was high on sugar and overtired, it was all too much for him, and by the end of the evening, he was sat in the cat bed. Nila waited until the men were fed around 10 o'clock and then wanted to leave as Musa was going crazy.

That evening, four different women told her off for leaving without having eaten the host's food, this was considered very rude, and she was painted as the bad guy. Nila is used to this kind of response and doesn't let it phase her anymore. People can be silly, making a specific request for her and her family to attend and then not catering for her children. Nila would like people to understand that her son is her priority and not make things harder for her.

Family's Lack of Understanding

Nila has heard a lot of competitive comparisons; people don't realise that every child with autism is unique. Often Nila will hear that so and so's child is out of nappies and they have autism, or so and so can speak now. They put it down to her or her husband's bad parenting.

When Nila takes her son anywhere, women will often say, "But his face is so normal" or "But he's so handsome". As if this has anything to do with anything. Nila explains that she finds this so offensive; she will often have to take time to explain Downs Syndrome and autism.

Nila's son Musa is named after a prominent prophet in the *Qur'an* (Muslim Holy Book). This prophet is known for not having clear speech; lots of people have told Nila to change her son's name. Nila considers this to be mumbo jumbo, but it hasn't stopped people from telling her that she should choose a name that will bring calmness to her son.

Family members keep saying superstitious things to Nila. A relative from America called and shared that someone had gone to a particular *imam* (religious leader), he blew over their son, and he can now talk. Although Nila has respect for her mum's relatives, she thinks they are talking absolute rubbish. People want a cure for Musa, something she's not looking for. So, she explained that she can become snappy with family depending on who they are. Nila's mother-in-law is looking desperately for a cure. They think what Musa has is curable. They have suggested she explore CBD oil, Chinese herbal medicine and Indian spices. Autism is not a curable condition; Nila believes that it's something that the Bengali community needs to learn more about.

Nila feels that the Bengali community feel her son's condition is either curable or *Jinn* (supernatural spirit, below the level of angels or devils) related. People have told Nila she needs to do *Ruqyah* (Qur'anic verses that are recited over a person for protection and healing) on her son because they think some *Jinn* or *shaitan* (the devil) has hurt her child.

Not long ago, her mother-in-law asked Nila to come over to meet someone. When she arrived, a man was there and wanted to speak with her. He told Nila that her son is afflicted, and autism is created by *Jinns.* To Nila, this is not even someone who believes in God because she feels that *Allah* (God) has given her a son with autism. There is a benefit for her from being in this situation, and she needs to look for it. For Nila, her son is a blessing. He is very special to her and brings so much joy to her home. When he smiles, everyone around him just stops and smiles with him.

At the time, she felt strongly that this man was not allowed to see Musa; no one is allowed to see her son if they think his autism is because of XYZ. Previously Nila would have felt pressured and given it a go. But on that day, Nila was deeply offended and left the house. Later on, women from the extended family called her and tried to persuade her that there was no harm in trying what the man was suggesting. She explained that it just left her fuming and made her blood boil. She recognises that they are not bad people, and they really honestly think that they are trying to be helpful. Instead, Nila would like to see them read a book, or take notice of the things she forwards on to them about autism or just educate themselves about it. To Nila, that would be the most helpful thing they could do.

Wanting to be Understood

NIla has now taken a step back and only visit houses that are willing to help them and accommodate Musa. Nila’s mother-in-law now comes to her house to see the kids. It’s sad that people won’t put these helpful things into place to enable the family visit. People just don’t understand the effort that goes into looking after children who are not neurotypical. So, they forget.

Musa attends a special needs school in an area where not many Bengalis live. Nila’s friendship circle includes parents from the school her son attends. She describes the group as closer than some family members because they all understand each other and accommodate each other and their child’s needs. She has been in situations where family members have wanted to watch what they want on TV and refuse to make changes for her son. It’s been deeply hurtful and upsetting.

Nila believes this happens because members of the Bengali community are not educated enough. They almost don’t really want to know; if it doesn't affect them within their household, they kind of don't want to know.

There was a huge uproar from the family when Nila decided to send her son to a special needs school; they felt strongly that he would look at all the other kids in mainstream school and become normal. This became a talking point for a lot of people. It was felt that by making this decision, Nila was institutionalising Musa, and it would only make him worse. Nila knew that he would be terrified of the number of children in a mainstream class, and he wouldn’t be able to do their routines.

People have always questioned Nila’s parenting skills; this scrutiny extended to her two daughters, but even more so for her son. The younger generation seems to understand, but anyone older than 45, just doesn't seem to get these things.

With her own family, she has been much more vocal. Making a point that this is autism, watch this documentary, read this book, get to know it. It's not going away. This has changed her own family's perceptions, and they've made adjustments that make her more comfortable to visit. Nila accepts that her approach with her own family is different to that with her in-laws; she can scream and make her point with her family, which is something she can’t do with her in-laws.

Journey to Diagnosis

Back to the beginning

Nila had two daughters and then her son Musa. She remembers that the girls hit their milestones really quickly. With her son, she would take him to the health visitor, and they would say, "He'll get there" or “He's a little bit slow”. There was no mention of the word autism. It wasn’t until they got to his 2-year-old review that they mentioned that there was something wrong. Nila recalls that the health visitor used a questionnaire, and there was not one single thing that Musa could do. The lady made Nila feel bad for not taking her son to playgroups. With three children under three years of age, it just hadn't been possible. The experience left Nila feeling bad and tearful.

Eventually, as the older children went to Nursery and Reception, Nila went along to children's groups with her son. Whilst all the other children were playing, Musa would just sit there and cry. One day he just started hitting his head against a bookshelf; Nila remembers he was really hurting himself, and she could see all the mums staring. She took Musa to the toilet and was trying to soothe him when a worker from the Children's Centre came in and offered her a cup of tea and a chat. Nila didn’t take her up on the offer; she put Musa in the stroller and recalls crying all the way home.

Autism was not something Nila knew much about; she had heard about it in passing, so it felt unknown when a member of staff asked if she thought her son might have autism. Nila met the most amazing people at the children’s centre, and they helped Musa get his diagnosis.

At the same time, Nila was still hopeful that the professionals were wrong, and that Musa was going to start talking. Her own family and in-laws were offering different reasons why Musa was the way he was. It felt like she had two different lives with Musa. Her family were saying that "He's was a boy, he's slower”, "You know he will pick it up", and “so and so spoke when they were three”. After doing her own research, Nila realised that Musa had every single trait of autism that she had ever read about. Even after the diagnosis, both families were telling Nila that everything would be fine, and she just had to pray and go to umrah and *hajj* (both different types of pilgrimages to Mecca). They saw his diagnosis as an illness. This is something that still gets to Nila to this day.

Dealing with the diagnosis as a father

Musa's father will often spend time explaining to family members that what Musa has is not an illness, it is something that he was born with, and it's a part of his son. Nila remembers that he wasn’t always so passionate about Musa. After two daughters and now a son, his family was complete. He imagined that Musa would play football with him, and they would go to the mosque together. Looking back, Nila saw that he had all these ideas of how he wanted his son to be. So, it took a long time to warm up to the idea of Musa, and he grieved for the son Musa was not.

Dealing with the diagnosis as a mother

In contrast, Nila, as a mum, had to make do with whatever was thrown at her; she was dealing with him 24 hours a day, seven days a week. Musa would never sleep, he would wake his dad, and that would disturb his work; as a result, he would be angry. Nila’s husband ended up sleeping in a different room, and she was left to deal with her son on her own. So, for Nila, she had to accept things straight away and get on with things herself.

Looking Back, Then and Now

Nila three years ago, Nila now

An experience in a park during Ramadan made Nila reflect on how her approach had changed. The family had taken her son to a park during lockdown, and Musa needed his physical activity. Musa had run towards the riverside; Nila and her husband were picking him off the floor and putting him in his stroller. Musa finds transitioning between activities hard and will lie on the floor and cry. Whilst this was happening, a lady walked past, giving them a very dirty look. Musa's dad knew what was coming. Nila was much stronger than she had been before. She recalls asking her husband to deal with her son, and she ran up to the woman. Nila made the woman know she had noticed her watching and explained that her son has autism, is nonverbal and has sensory processing needs. He was finding it difficult to transition back into the car. The woman’s face dropped, and she walked away. Later, at the car, the same lady approached the family, and Nila thought she was coming to start a fight, and to her surprise, the woman apologised. Nila felt it important for the woman to know about her son's needs; his crying can make people think they are hurting him. To Nila, if passers-by actually think she is hurting her child, they should proactively get involved and ask what's happening. Instead, people just stare in a really dirty way.

After the incident, Nila’s husband looked at her in a different way. He was used to seeing her as this little lady who never says anything. But she had just yelled at a woman and got her to apologise. Looking back, Nila is in two minds about whether she should have yelled at the woman, but it gave her a confidence boost, she can now speak to anyone and everyone about her son, she is not ashamed. In recent times, Nila has found herself challenging even Bengali women who are calling her son naughty.

Nila has told them that her son is exempt and does not have to adhere to their rules, and he is free to do whatever he wants; she's sorry but is going to basically let him do what he needs to do.

In describing all the small parts of her life, she realises how incredibly hard it's been. Having lived it, it feels like a lifetime ago, but the family continues to live it every day, so it feels kind of bizarre.

Language Differences

Nila has been trying to explain to family members about what autism is; it's been really hard; the word autism means nothing to them. They think it's some kind of mental health problem. Looking back, she realises that you would hear someone had a child or a sibling in a residential home; it was classified as a mental health problem when actually they had autism. The word autism was never in their vocabulary, so people would just class everyone under one box.

‘But that’s Bengali’s For You.'

Musa’s dad’s Bengali is much better than Nila’s. She describes herself as using lots of English terminology, whereas her husband will take more time and patiently explain that children are born this way. Soon after Musa was born, his dad decided he wanted to train to be a doctor and is now in his final year. Nila explains that now as he is about to qualify *Insha-Allah* (God willing), people take his words more seriously than they would have in the past. Even though he has taken time to explain in a way that they might understand, the next time they visit, he has to go through the same explanation all over again. So, it just feels like repetitive explanations, again and again, but that's what the older Bengali generation are like.

This is a condensed version of Nila’s story, please see Appendix 20-24 for all 5 parent narratives in full.

4.3 Shared Storylines – Narrative themes and Sub themes

This section explores all five of participant’s shared storylines in order to answer the central research question:

‘What are the experiences of being a Bangladeshi parent of a child with autism?’

Participant’s storied narratives were analysed using their thematic stanzas, as outlined in greater detail in 3.8.4. Although this stage of analysis emphasized the commonalities of participant experiences, the researcher did not wish to decontextualize the participants’ experience and detract from the individual and unique aspects of the participants’ narratives. Therefore, it is crucial that this process be viewed in conjunction with the storied narratives of each participant. The combination of both these aspects of analysis will answer the research question in this study. (Please see Appendix 20-24 for all 5 parent narratives in full).

Table 8 below provides a summary of the identified narrative themes and sub themes generated from the storied narratives and original transcript. The exploration of narrative themes or subthemes was not determined by frequency and dominance in the data but rather the experience itself and its significance to the participants' narrative. (See Appendix 18 and 19 for the overview of narrative stanzas).

Table 8

Summary of Identified Narrative Themes and Corresponding Sub-themes from a combination of the storied narrative

Narrative theme	Sub theme
A: Parental Meaning Making	- Autism as an Unknown - Making sense of the Causes - Accepting the Diagnosis - Gendered Experiences - Adapting to the Child
B: The Emotional Impact of Parenting a Child with Autism	- Emotional Pressures - Pressures around Food - Feelings of Isolations and Disconnection
C: Extended Family Relationships and Wider Support	- Understanding and support
D: Extended Family Understandings and Responses	- Alternate Faith Based Understandings - Autism as Something that can be 'fixed' - Bad Parenting and Blame
E: Lack of Understanding from the Older Generation	- Sharing the Diagnosis - Not having the Language to Explain in a Meaningful Way - Sensory Difficulties are Hard to Explain and Understand
F: Connections that Support a Cultural Identity	- Connection through Food - Language and Identity - Connection through Religious Faith
G: "then and now"	- Nila then, and Nila now - Mim's "Wow" Moment - Not Caring / Rejecting Traditional Roles

Narrative theme	Sub theme
	- Advocating for your Child with Professionals
H: The Future	- The Potential Barriers and Raising Awareness - Hopes and Worries about the Future - The Future is Not Without Hope

The following sections will discuss and provide a commentary on the 'narrative themes' and 'sub-themes' in more detail. The researcher returned to the original transcript to further support the narrative theme and subtheme, respectively. Extracts from the original transcripts can be found throughout the commentary; the number in each bracket indicates corresponding number lines.

4.4 Narrative Theme: Parental Meaning Making

Every parent’s story illustrated how they sought to make meaning of their child’s behaviours. Mim's story, like that of Aliya’s and Tahira’s looked for developmental explanations:

> *“......he’d grow up, you know, slowly, everything he would catch up basically” (Mim, line 42)*

> *“At the time, because I just thought it was something. That that he would sort of get over, and it's just a phase in his life that he would just sort of. He would you know, grow out of it" (Tahira, line 62-65)*

Nila’s story is characterised by conflicting feelings regarding her son's journey to diagnosis.

> *"And at that time, I'm still hopeful they've got it wrong. You know, he's gonna start talking. Because at the same time that I was doing this, I was talking to my family, talking to my in-laws and all of them are saying the same thing to me. He's a boy. He's slower. You know he'll pick it up and so and so spoke at three so and so you know. So, I'm dealing with all of that, and then I'm dealing with, …..I had two kind of different lives with him and so then I'm kinda doing his diagnosis. And I knew by the time I had done all my research I knew this is what he's got. Every single trait, he's got it" (Nila, line 217-231)*

In Raina's story, she relates that her experience is unique and attributes this to the diverse range of needs in those diagnosed with autism:

> *“I think with most parents were just kind of like taking it day by day. I wouldn't say that any parent has an in-depth knowledge because every child seems to be different” (Raina, line 32-34)*

4.4.1 *Sub-theme:* Autism as an Unknown

In all the parents' stories, a familiar story theme related to 'autism' being something that they had very little experience of:

> *“I hadn't like no one in my family had had autism, I didn't know anyone with a diagnosis” (Aliya, line 111)*

Mim’s son Riz initially did not meet the threshold for a diagnosis, and she describes some initial relief that her son's behaviours did not warrant a diagnosis:

> “*I wasn't sure what you what this would mean for my child really. Maybe that's probably why I was relieved. I came away, you know, like yes, it’s, you know it's not autism and whatever that is.”* (Mim line, 72-76)

Almost all of the parent stories expressed some surprise at receiving the diagnosis. In Tahira's story, she had noticed that her son seemed to struggle with social interactions; he was sensitive and very attached to her. To be told her son had autism was unexpected:

> “*So, it was a shock. I was so shocked when he got diagnosed I just did not think at all it had anything to do that, and I didn't really know much about autism either (Tahira, line 527-529)*

In all the parent stories, a common idea about autism was the lack of speech and communication skills:

> *"Uhm, I always thought autism was, this one thing that I had seen when. Children, they don't speak they. You know have very limited language, very kind of you know. Now I know, is that whole spectrum. And you can fall. You know anywhere within that. And still be kind of under that sort of autism umbrella, which was a shock to me because he's so articulate" (Tahira, line 529-543)*

Three out of five of the stories described how speech and language professionals became involved and despite their child's language 'coming along' and, in the case of Aliya, becoming age-appropriate, there was a sense that autism remained.

> *"There are things there which I cannot reject, and you know there are signs. There are things that you know Riz is not able to sort of do, and you know things, mannerisms and things like that, and sort of you know it was still there and just because the consultant had said its' borderline doesn't mean it's gone" (Mim, line 290-292)*

4.4.2 *Sub-theme*: Making Sense of the Causes

All the parents' stories explored reasons that might explain why their child had been given a diagnosis of autism. These included the parent's hypotheses about the child's behaviour. Amongst these ideas was the impact of past events (Tahira) as a result of medical difficulties (Raina) or part of their character (Mim and Aliya)

Raina’s story described how her son Taha initially had glue ear, which meant he displayed some language delay. Later on, her story illustrates a need to understand how this has come about.

“So, I'm trying to think back to how his behaviour used to be as a child, and it was a perfectly normal child other than the speech” (Raina, line 232-234)

"So, when they first told us, we were completely in denial… he didn't display all the traits such as walking on tiptoes, not making eye contact, not being social around people. But as time progresses. He seems to be displaying more autistic traits than before" (Raina, line 216-222)

"Maybe it is the MMR. Maybe it's genetic. I have no way of knowing, but I think if I could understand that, it would give me a sense of closure on his whole condition, I guess. (Raina, line 235 – 238)

Tahira’s story initially attributed her son Sameer’s difficulties to early childhood experiences and the upheaval that the family had experienced at that time:

“They've had quite difficult childhood …..So, in my mind, I always thought it was to do with that" (Tahira, line 71-74)

4.4.3 *Sub-theme*: Accepting the Diagnosis

The parents' stories illustrate the importance of coming to terms with their child’s diagnosis. Some stories alluded to it (Raina, Aliya and Tahira); others were more explicit in how it was framed.

“When we had the official diagnosis..... by that time, we kind of got our head around it, and we told family and friends that you know it's possible that he could be autistic and this kind of explains his behaviour” (Raina, line 338-339)

Mim’s story contrasts the emotional aspects of coming to terms with her son Riz’s diagnosis and accepting her conflicting feelings. Mim's stance in this stanza accentuates her active choice to accept the diagnosis whilst simultaneously rejecting self-pity and negative thinking.

“...... but for myself. I think it was like…. accepting that I have a child who has autism. It's fine; it's OK. It doesn't mean you know the end of the world. It doesn't mean that there's something wrong with me or my family, my child. Uhm, that emotional bit accepting it is….. So you don't need to be, you know, upset about or, you know, be like, Oh my gosh, why me?" (Mim, line 498-504)

4.4.4 *Sub-theme:* Gendered Experiences

In four stories, a prominent and recurring theme was how mothers and fathers managed and accepted their child's diagnoses differently. Nila's story describes how her husband is now a strong advocate for their son Musa, but he was not always like this:

"at first he wasn't like that; he almost grieved for his son" (Nila, line 246)

"He had all the ideas of how he wanted his son to be. And so, it took him a long time to kind of warm up to the idea" (Nila, line 253 – 258)

Nila's story contrasts this with her own very different experience:

"Whereas with a mum, I feel like. We kind of just have to make do with whatever we're thrown" (Nila, line 260-262)

Aliya's story includes a similar idea. For example, the greater part of the caring responsibilities falls on her and is a cause of stress and is impacting her relationship with her son:

"It's become very detrimental in my relationship with him. I was saying to my husband; I'm, I'm the police, I'm, I'm constantly the policeman...... if he's being difficult with this food, I'm telling him off. If he's being difficult with his cleanliness, I'm telling him off; if he's not doing his work, I'm telling him. If he's forgotten his hat for the third day in a row. It's, it's just me" (Aliya, line 354-384)

Conversely, Mim's story looks outwards into the community and considers the gendered roles that both fathers and mother's play.

"You know, within our community, I would say the mum takes the brunt of everything, really. And because it's all left, dad goes out to work, or it's a cultural thing, I would say and not a man thing. But it's a cultural thing where the dads. You know, like a brick wall and this like say its, OK, I don't need, don't want talk about it. I don't want to deal with it" (Mim, line 822 – 825)

Both Nila and Aliya's stories describe the impact of their respective husbands' external work on the domestic sphere of mothering.

"I felt like I had to control my son to not, you know, not to stress my husband" (Aliya, line 839-841)

"So, it was just constant. The weight (was) on me" (Aliya, line 845)

"I was dealing with him 24/7, and he would just come in in the evenings and almost after his bedtime….my son never slept, so he would wake him (father) up and then his work would get disturbed and then he would be angry. You know my husband slept in a

different room, and I just had to kind of, you know, deal with my son by myself" (Nila, line 262-270)

4.4.5 *Sub-theme*: Adapting to the Child

A prominent theme that was found in all the stories was the idea of being child-led, making adjustments in everyday life to accommodate the child with additional needs.

> *"… You know we would work around him, and it's better we work around him rather than trying to make him fit in, because I think one of the things that you know we always try to do. We try to fit the child around us, with 'our' normal, you know, we need to work around the child. (Mim, line 539-543)*

Raina's story describes the tension between being an adult-led *"disciplinarian"* or having a *"happy and calm" (Raina, line 57)* child. Approaches previously used with her other children simply do not work with her son.

> *"I take my cues from him basically, and I find that's what works" (Raina, line 57-58)*

Raina's story is characterised by the critical scrutiny of others. This causes frustration and leaves Raina with a sense that she is under scrutiny and her parenting is being questioned.

> *"I'm spoiling him when I give in to his behaviour" (Raina, line 58-59)*

> *".....surely, we should be trying this, and surely you should be trying that? Or giving him this or giving him that, it doesn't work that way and they just don't understand that" (Raina, line 51-52)*

In all of the stories shared by the parents, choosing to prioritise their child's needs often meant parents 'stood out' and felt 'judged'.

> *"It was a bit of like a point of ridicule by some people, like oh God, they've got a bedtime, and it's 7 o'clock. Because….us growing up. There was no such thing as bedtime. You just rolled into your room and just went to bed when you felt like it; no one instilled that. So, it was just a bit of a foreign concept. (Aliya, line 561-564)*

4.5 Narrative Theme: The Emotional Impact of Parenting a Child with Autism

All the parent stories made direct references to the emotional impact of parenting their autistic child. Each parent's stories described interactions with their immediate family, mother or spouse. In addition, their stories gave examples of how they managed relationships within a wider family. For Tahira, this was about how her child's diagnosis impacted her relationship with her parents. It is interesting to note that Tahira was the only lone parent in the participant group. Nila, Mim, Raina and Aliya's stories related their experiences of managing relationships with their spouses, own families, and in-laws.

In Nila's story, negotiating the wider family's understanding of autism and their familial expectations features prominently. Nila describes how people are comfortable inquiring about her older neurotypical daughters, *"How are the girls?" (Nila, line 282),* but her autistic son is ignored or omitted from family gatherings. Nila's story illustrates the familial 'difference' experienced by some parents of autistic children.

> *"When it comes to social gatherings, or just I don't know, a lot of people don't see my son as another being… he's often ignored." (Nila, line 33-34)*

4.5.1 *Sub-theme*: Emotional Pressures

Parents often describe the critical gaze of others as a source of pressure; Raina's story describes needing to be "very careful" when she takes her son anywhere:

> *".....constantly having to explain yourselves,...that's very difficult….the knowledge about autism in our Bangladeshi community is very, very small" (Raina, line 76 -77)*

Similarly, Aliya's story shows how her early years were spent managing his behaviours during family gatherings. The word "constant" is used by both Raina and Aliya and shows the level and duration of the pressures experienced.

> *"....I was just constantly on guard, like intercepting his behaviour before it happened, and that's what it felt like. It was just super stressful". (Aliya, line 32-33).*

Aliya's story illustrates how many of the pressures she experiences come from within herself; despite moving into their own home, the need to manage her son's behaviour persists:

> *"I'm 100 % Duracell battery. I'm on guard, I'm watching him like a hawk, and he's like a bunny til he goes to sleep, and then that was my time to regroup myself" (Aliya, line 653-656)*

Several parents' stories included times when their child experienced emotional dysregulation. Raina's story describes how powerless she sometimes feels when she is unable to locate what had caused him to become upset.

> *"So, when there's things that distress him, like, for example, when he's not able to get his head around things, and he starts hurting himself, I find that quite distressing because I can't comfort him. I don't know what it is that he wants. I don't know how to help him, and I find that quite difficult. And as a parent that my child is in distress and I can't help him" (Raina, line 439-444)*

Nila's story relates how she had taken her son to a stay and play in a local children's centre when his usual level of distress (crying) became heightened. Her son Musa began to bang his head 'really hard' against a bookshelf. For Nila, this experience was further exacerbated by having other mums present; she describes feeling their gaze and standing out.

> *"...he was really hurting himself and I kind of all the mums they can see. They're kinda staring at you. And, and I had picked him up and I, I just started crying, and I took him into the toilets quickly" (Nila, line 185-186)*

In Nila's story, she describes her many attempts to 'educate' and 'prepare' family members about how extended family could support her and her family to visit or be around one another. Several pervasive themes in Nila's story include 'hurt', 'disappointment,' 'sadness' and 'rejection.' These feelings were often related to a belief that family members did not take care or make an effort for their grandson or nephew.

> *"We're, we're at that point where we've tried explaining to you how you can best help us, and you can't help us by doing these small things. So, we just kind of have to like, take a step back and go to the houses that can help us" (Nila, line 84-93)*

> *"The emotional distress after coming from someone's house. We just, we don't bother anymore." (Nila, line 49)*

4.5.2 *Sub-theme*: Pressures around Food

The stories collected illustrate the importance of food and eating for this group of parents. What children eat and when they eat feature in all of the parent stories. The experiences most of the parents narrated were particularly stressful for each of them. Raina's story illustrates how food and Bengali mothering are intertwined:

> *"So, you know how Bangladeshi people are about feeding. It's like you know you must constantly be feeding your child; otherwise, you're not a good parent" (Raina, line 44-45)*

For Raina, relatives around her have commented on the food she provides for her autistic son. The advice is unsolicited and is experienced as criticism. Raina's story illustrates how the creation and consumption of traditional Bengali dishes are considered an important part of parenting. Bangladeshi parent stories about food demonstrate the tension between what parents consider appropriate for their child and the pressure felt and exerted by the influence of others.

> *"But surely, you should be trying this, and surely you should be trying that? Or giving him this or giving him that, it doesn't work that way, and they just don't understand that. And I find that very frustrating" (Raina, line 51-53)*

Food in Aliya's story was also a cause of stress. The timings and type of food that Aliya provides would often mean they stood out as a family.

"Whatever we did was worked around him… I would take my own food to other people's houses. There was a stage where he only ate beige food. He only ate beige food that didn't touch each other" (Aliya, line 553-557)

4.5.3 *Sub-theme:* Feelings of Isolation and Disconnection

The very first stanza in Aliya's story describes how Bengali culture is all about being social and family-orientated:

"So, I felt within our community. I felt very isolated because I felt like I had to. manage him, and therefore I wasn't present in whatever was really going on at that time" (Aliya, line 44-47)

The lack of support that Nila has experienced in some places has contributed to her withdrawing from these spaces:

"With some people would come along way. But with others were still. At the beginning it's still a constant battle with a lot of people, and it has made us isolated" (Nila, line 28-32)

4.6 Story Theme*:* Extended Family, Understandings and Responses

Each parent's story demonstrated how the wider family perceived and made sense of their child's autism. Aliya's story describes autism as an invisible disability; similarly, Mim recognises that her son is well-spoken, and his autism is not always visible unless she shares it. Nila's story illustrates how the lack of outward 'difference' means people often make hurtful comments that show a misunderstanding of the nature of his need.

"Oh, I forgot to tell you one thing that they keep saying to me, Bengali people. The women in general. If I take him anywhere, they say, but his face is normal. I find that so offensive because then I have to explain Down's syndrome and then autism" (Nila, line 611-620)

"Yeah, and, and then they'll say. But he's so handsome. Well, he's so this or so like that, but that has nothing to do with anything" (Nila, line 625-626)

4.6.1 Subtheme: Relationships and Wider Support

Nila, Raina, Mim and Aliya's stories highlighted the places where this group of parents did experience support. Feeling supported in spaces outside the home was important and was experienced as encouraging, reassuring and sympathetic. These pockets of support contrasted with the sense of isolation and disconnection described by parents in 4.5.3 (above).

> *“We decided not to tell the parents, but what we did do, we told a select few people who were invaluable for me in terms of support, and they almost they almost acted like respite for me” (Aliya, line 509-511)*

> *“And, and they've made adjustments, so I'm really, really happy with that and I feel comfortable in their homes visiting, I still don't find that comfort going anywhere else” (Nila, line 295-298)*

Nila often feels the need to educate and explain her understanding of autism. Nila’s story explains how she has had to make sense of autism and share that understanding with family members.

> *"I had to really drill it into my sisters and my brother, my parents, and I was just like, look, this is autism watch this documentary. Read this book. Get to know it because it's not going away. And, and they've made adjustments, so I'm really, really happy with that” (Nila, line 291-295)*

In Nila, Mim and Raina's stories, they each describe how their side of the family has made greater adjustments and displayed a higher level of acceptance when compared to their in-laws. Nila’s story is candid and describes the differences between the approaches she has employed with her own family.

> “And but it's also because I can scream at my family, but I can't scream at my in-laws" *(Nila, line 302)*

Nila and Aliya's story illustrates the closeness and understanding that comes from friends who have had similar experiences to their own. It was interesting to note that parents did not gravitate toward other parents that looked like them, rather ones that shared similar values as them:

> *“…… I feel like because they all have special needs children, were much closer than other family members because we all understand” (Nila, line 115-118)*

4.6.2 *Sub-theme:* Alternate Faith Based Understandings

Nila’s story focused on her extended family's meaning-making and described the varying responses these have elicited. After her son Musa's initial diagnosis, both sides of the family employed religious coping strategies.

> *“And then when we got the diagnosis, they're still telling me, both families. Oh, you know that's fine. Just, just pray. Just pray, maybe go hajj. Maybe go umrah, he'll be fine. You know they're kind of seeing it as an illness" (Nila, line 233-235)*

Nila’s story shows how various family members attempt to share their spiritual meaning-making with her.

> *“And that's another thing, and I, oh oh my gosh. And then they also say that I need Ruqyah (Qur'anic verses are said over a person for protection and healing) done on my son” (Nila, line 630-631)*

> *“They'll come up and say the most craziest things like we think you should change your son's name” (Nila, line 67-68)*

Nila’s faith forms part of her own meaning-making and forms part of her story:

> *"Allah (God) has given me this; it's for my benefit. I see it as a blessing like my son is the biggest blessing in my life; he brings so much joy to my house. When he's smiling. I swear to God everyone stops, and we just smile with him like that's how special he is" (Nila, line 653-656)*

For Nila, the alternate religious meaning-making made by others represents a challenge to her own meaning-making *“....and I'm just like what is this mumbo jumbo, you know?” (Nila, line 78)*

4.6.3 *Sub-theme:* Autism as Something that can be 'Fixed’

Several stories were characterised by family members' desire to find ways to 'fix' or cure autism. Each story illustrates how once the parent shares the diagnosis with the family, they respond by asking if there is something, that can be 'given' to the child to help. For Nila, the helping was through religious coping.

> *"My mother-in-law is desperately looking for a cure. She's looking for CBD, oils, and so and so said this Indian spice. This Chinese thing and it's just. They, just think it's curable" (Nila, line 539-542)*

Mim’s story illustrates the initial medical model of understanding.

> *“…. telling my parents, my you know my parents. Very, you know, the older generation where you know, these things, you know they don't know about, so explaining it to my parents was one of the hardest things, probably for me to do. Was hard in the sense that I was trying to find the right words …. I just said, you know, he is ... there's a word for it. It is called autism. It's a diagnosis like that. And then you know she was very curious. Like you know what does it mean? What's wrong? Is there, no? Can they give you something for it and all of that sort of thing" (Mim, line 521-530)*

Tahira’s story highlights how her parents see her son as a *“sensitive boy” (Tahira, line 301*), one that she needs to *“stop babying” (Tahira, line 202)*, and his difficulties can be resolved or 'fixed' by adopting a different parenting style. It is interesting to note that Tahira was the only lone parent in the participant group.

> *“And they think I need to give him a good talking time needed to solve, straighten him up and you know be a bit tougher with him and things like that. But I'm the same with*

both of my children, but he's just very, very. A lot more hard work" (Tahira, line 408-413)

4.6.4 *Sub-theme:* Bad Parenting and Blame

Nila, Tahira, Raina and Aliya's stories describe how they felt under scrutiny and were somehow made to feel like they were responsible for their child's diagnosis:

"And I feel like my parenting skills have always been questioned when it comes to him" (Nila, line 702)

"Uh, I guess embarrassed sometimes, and like judged because they weren't aware of, well to a certain point, we weren't aware that there was anything different going on, so yeah, probably judged" (Aliya, line 57-59)

Raina's story contrasts her understanding of her child's needs with the alternative made by others. When other people impose their sense-making on to parents, it is experienced as pressure and assigning blame.

"Like I say, they think a lot of it is down to parenting. And not like that he has behavioural challenges within himself, like the fact that he doesn't comprehend the world the way they would, or other children would "(Raina, line 85- 89)

4.7 Narrative Theme: Lack of Understanding from the Older Generation

A very prominent theme in all the parent stories was a lack of understanding from the older generation. Nila, Tahira and Mim's stories put the lack of understanding down to these family members not growing up in a time or place where a hidden disability is talked about or known.

"......yeah, you know what it is. It is also the language difference. Because when you have to say in Bengali, it's really hard, like autism, autism means nothing to them, and you say autism. They think it's some mental health, something you know they just don't get it. And I feel like we need to really, really let them know" (Nila, line 514-518)

Similarly, Tahira's story highlights how challenging it can be to explain a hidden disability; her efforts have often led to misunderstandings and confusion.

"I don't think they accept it as a sort of. Not an illness, but like a condition" (Tahira, line 428)

"I just think it's lack of education. I don't think they mean it in any kind of malice or anything like that. I think they just don't understand" (Tahira, line 405-406)

In Naila's story, her extended family make sense of her son’s autism in a way that is different to her own understanding:

“I feel like Bengali's have they always think that is Jinn related.... curable and Jinn related” (Nila, line 663-666)

“I just feel like they're not educated enough. They don't know, um. And they just kind of, they almost don't really want to know if it doesn't affect them within their household. They kind of don't want to know what happens” Nila, line 127-132)

Despite feeling that their respective families do not share their understanding of autism, Nila, Tahira and Mim’s stories all illustrate an awareness that attempts made by family members to make meaning is complex and can draw out a mixture of emotions in the parent.

“They are lovely people, but they just can't. Understand this (autism)” (Nila, line 581-54)

"It's not because they're bad people; they, they really, honestly feel like they're trying to help. And but I just feel like you'd help me if you would just educate yourself and read a book. You know, read the forwards I keep giving you, and then that would help me more than anything" (Nila, line 678-684)

In wanting to be understood, Tahira’s story explained why these important people in her and her children’s life found it hard to understand:

"They, they kind of grew up in a different generation, and they don't understand this autism thing at all" (Tahira, line 200-202)

4.7.1 *Sub-theme:* Sharing the Diagnosis

What distinguishes several of the stories is that some parents tried to share the diagnosis and were met with misunderstandings (Raina and Naila’s stories) and other parents were more tentative about their sharing. Aliya, Nila and Tahira's stories illustrate how they anticipated the responses they would get from family members and therefore took a different approach, choosing to wait and share later.

In Mim's story, she took some time to make sense of the diagnosis herself before feeling ready to share the diagnosis with others:

“Even though I'm, you know, educated and you know born and brought up here. I think you can't help but you know, worry about the stigma, and you know the social aspect" (Mim, line 129-131)

“It took me that long; I think to sort of. Be OK to tell someone else about it, apart from the professionals we were working with us” (Mim, line 571-572)

> *"Initially, I was very sort of, you know, I kept it to myself really. You know, as a family, we just kept it to ourselves. I didn't really want to discuss it with anybody. I didn't want anyone, you know, people to sort of, you know, look at him differently." (Mim, line 237-242)*

4.7.2 *Sub-theme:* Not having the Language to Explain in a Meaningful Way

Tahira, Mim and Nila's stories describe how they felt the need for their families to understand their child's diagnosis, but each commented on how they struggled to communicate about it with family members:

> *"It's not something they fully understand, and I don't have the language myself to explain it to them 'cause they speak Bengali. So, I don't have …... language to kind of explain it to them because my Bengali is very broken" (Tahira, line 320-326)*

> *"Well, to be honest, my husband's Bengali is much better than mine….he deals with it really, really well now because he's just like kind of say look, this is him, you know, children are born this way" (Nila, line 559-567)*

Mim's story shared some of the negative connotations that can come about in trying to explain using words that are found in the Bengali language. For example, phagol (madness or mental health difficulties)

> *"So, we know someone might say… he's delayed. Or is you know at you use Bangladeshi words like phagol you know all of that stuff. Uhm, you know and, and, and I mean those are absolutely horrendous words…..but again, it's just because people would not know any better.. So, you can't, sort of bash them down for thinking like that" (Mim, line 797-804)*

4.7.3 *Sub-theme:* How the Lack of Understanding Impacts Parents

Nila, Raina and Tahira's stories illustrated how the lack of awareness about autism had impacted them, leaving them feeling misunderstood.

> *"There's been a lot of competitive comparisons. So and so can speak now, so and so's out of nappies, and they have autism. They, they don't realise that every different case is unique to that child" (Nila, line 64-66)*

> *"…....for example, if, if someone talks to him and he doesn't respond 'cause he doesn't like talking to strangers they don't get that they think is being rude. But you're constantly having to explain yourselves, and that's very difficult" (Raina, line 72-76)*

Tahira's story highlights how the lack of awareness has a detrimental impact on how people behave around her son:

"He'd have his, little behaviours and things like that, and they would just sort of kind of make fun of it a little bit. Uh, making him even more sort of angry and upset, and they, they couldn't see that that was actually upsetting him. (They thought) It's just a little bit of fun because he's a bit weird. There's things like that. And so, I, I think I struggle in that sense quite a bit" (Tahira, line 167-178)

4.7.4 *Sub-theme:* Sensory Difficulties are Hard to Explain and Understand

Tahira's story relates how her parents misunderstand her son's sensory sensitivities; their disapproval is a recurring theme in her story.

"Even…haircuts and things like that. It takes a lot for me to get him to have a haircut. He just doesn't like the feeling of the blade…... So, often his hair is very long, looking unkempt… my parents really hate that. They really don't like it when boys have wild or unkempt hair and things like that" (Tahira, line 365-368)

In Tahira's story, her son's sensory needs manifest in ways that trouble her parents. Her son's choice in clothing makes him stand out to her parents; for example, he insists on wearing a polo neck whatever the weather or a coat and rucksack indoors because he finds the sensory feedback comforting. Not understanding means that her parents can "nit-pick", poke fun of him to lighten the mood and cannot see how their responses *"wind him up" (Tahira, line 347).*

"It's just everything. The way he eats the kind of food he eats so he doesn't eat em. food of a certain texture. He doesn't like, he doesn't like the consistency of things, and it's not because. He doesn't like that the taste is just. The texture of it he doesn't like." (Tahira, line 365-385)

Tahira's story acknowledges that while her awareness of autism has grown, her numerous and varied attempts to explain it have not always led to the kind of understanding she would have hoped for. So, there is an underlying sense of disappointment and needs remaining unmet.

"But the main thing. Is for me, is my parents to understand him. I understand him now. I didn't at first, but I do. Uhm, but I would like my parents to understand, that generation to understand. I think there's a big sort of gap" (Tahira, line 419-428)

"I have tried to explain to them, you know, he is like this not by choice; he's just finding everything a bit overwhelming. He likes the security of his own little areas …comfort zones, and things like that; when he's out of that, it stresses him out. And, um, so I, I think they're coming round to it, but it's not. It's not something they fully understand" (Tahira, line 308-321)

4.8 Story Theme: Connections that Support Cultural Identity

The community was initially represented and experienced in every parent's story through the extended family. Mim's story was the only one that reflected on values that were important for her and how she was going about sharing them with him in ways that her son understood.

> *"There are certain things, cultural things that are really important to me…. Part of our heritage, and I would want that to be carried on" (Mim, line 551-552)*

The cultural aspects of identity outlined here represent a way to anchor the parent and child to the community. Parents from this community would have to navigate these same cultural identity markers with their neurotypical children. However, Mim's story highlights the added dimension that autism brings to parents navigating the intersectional identity of being a Bangladeshi parent of a child with autism.

There was an understanding that the Bengali researcher would relate to the significance of some of the situations that Mim narrates; she uses phrases such as "our heritage" or "you know". This is reflected on further in the researcher's reflective diary (Appendix 26).

4.8.1 *Sub-theme*: Connections through Food

Mim's story reflected on a recent experience at her mother's home. Bangladeshi families will often eat rice and curry with their right hand at home. However, for a variety of reasons related / unrelated to a child with needs, this is not something that members of the younger generation born and brought up in this country have adhered to. So, when Mim's mother expresses her surprise to Mim on seeing her grandson not only eat fish (a very traditional part of the Bengali diet) but confidently doing this using his hand, it is a noteworthy event for Mim.

> *"….we were at my parents' house, and he ate you know, ate fish with his hand, and my mom was so proud. She was like, wow, he's eating so well, and you know, and she was like you know…praising him" (Mim, line 553-556)*

4.8.2 *Sub-theme*: Language and Identity

Mim's story describes living in a part of London with a predominantly Bangladeshi community. This story is unique in relation to the ones shared by other parents; it consists of accounts where Mim explores her desire for her son to know his cultural identity and faith.

> *“...so that he identifies, who he identifies with, a Bangladeshi boy.....man growing up, he should know where we come from, the heritage that we have, the language that we speak, and it's quite important for me” (Mim, line 620-622).*

Mim's story describes an event where a professional asked her to choose which language, she would like her son Riz to speak. It is noteworthy that Mim's family are bilingual. At the time, Riz displayed some language delay and professionals had become involved. The story illustrates how Mim was asked to make an important decision during a stressful time without having all the information she now has at her disposal. In addition, this theme indicates some regret that Riz has not benefited from access to his heritage language.

> *"I thought that I was like, oh no, you know he'll get confused. He won't know how to speak, and I sort of spoke just with him in English. But I wish I had been, you know, been better informed…having that information would have been so much more helpful” (Mim, line 633-636)*

Mim’s story puts forward the idea that Riz is *“capable of understanding” (Mim, line 642)* his place in the community as a British Bangladeshi man, and the responsibility of facilitating this to happen is something she takes on herself.

4.8.3 *Sub-theme*: Connections through Religious Faith

Mim's story describes how her child has exerted his "own free will" (Mim, line 687) and kept the thirty fasts during Ramadan, which practising Muslims are obligated to keep. Mim is encouraged by her son's emotional strength and understanding of their faith, which brings with it pride in her son and togetherness for her family. It is noted that Mim wears a hijab (head covering that some Muslim women wear) and describes her faith as being of paramount importance in her and her family's lives.

> *“He actually said he wanted to do it, and I was so shocked and surprised. That was one of the biggest joyous moments for me…… it also helped me,……you know, put things. things into perspective … Things are getting much better is if he's able to do this….he is strong psychologically and physically… I was blown away really by his, you know, his integrity” (Mim, line 687-698*)

4.9 Narrative Theme: *“*Then and Now”

In relating their stories, each parent considered it important to relate how they got to their current situation. Looking back at the past helped them to tell their story.

4.9.1 *Sub-theme:* Nila then, and Nila now

Nila's story used the language of change and growth. In looking back on her experiences, she reflected on the changes she has noticed in herself:

> *"I felt like the me that I was three years ago is completely different to me now. I, I put up with a lot of rubbish that was said to me, whereas now I'm just like no. You know, if my son doesn't talk, I don't care; that's how he is. He can communicate in other ways" (Nila, line 272- 279)*

An empowering episode that that stood out in Nila's story was when she challenged a stranger who had been staring at her and her husband as they struggled to return their son to the car safely.

> "*.....this lady was literally walking past, and she was just giving me really dirty looks. I was as a lot more stronger than before. Uh, and I literally, I said I'm gonna deal with this lady, and then I ran up to her, and I said excuse me, I see that you're staring, but my son actually has autism, and he has sensory processing needs, and he's finding it difficult to transition back to the car. And he cries because he's nonverbal, and she, her face kind of dropped. And then she kind of walked away"* (Nila, 461-474)

Nila's story relates how the incident resulted in an apology and a shift in how she began to see herself and was viewed by her husband:

> *"....my husband looked at me 'cause he, he just knows me as this little lady that never says a thing. He said oh, you just yelled at her and she apologised to you, and I was like, yeah" (Nila, line 487-489)*

4.9.2 *Sub-theme:* Mim's 'Wow Moment

A significant moment in Mim's story was when she went to a workshop at her son's school. Towards the end of the session, the speaker shared that he himself was autistic. Mim's story illustrates how once some of her worries had been addressed; she recognised that she had been *"carrying the burden of autism*" *(Mim, line 185)* without realising it. The experience Mim describes lifted the weight of her worries and provided an impetus for change and growth.

> *"I don't know what happened, but I just sort of got this relief from, you know, and this connection…... Honestly, I was just like, wow. He has autism, and he's here…He's married. He has children, his living. He's working…. It was like one of those light bulb moments for me, OK, life can be OK for people who have autism, and they can survive, and they can do this" (Mim, line 168-173)*

> *"I'm going to go out there and educate myself. And really, you know. Live a better life now" (Mim, line 182-184)*

Mim’s story illustrates her growing confidence in advocating for her son, something she has not always felt comfortable doing. She actively seeks out places that will cater to her son; she recognises that autism is a hidden disability and sometimes you have to explain things to people.

> *“… now, I’m not over worried or have any kind of inhibitions..... Shall I go here? What would people ask me? Things like that, I am more forthcoming. I would rather first say that this is the situation. Can you cater for me?” (Mim, line 271-276)*

4.9.3 *Sub-theme:* Not Caring / Rejecting Traditional Roles

Each parent's story highlighted how caring about what others thought of them or their child came at a personal cost. Aliya's story illustrates how she came to the realisation that she could not care what others thought. She made a conscious decision not to put her then young son in situations that were causing him to feel distressed:

> *" I remember running around, and it was just the worst experience. It was that experience where I turned around and said I'm no longer being part of these things, and that was the last straw basically, and I think I realised, you know what. I can’t care if that person is going to be upset that I don't go to this or if my in-laws expect me to do something. You know certain duties and, and I can't. I can't care about that anymore….I have to realise that actually … he's playing up because those situations environments, he is so hyper, he's hypersensitive to the sounds and the energies, and it's actually stressful for him. And, and it's not. It's not worth it” (Aliya, line 91-100)*

Similarly, Nila’s story highlights how in choosing to prioritise her son in extended family situations, she has challenged traditional cultural expectations around appropriate behaviour for a daughter-in-law.

> *"And I got. I think I got told off by maybe like four different women that day. Saying you've come to someone's house, and you haven't eaten their dinner. That's rude. And then I got painted as the bad guy…but it didn't faze me in that sense because I was already so used to that, you need to understand my son is my priority" (Nila, line 754-762)*

4.9.4 *Sub-theme:* Advocating for your Child with Professionals

Aliya's story highlighted how she would need to present herself to professionals in order for her voice to be heard:

> *“... I found that I unless you present yourself as being like uber knowledgeable. It's really hard to assert yourself. So, I have to go into the room and know autism, know isms, Like, I need to talk the jargon to feel like I have to be taken seriously” (Aliya, line 1006-119)*

Aliya's story acknowledges that some parents will find it challenging to advocate for their children and will not be as confident in approaching schools as she has been. There have been times she has not felt listened to in the past.

> *"Sometimes where it's people who don't speak English very well or their new immigrants here, sometimes it's easy for them to be fobbed off to a certain extent... even I have felt that" (Aliya, line 983-990)*

4.10 Narrative Theme: The Future

Tahira, Mim, Raina and Aliya's stories made connections with their present experiences and looked to the future for their child and the wider Bengali community.

> *"I think as a Bangladeshi parent with a child with autism. Nothing about my journey is unique. I would say, there are, you know, hundreds and thousands of you know other Bangladeshi parents out there who, who have children with needs of different scales and levels out there. Uhm, I think my journey is one of many, but it's a journey that is not…not (one) every other parent out there has." (Mim, line 364-368)*

4.10.1 *Sub-theme:* Potential Barriers and Raising Awareness

Raina has clear ideas about the need for information and support; for her, it is not simply about accessing additional money and resources:

> *"And I think if more people had that or support groups, one, we would learn how to deal with the condition better with our children. And two, we could support one another. And three, we would know what to expect because. Every day is like a new day for us every day. But it seems with an autistic child there's a lot of uncertainty of the future and what to expect" (Raina, line 291-299)*

Mim, Aliya and Raina's stories recognised their own difficulties and considered how these might impact other parents in similar situations.

> *" Even people who, who sort of you know bought are raised and educated and born and bought up in this in this country in this day and age. Still, stigma is a big issue…. shaming is a big issue. You know, not wanting to go out in the world" (Mim, line 364-365)*

Raina is a benefits advisor and has noticed an increase in the number of Bangladeshi parents approaching her for support with disability applications.

> *" ….. the actual information out there and the help out there is very limited. So, you kinda have to go searching for it yourself" (Raina, line 278-280)*

Mim's story reflects on the impact on her and potentially on others that the information available to parents is from a non- Bengali perspective.

> *"The awareness, you know awareness, education around this, you know, is just non-existent at the moment. I would say there is hardly anything out there. Because everything that I read and everything is …it's mostly based around non-Bengali's. I was OK with that, but others might not" (Mim, line 379-383)*

Tahira's story illustrates the difficulty of having resources designed for an English-speaking audience. She considers this a barrier to understanding and accessing support for the older non-English-speaking generation. This generation plays an important role in her everyday life.

> *".... I wish they were sort of like come Bengali kind of literature. For, for this, like you know how we have loads of resources now. Um, you know, for us, you know English speaking people. There's a lot of resources. There's lots of like leaflets and some websites and things like that. I wish there was something in Bengali for grandparents, particularly that generation (Tahira, line 326-333)*

4.10.2 *Sub-theme:* Hopes and Worries about the Future

All of the parents' stories expressed concerns about the future for their autistic child. Most of the anxiety expressed was around independent living, navigating education, relationships and future employment.

> *"I think to myself, will he ever get married, will you ever have a family? Will he ever be able to live by himself? I don't know, and that's what scares me. I don't know what the future holds" (Raina, line 288-307)*

In Mim and Aliya's stories, anxiety about the long-term future was the impetus to make changes for their respective child. Mim's story describes how she is *"fighting with the school to get (her son) a laptop to use in his classroom because his typing is so much better than his writing" (MIm, line 480-481).* For Aliya, she has decided to *"arm him with the skills" (Aliya, line 1075)* to manage life and relationships.

Tahira's story contrasts her understanding of life in an extended family in Bangladesh for someone with additional needs with that of life here in the UK.

> *"But in, in Bangladesh, there's a lot more support. I think families kind of lean on each other a lot more, and if someone isn't able to like work or, you know, hold a job, there's always something for them to do. Here. I don't know. I feel like there's a lot of pressure on them to do really well at school in every single subject and then get a really good job and then have a family, and I just don't know if he's…ever gonna be in that place…where he can sort of be independent. I do worry about that" (Tahira, line 431-437)*

4.10.3 *Sub-theme:* The Future is Not Without Hope

Aliya’s story suggests that there is a shift in understanding within the Bengali community, especially in the younger generation.

> *"So, if you take it back to our culture, I think there is a change, in the sense that I think where, we've got like the second generation: Uhm, our age. People who are sort of you have been through the education system here who are aware, I think, things have changed…it's not a taboo to go and get interventions, go on and get help. I think. It is a lot better" (Aliya, line 970-981)*

Raina’s story also describes a generational change that makes her hopeful for her son:

> *"I don't know if he's ever going to be able to live a fully independent life, but I see other people have come to me, and their children have grown up with autism, and now their children are a lot more independent, and I hope that he's going to be like that" (Raina, line 300-302)*

Several parent stories base their hopefulness about the future on their child’s successful interactions in extended family settings. The ability to communicate with the wider family is key to these interactions.

> *“I'm very fortunate, you know, Riz is pretty, you know, well-spoken" (Mim, line 546-547)*

> *“Everybody knows it (diagnosis of autism).. no issues about it now. You know he's very popular in the family as well. (Mim, line 582-583)*

> *"......he has had exposure, to a lot of family growing up, I do feel like he's a lot better at masking, and that's what I've noticed, is with high functioning people, they mask so well. And I think he does that quite well, now" (Aliya, line 442-452)*

4.11 Conclusion of Chapter Four

This chapter outlined the narrative analysis approach employed. One of the five storied narratives was presented; the remaining four can be found in Appendix 20-24. In addition, a commentary was presented on the narrative themes and sub-themes found across the stories. In the next chapter, the findings will be discussed in more detail in relation to the theoretical underpinnings of the research and its relevance to the literature discussed in Chapter Two.

Chapter 5 Discussion

5.1 Introduction

The first section of this chapter will give an overview of the research findings and critically consider how they answer the research question. Links will be made to relevant literature and psychological theory. In the second part of the chapter, the researcher will critique the research, consider their role in the process, and conclude the study.

5.2 Central Research Questions and the Aims of the Current Study

This research aimed to gather an in-depth understanding of the experiences of Bangladeshi parents who have a child with a diagnosis of autism. By sharing participants' experiences, the researcher hoped to raise awareness about the varied and multiple ways; Bangladeshi parents experience parenting a child with a diagnosis of autism.

The current study aimed to answer the central research question:

'What are the experiences of being a Bangladeshi parent of a child with autism?'

The researcher viewed each participant's insights into their experience as unique and individual to them. In addition, common themes across the narratives were explored. These were aspects of the stories shared that held meaning and were seen as emotive for the participant, as outlined in Table 8 (Appendix 19). The identification of these shared storylines in the participant's stories suggests that some experiences are common across the stories shared.

To address the central research, the next section will consider the insights gained from the participant's stories in greater depth, with reference to previous literature and relevant psychological theory.

5.3 Current Findings and Relevance to Previous Literature

The sections below will discuss four overarching themes the researcher, after data analysis, considered to be the most pertinent aspects of the participant's narratives and, therefore, provide an answer to the research question, 'What are the experiences of being a Bangladeshi parent of a child with autism?'
The themes discussed will include the following:

- Parental Meaning Making
- Gendered Experiences
- Sharing the Diagnosis – Difficulties and Responses
- Growth and Change

5.4 Parental Meaning Making

The parental stories in this study described an individual, unique and non-linear journey in making sense of their child's diagnosis. Each of the parental narratives shared how they knew very little about autism before their child was diagnosed. If parents did have previous experience, it was not a presentation that looked like their child's. Ratto et al. (2016) found that culturally based differences were one of the factors likely to impact parents' early perception of autism. Parents like Nila straddled contradictory ideas from clinical professionals and her wider extended family. A common idea in South Asian families is that boys' language development is often delayed (Perepa, 2019). Nila, Mim and Raina were told by their extended families or had absorbed the idea that their child was shy or that their' language' would eventually come along, and they would 'catch up' with their peers. The delay in language development shown by some children in the parental stories was considered within the family norm and, as such, was not perceived by family members as a significant difficulty.

Extended family members saw the early intervention of professionals as problematising a situation that did not warrant the intrusion. This perspective did impact how reliable the autism diagnosis is considered by extended family members. Several parents described this early diagnosis period as a stressful time. Parents whose child displayed a language delay that was apparent to family members were navigating family understandings and managing the stressors associated with the diagnostic process.

5.4.1 The Diagnosis Process

In Doig (2012), the diagnosis was perceived by Bangladeshi parents as a medical examination, not requiring their input (Nair, 2015). Parents in this study experienced the diagnosis process in an ongoing way; three of the parents experienced a diagnosis period stretched out over several years. Attribution theory asks us to consider how we look for causal attributions to help us understand, control and eventually overcome a difficult or stress-inducing situation (Barrowclough & White, 1998). In this study, both Aliya and Mim’s stories illustrate how their engagement with professionals compelled them to consider causal relationships and the degree of controllability (Weiner, 2018) they had in accepting and making sense of their child’s diagnosis. For example, Aliya describes “not taking the diagnosis” initially but coming back several years later when she felt it would be a helpful label going forward. In Mim’s story, the ability to revisit her son’s initial borderline diagnosis with the same experienced professional some years later also impacted her rationale or causal attributions.

The theory could be applied in a similar way to Raina’s story. The family implemented an attribution that recognised that her son was displaying internal personal traits that were not improving over time (stability) and out of their sphere of controllability. As a result, it could be argued that the parent experienced a reduction in guilt and distress and an increase in sympathy and compassion towards their child (Weiner, 2018). This is similar to the findings in Doig (2012) and Habib et al. (2018), where parents favoured a medical diagnosis, the attribution is external, and there is limited controllability. Causal attributions are important as they can indicate how a parent is making sense in the present but can also be indicative of future actions.

5.4.2 Explanatory Models and Acceptance

The stories in this study illustrated that Bangladeshi parents employed diverse explanatory models. These were not contradictory; rather, they were multi-dimensional frameworks that incorporated their religious and cultural world views alongside medical and social models of disability. In Chapter 2, we saw how parents from minority ethnic groups would be at different acculturation stages, which may be a part of the explanatory model employed by parents (Perepa, 2014). In addition, we saw an attribution approach (Weiner, 2018) where persons are driven by a desire to consider and attribute causality to make sense of an event, especially if it is considered negative or unexpected. The stories shared in this study showed how parents were able to hold multiple levels of meaning-making and employ them in spaces that required the activation of one aspect of meaning-making to co-exist with another that may not initially appear to align. Raina's story illustrates her conceptualisation of her son's social disability and her religious acceptance that this was how things were meant to be for her. Rizvi (2021) had similar findings in her study with South Asian Muslim mothers, where "disabled families had simultaneously developed a meaningful framework to understand their child disability at the intersections of culture, gender immigrant history and religion" (Rizvi, 2021, p. 19).

5.4.3 Religious Explanations

Although faith-based explanations featured to some degree in all the stories shared, they were explored in more detail in Mim and Nila's stories. Mim described how it was an important part of her identity and helped her counteract negative thinking. Croot et al.'s (2008) findings were similar, all parents in that particular study held religious beliefs about their child's disability, but differences were apparent in the applications of their religious explanations. Beliefs borne out of religious meaning-making did not mean parents applied them uniformly; however, they are seen as a strong protective factor for families that have a child with autism (Habib et al., 2017; Warner, 1999). Faith and belief framed how parents made sense of their child's diagnosis in Jegatheesan et al. (2010a, 20110b) and Jegatheesan's (2011) longitudinal US study. Both in the literature and the present study, a religious perspective offers parents a coping mechanism to accept their child's diagnosis.

In Nila's story, we see two contrasting religious frames being applied to her son's diagnosis of autism. Her extended family appear to be applying a religious explanation that is divergent from her own, where her son's autism can be alleviated through prayer and religious pilgrimage. In the initial stages of her diagnosis, this is experienced as comfort and support by Nila. Later in Nila's story, we see her wider family trying to attribute autism to the presence of shaitan (the devil) and jinns (supernatural spirit, below the level of angels or devils). Nila strongly rejects this assertion and displays the ability to hold both religious views that her son is a "blessing" and that he was born with needs that have been 'diagnosed' and are therefore medically explained. Holding on to these contrasting models of meaning were experienced by this parent as stressful. Attributions assigned by parents or family can impact parents' mental states (Sabharwal, 2021).

5.4.4 Medical Explanations

Understanding autism as a medical diagnosis was favoured by all of the parents in the study; this is in keeping with research completed with other South Asian parents (Theara & Abbott, 2015; Habib et al., 2018; Doig, 2012). The implications of privileging the medical model are multiple and varied for the parents in this study. Medicalising autism meant that parents like Nila and Raina were able to challenge unwarranted attributions about their child as ‘naughty’ or ‘rude’, to a non-stigmatising physiological reason which increases the likelihood of acceptance for both the child and parent in the wider community (Theara & Abbott, 2015). The acceptance of the medical model had wider implications for all the parent stories in the study. Mim powerfully describes how autism is ‘real’, and the Bengali community need to accept its validity because it is here to stay.

5.4.5 Making Sense of Autism in a Context

Each narrative illustrated how parents’ conceptualisation of their child’s diagnosis had evolved over time. One aspect of accepting their child’s diagnosis included navigating feelings of shame and stigma associated with having a child with autism. Several parent narratives attributed these negative perceptions to their wider family and others to the wider Bengali community. This resonated with findings from Rizvi (2015), where parents did not perceive themselves to have these negative associations but showed an awareness that these were possible views held by members of the wider community. Mim’s narrative reflected on the possibility that when a parent resides and interacts with a community that may hold those views, they are not immune to letting those negative, culturally stereotypical ways of thinking about disability enter their thoughts. It is apparent from findings in this study that parents are navigating views on autism in a cultural and community context.

5.5 Gendered Experiences

Gendered experiences were discussed in all of the stories. Nila and Aliya both described the continuous and exhausting pressures of gendered caregiving. Both of these mothers describe physical and emotional exhaustion and lack of support from their partners, specifically in the early days of their child's diagnosis. Fathers in these stories came home to the domestic sphere; their sleep and employment are prioritised in these spaces. The caregiving offered by fathers in these stories is represented by external paid labour. Mim's story makes the distinction that the Bengali male experience of parenting a child with autism is a gendered rather than culturally bound one. Rizvi (2021) argues that there are very unique pressures on South Asian mothers navigating cultural contexts, gendered care and patriarchy.

Hutton and Carron (2005) found that some parents who received a diagnosis of autism for their child experienced feelings of grief and loss, whilst others met it with shock and surprise. Nila's story describes being so caught up in the daily pressures of parenting that she did not have the 'luxury' afforded to her husband. In contrast, Her husband was able to 'grieve' for the 'son' and 'fathering' experiences he had previously imagined. However, both of these stories counter these initial experiences of disappointment in their partners by describing how they now advocate for their respective children in ways that challenge community prejudice. Nila's story describes her husband's endless patience in continually explaining to family members that Musa's autism is something he was born with and how it is simply a part of him. Both Doig (2012) and (Jegatheesan et al., 2010a) found similar findings with fathers who saw the positive aspect of obtaining a diagnosis. They would often be the ones communicating this to wider family members. This study had similar findings, fathers sought to employ a medical model of understanding in order to protect themselves and the child from further scrutiny.

Several mothers in this study described how the greatest pressure put on them was from other Bengali women. This was not apparent in other studies and was unique to this research. Nila, Tahira and Raina's stories shared experiences of being chastised by women for not performing the expected mothering or daughter-in-law duties. Nila's story described that it was always 'Bengali women' who found a way to direct comments to her, whether through phone calls, direct in-person conversations or when they visited her. There is something unique about women having unfettered access to the physical spaces that the parents in this study occupy. In addition, there is an underlying assumption that there is validity in what they feel needs to be shared. Parents describe these experiences as frustrating and intrusive, but in the sharing of these experiences, there is a refusal to modify ways of being imposed on them. Conversely, the stories suggest that Bengali fathers are not singled out for similar attention by their extended family or wider community members. Space, opportunity, and gender appear to be important factors in these exchanges between women.

5.6 Sharing the Diagnosis – Difficulties and Responses

Parents in the study shared a variety of experiences in relation to when and how they shared their child's diagnosis. Several parents described initially feeling more comfortable talking with professionals involved in their child's care rather than family members. Parents related making pragmatic choices about whom they shared with initially and tentatively broadening out the group who were aware of the diagnosis. However, it is notable that the level of needs displayed by some children in this study meant that several parents were not afforded the choice as to whether they shared their child's diagnosis.

5.6.1 Not Wanting to Worry Family

Not wanting to share the diagnosis with the wider family was attributed by Theara and Abbott (2015) to parents not understanding the diagnosis. Struggling to find the appropriate language to communicate their child's needs with the wider family was a familiar experience for many parents in the present study. Parents' responses in several studies have highlighted that they did not fully comprehend their child's diagnosis and its wider implications (Doig, 2012; Theara & Abbott, 2015). The authors attribute the lack of understanding to not having an equivalent for the word 'autism' in home languages. Attempts to explain the diagnosis often left them with deficit model explanations, which held connotations of mental retardation or being 'less than' a person (Doig, 2012).

In this study, parents described a more nuanced experience. Several parents shared how they adapted the way in which they communicated or shared their understanding of their child's diagnosis. They would often adjust what they said based on their own ability and confidence to explain in Bengali. In addition, they would often preempt how the person receiving the information might respond and would modify their explanation so it would be received favourably. Acculturation differences meant that some parents, such as Mim, were able to use their home language to describe the behaviours that were apparent in their child and relate that presentation of these behaviours had a name 'autism'. Other parents recognised that attempts to explain using their home language were often dispersed with English and were unsatisfactorily received by those with whom they were communicating. Other parents sought out family members and partners that were more fluent than themselves to communicate their child's label.

Several parents chose not to share the diagnosis with the older generation because it would lead to confusion and undue worry. Aliya's story related that the use of the word 'diagnosis' would activate the medical model of understanding, leading to connotations of a 'cure', 'remedy' or a 'fix' drawn from the medical world. This was similar to the findings in Jegatheesan et al. (2010a). However, grandparents in several stories told about their grandchild's diagnosis expressed curiosity about the implications of a diagnosis, and another was perplexed as there was no obvious physical disability. Variability in how autism presents has contributed to several grandparents feeling distrustful of the diagnosis (Theara & Abbott, 2015). Nila and Raina's story illustrates how inconsistencies in how children with autism develop are often used to make competitive critical comparisons about speech production and developmental markers such as toileting.

5.6.2 A Hidden Disability Can Lead to Misunderstandings and Rejection

The 'newness' of autism as a construct creates some doubt and conflict for families. Several parents related how the mistrust of the label created the space for family members to assign alternate meaning-making. This often resulted in parents experiencing unhelpful scrutiny and being made to feel like they were 'bad parents'. Tahira's story explicitly detailed her difficulty in explaining her son's autism in a way that made sense to her parents. Her son's sensory sensitivities are acutely experienced but remain only partially understood by her parents. Subharal's (2021) study looks at the intergenerational understanding and support for South Asian mothers of a child with autism. The study found that when grandparents made negative culturally based attributions, mothers often experienced emotional distress.

The parents in the study attributed the older generation's inability to understand their child's hidden disability to a lack of 'education'. The word 'education' was used by several parents but held a variety of meanings. Overall, it represented the older generations' inability to move beyond traditional cultural meanings in relation to autism. If grandparents are distrustful of autism as a diagnosis, it follows that they will make alternative attributions, and these will be shared with their children, the parents in this study. Often when grandparents did share their alternative attributions, this was a source of emotional distress for parents in this study.

5.6.3 Being able to Overcome Autism

In Tahira's story, her parents do not ascribe to the label of autism. As a child of immigrants, she has grown up hearing about various family members who are accepted as 'different'; however, the various roles within families in Bangladesh mean that there is scope to adapt and enable participation and inclusion. Tahira contrasts this to the representation of the immigrant family favoured by her parents here in the UK, which follows a different trajectory. Tahira is a child of immigrant parents, and there is an expectation that she and, in turn, her children will follow a pre-set and determined pattern. This includes doing well academically, acquiring employment, and leading as 'normal a life' as possible.

Tahira's story explores this contrast, suggesting that there is an expectation and pressure on her and her child to avail themselves of the educational opportunities afforded here in the UK, thereby increasing the possibility of mitigating autism. Jegatheesan et al. (2010b) had similar findings about educational aspirations with a group of first-generation Muslim parents in the US.

5.6.4 Autism has Always Been Here

Nila, Raina and Aliya's stories challenge the attribution made by some members of their parent's generation that autism does not exist in Bangladesh and is considered a Western innovation. Therefore, the label has little or no relevance to their particular familial context. Findings in this study show how this is further exacerbated when a child does not display outward signs of 'difference'.

This represents a cultural barrier in sense-making employed by some grandparents in this study and impacts on their understanding and acceptance of autism. Through interactions with professionals, the formal diagnosis process, and their own reading, parents in this study have come to acquire an awareness about autism that is not always accepted by their parents. The parents in the study described how, in the past, certain needs or differences had been mistakenly ascribed by the older generation to mental health difficulties or as learning disabilities rather than autism. Parents in this study acknowledged that these labels are probably used by the older generation because there is no equivalent for the word autism in Bengali. As immigrants, their parents' generations would have made connections with ideas around mental health and cognitive impairment that are already established in the Bengali language. It can be argued that these contrasting ways of understanding autism represent an intergenerational acculturative tension. However, the stories shared by parents in this study offer a counter-narrative that is borne from these parents' growing confidence as cultural navigators between the intersectional experience of being second-generation Bangladeshi and parenting a child with autism.

5.6.5 Seeking out Places Where You Can ‘Be’

Several parent stories shared experiences of isolation and disconnection from families in local communities, especially in the early diagnosis phase of their child's development. These were similar to findings in Theara and Abbott's (2015) study. Parents in Rizvi's (2015) study were less attached to their local community as a result of their own experiences of exclusion. The majority of parental stories in this study highlighted a shift in who they perceived as supportive of their needs. Parents in this study have acquired an understanding of safe spaces for themselves and their autistic children. This is similar to the findings in Habib et al. (2018).

Nila, Raina and Mim's stories indicate a slightly more accepting and inclusive attitude from their own families as opposed to their husbands' families. Nila's story suggests that she is more comfortable vocalising her emotional and practical needs to her own family. She goes on to relate how these needs have been met more often than not in her own familial spaces. Like all of the other parents in this study, Nila occupies multiple intersecting identities that require her to navigate various cultural expectations around motherhood, being a daughter-in-law and a daughter, amongst many others. It can be argued that these parents were afforded more sympathy and acceptance from their own families as a result of their perceived vulnerability and experiences of exclusion (Rizvi, 2021) from the wider family and community. This represents a shift away from the expectation of wider community support to more familial bounded support. Where parents can expect and receive support while they parent a child with autism.

5.7 Growth and Change – Advocating for their Child

Rizvi (2015) described how British Pakistani mothers of disabled children had "forged new cultural identities that helped them better navigate their child's disability" (Rizvi, 2015, p. 145). Similarly, all the parental stories in this study highlighted how parenting a child with autism had necessitated both internal and external changes. Several parental stories described moments that they associate with conscious decision-making and enacting change. These were often related to attending family gatherings which were causing their child to experience feelings of distress. By choosing not to put themselves in these situations, parents exercised agency, often rejecting family expectations around the roles that daughters-in-law are expected to play. For some families, prioritising their child over extended family expectations has contributed to experiences of isolation. However, all parents expressed some satisfaction in doing what they considered to be in their autistic child's interest. Habib et al's (2018) study similarly found that prioritising their child's needs played a part in parental wellbeing.

Some stories related significant moments that contributed to personal change. Nila's story highlighted her growing confidence in challenging the critical gaze of others in outdoor spaces. Whilst Mim's story illustrated the impact of attending a workshop where the trainer themselves was autistic. One story illustrates a growing confidence to challenge prejudice; the latter is the impetus to advocate on behalf of her son.

Rizvi (2021) discussed the navigation of wider family and "institutional spaces" (Rizvi, 2021, p. 148). Parental stories shared in this study indicate that parents actively seek to empower their autistic child, develop independence and self-help skills to navigate public spaces. In contrast to Rizvi's (2015) study, parental stories in this study indicated that these skills should develop in tandem with community networks rather than by replacing them. Continuing these wider connections with the community was important for Aliya and Mim. The promotion of home language, faith, food and living in proximity to extended family members as ways of maintaining those links was especially important in Mim's story. These two stories also highlight how their respective sons successfully navigated supportive extended family spaces. This appeared to imbue parents with some hopefulness about their child navigating external spaces such as future employment.

All of the parental stories describe navigating their child's schooling. Reay (2004) outlines a parent's cultural capital as the strategies of support, knowledge, and resources parents can call upon to impact a child's educational opportunities. Aliya and Mim's stories described situations where they needed to advocate for their child to ensure the school environment met their child's needs. Aliya's story relates how she feels the need to be knowledgeable about autism and know it inside and out to ensure her concerns are not dismissed, so she can feel confident about being taken seriously during school meetings.

She describes the potential challenges for someone doing something similar if English is not their first language or they are not comfortable navigating complex systems. This suggests that systems are complicated and are perceived as barriers. In addition, Aliya's story illustrates how as a minority ethnic parent, she needs to be equipped high level of knowledge and expertise to ensure her voice is heard. The implication is that without these resources (her cultural capital), Aliya's concerns would not be listened to in a similar way.

The feature most apparent across Mim, Nila and Aliya's stories of navigating schooling is their confidence. But there is also a sense of entitlement that comes from knowing their child's needs and feeling "empowered to intervene" (Reay, 2004, p.78). Raina's story highlights how supportive inclusive spaces can mean parents are not required to have or draw upon the skills attributed to cultural capital. In describing her experience of her child's school, we see how schools can mobilise to support parents through inclusive practices rather than perpetuate educational inequalities (Reay, 2004).

5.8 Summary of the findings

‘What are the experiences of being a Bangladeshi parent of a child with a diagnosis of autism?’

The aim of this study was to explore the experiences of Bangladeshi parents who have a child with a diagnosis of autism. These stories do that for the participant group. The stories consisted of connected events that illustrate parents becoming aware and learning more about their child's autism, and how this has impacted how they navigate family life. In addition, each story spoke about aspirations for their child and hoped for a better understanding of autism in the Bengali community more generally.

The stories and subsequent themes of this research highlighted the following findings:

The stories illustrate how parents employed multiple explanatory models, such as religious meanings, medical and social models of disability, without experiencing them as binary, contradictory or conflicting. Instead, parents employed the model that suited their understanding at that time and the context in which it was being employed.

The stories in this study highlighted the challenge of not only making sense of their child's diagnosis for themselves but also managing and mediating the sense-making of family members and the wider family groups. The meaning-making adopted by parents was often experienced as different and contradictory to those held by the wider family, contributing to a sense of isolation and pressure on them and their families.

Not having the word for autism in Bengali meant that parents found it challenging to share their understanding with the wider family. Parents were conscious that utilising the medical model to explain often created the impression that there was a discernible 'cure' for autism, rather than the adaptions each parent was employing to negotiate everyday life. This meant that parents explained autism to family members in ways that were meaningful to the recipient of the information, rather than the parent's understanding of the diagnosis. Medicalising autism enabled parents to challenge stigma and increased the likelihood of acceptance for both child and parent in the Bengali community.

The lack of intergenerational understanding was identified by parents as a key barrier. Parental stories highlighted how negative experiences with extended family members, and the Bengali community more generally were attributed to a lack of 'education'. Parents understood that the older generation, represented by grandparents, found autism as a hidden disability difficult to accept. This created feelings of distrust in the diagnosis and strengthened alternate explanations that grandparents employed.

Parental stories displayed not only a sense of the issue as they perceived it but also an insight into approaches that should be adopted to counter these difficulties. This suggests that parents are looking beyond their own situations and wanting to enact change that will impact their current context in the present and wider community needs now and in the future.

Parents showed an understanding that their child's diagnosis would necessitate that they advocate on their behalf in the domestic sphere as well as the wider family and school context; this often meant challenging traditional gendered and cultural expectations. This did contribute to a sense of isolation for some parents. Parents' sense of well-being and overall satisfaction was enhanced by adjusting and adapting family life to what their child appeared to need and benefit from. Parents who managed to navigate these situations in the domestic sphere were more comfortable advocating for their child in both school and wider environment.

Educational opportunities are considered important and are often seen as a way to increase the possibility of mitigating the impact of autism. This can be experienced as an additional pressure for parents navigating educational experiences for their child.

Parents initially shared their child's diagnosis and related needs in safe extended family spaces. The experiences of successes in these spaces encouraged parents to feel more confident about sharing in wider spaces. This also contributed to feelings of hopefulness that their child could navigate the external world, relationships and employment in the future.

5.9 Trustworthiness of the current study

Braun and Clarke (2013) describe how 'trustworthiness' rather than 'validity' is increasingly referred to when judging the quality of data collection and analysis of qualitative studies. Trustworthiness can be explored using the following four areas: credibility, transferability, dependability, and confirmability.

Credibility refers to the degree of confidence one has in the 'truth' of the findings, with special consideration of the process of data collection and research design (Cresswell, 2007). Polkingthorne (2007) argues that narrative researchers need to endeavour to present an accurate account of the research process. This researcher acknowledges their own biases and assumptions that have the potential to shape the data by utilising and reflecting in a research journal. In addition, member checking was employed to ensure both accuracy and credibility. Finally, the researcher's academic supervisor peer-reviewed interim narratives and narrative themes across the stories.

To address the issue of dependability in the current research, the researcher provided methodological descriptions relating to the research design and method, details about how the data was gathered and analysed and the reflective appraisal undertaken. Appendix 14-19 outlines details on the process of analysis of raw data, to the interim narrative, restorying and narrative themes across all five stories. Furthermore, Appendix 5 provides details of key points in data collection and when they were carried out.

In terms of transferability, NI seeks to "issue claims about the meaning of life events hold for people. It makes claims about how people understand situations, others, and themselves." (Polkingthorne, 2007, p.476). Although the aim of the current study is not to generalise findings, it is the hope that providing thick descriptions about participants" experiences and "sufficient detail of the context of the fieldwork" (Shenton, 2004, p. 63) will enable a reader to decide whether the context is sufficiently similar to their own context or situation and determine if they consider the findings to be transferable and to what degree.

Confirmability relates to the measures undertaken to reduce researcher bias. Miles and Huberman (1994) consider the key criteria of confirmability to be reliant on the degree to which the researcher is transparent about the values and beliefs they bring to the research process. To these ends, I engaged with reflective practices to ensure that my personal values were always apparent. The potential impact of the researcher's beliefs was reflected on, the thinking behind the decisions made, and the methods employed were made clear throughout the research process.

5.10 Reflexivity – In Practice

Reflexivity requires the researcher to critically reflect on the research process, ensuring that consideration is given to how the researcher “positions themselves” within it (Cresswell & Poth, 2013). Reflexivity was outlined in Chapter Three and was regularly evaluated throughout the research process. As outlined in the section above, it is an important element of a study’s credibility and confirmability (Cresswell & Miller, 2000)

At every step of this study, I have been the primary research “instrument”, which makes reflexivity all the more crucial. I sought to maintain a reflexive approach (Watt, 2007). I have been open and honest about all matters relating to my values and my cultural, religious and professional background. In addition, I have been open about ontological and epistemological viewpoints and have recorded and shared reflections on the research process throughout.

My reflexive attitude was maintained throughout the study in the following ways:

- A reflective diary. This diary supported the researcher’s thinking at every stage of the research process, especially during the analysis and 'restorying' of participants' experiences. Excerpts from the reflective diary can be found in Appendix 25-28.
- Using an unstructured interview approach encouraged participants to share the storylines they wished to share.
- The use of the participant's language ensured that their story was told as accurately as possible.

- 'Member checking' during the reauthoring phase confirmed that participants were happy with the storied narrative and for it to continue to be part of the research.
- Ongoing discussions with their academic and professional tutor at the University of East London.
- Ongoing discussions with colleagues who were employing a similar approach in their research.

5. 11 Critical Evaluation of the current study

5.11.1 Strengths

This research aimed to explore the experiences of Bangladeshi parents whose child has a diagnosis of autism. This was identified as a gap in the existing literature and led to the researcher using a narrative approach to gather detailed descriptions that offer a distinct contribution to the research base. This researcher does not consider this current study to be representative of the experiences of all Bangladeshi parents with a child with autism; rather, it illustrates the various intersecting ways that Bangladeshi parents navigate and make meaning of their parenting experiences of a child with autism. As outlined in Chapter 1, this is a culturally informed piece of research, whereby the insider perspective has the potential to "facilitate the cultural knowledge of both the researched and the researcher" (Tillman, 2002, p. 4). In addition to utilising culturally sensitive research approaches, it also amplifies the voices that are often not heard in the literature, which is a starting point for empowerment, agency and broader social justice.

5.11.2 Intersectional Aspects of the Research

As outlined in section 3.2.1, the researcher acknowledges that production of knowledge is shaped by the ontological and epistemological position of the researcher. The research sought to examine the intersectional experience of being a Bangladeshi and a parent of a child with autism. The framing of the research may have privileged the Bangladeshi aspect of the parental experiences, over those related to parenting a child with autism. It could be argued that this approach limited or ‘sectioned off’ aspects of parental experience and these dimensions were not given equal weighting in the present study. However, it is important to keep in mind that the research question in this study was both broad and open. This was in accordance with the social constructivist epistemology outlined in section 3.2.2. Employing this approach ensured parents could relate their subjective experiences and prioritise the dimension of their experience that was pertinent to them. The reader may wish to bear these arguments in mind when considering the findings presented here.

5.11.3 The Use of a Narrative Approach

A narrative approach was chosen because it could provide a detailed and rich understanding of the experiences of Bangladeshi parents who have a child with autism.

However, the storied narratives that feature as part of this approach are co-constructed collaborations between the researcher and participant. Being mindful of the impact of personal narratives on the research process is a key feature of narrative inquiry and was managed by the critical self-awareness of reflexive practice.

5.11.4 Sample of Parents

The parents who participated in this research were recruited online and through a LA. This meant that the context varied, as did the specific services and professionals they accessed relating to their child's diagnosis and educational experiences. That more parents from online rather than the LA context took part could be argued as a limitation, as the voices of online parents are more present in the research, and the findings are therefore more representative of those parental experiences. The original recruitment plans would have reduced this imbalance and might usefully be replicated in further studies.

5.11.5 Interviews

All participants accessed online interviews and were sent a Life story prompt sheet prior to the interview (Appendix 7) to support them to reflect on their parenting journey before they came to the interview. Each parent conducted the interview from their home, which may have prompted them to consider and share home-based experiences. It would be interesting to consider how the interview settings might impact the interviews, for example, a Child Development Clinic or a school-based setting. Since the research aims were to explore parental experiences, it was considered appropriate that parents shared their experiences from domestic settings.

5.11.6 Unstructured Interviews

The researcher used a prompt question to start the conversation, and parents chose the topics and time periods they wished to share. When a parent mentioned a topic in passing that the interviewer considered needed more elaboration or explanation, the researcher used the words the parent had supplied and asked them to tell them more about this aspect of their story. For example, Mim said that her faith was paramount in her and her family's lives. The researcher reflected those words back to her and "Could you tell me more about what that means?" Since the researcher never introduced a topic, some aspects of the parent's story may have remained unexplored. At the end of the interview, the researcher used an additional prompt question (see section 3.7.4 for more details), "How does it feel talking about your child today?"). This was utilised as an emotional 'check-in' to ensure that the parent was leaving the interview in a way that meant that they did not require further emotional support.

Other stories may have been consciously or unconsciously omitted from the interview. Parents may not have felt comfortable disclosing aspects of their personal experiences. For example, hypothetically, experiences around their own thoughts and behaviours, those of their spouse or wider family or those related to their emotional wellbeing may have been omitted from the interview process. The stories shared in this research are the ones shared on that day at that time. Had the same parents been interviewed on another day or time, the stories they told could have resulted in an entirely different account. Whilst acknowledging this possible variability, it does not detract from the way in which the study was designed to elicit and explore experiences that parents wished to share.

Whilst the culturally sensitive approach employed by the researcher is considered a unique and valuable contribution, the researcher is aware that the parents in the study may have felt inhibited to share aspects of their experience with someone very closely associated with the Bengali community. Despite reassurances of anonymity and confidentiality, these measures may not have sufficiently ameliorated parental concerns. These are, of course, suppositions, and it would be difficult to identify with any confidence what parents may choose not to share or their reasons for doing so. However, some reasons might be to protect themselves, their child or partner or family members from further scrutiny, experiences, or emotions that they had not yet made sense of effectively. Although this issue is worth bearing in mind, it does not detract from the trustworthiness of the study; its purpose was to explore the experiences associated with being Bengali and parenting a child with autism. The focus of the study was and remained the experiences that were relevant to the parent.

In addition, the study considered potential language barriers that may have prevented parents from taking part in the research. The researcher made it clear through the literature distributed to the relevant organisations, both in-person and online, that they were bilingual and could accommodate parents whose first language was not English.

5.11.7 Characteristics of the Participants

The parents who took part in the study were all second-generation Bengali parents and did not require linguistic support. Also, the sample of five parents who took part were all mothers. Therefore, the experiences and perceptions of mothers are privileged.

More importantly, the participants were required to have access to an online platform to participate in the interview (Covid-19-related restrictions necessitated this). This was a limitation of the study as it meant that parents had to have access to and be able to navigate online platforms, sign permission forms online, and read the storyed narrative that was shared with them. Not conducting interviews in person was also considered a limitation. It meant that the interpersonal aspects of relationship-building could not happen in as natural a way as is possible if interviews were conducted in person. One of the parents chose to keep her camera off during our interview, so the variability even within online interviewing is likely to have impacted the content and the richness of the data shared. However, the open-ended nature of the interviews and the nature of the design means that these limitations are apparent; it does not detract from findings that explore parental experiences.

5.12 impact of Covid-19 on the Research

This research was conducted during the Covid-19 pandemic. This was an uncertain and stressful time for children, their families and those that support them. The researcher was mindful that all data gathering would need to happen remotely in accordance with university ethical guidelines; the rationale for this was to keep all of those involved safe. However, it should be acknowledged that this potentially impacted social interaction and the richness of the data gathered. The researcher also considered the impact of the Covid-19 pandemic; the group of parents highlighted to participate in this research are from minoritised ethnic groups who were disproportionately impacted by Covid-19 and the resulting lockdown (Lally, 2020).

In addition, parents would have been experiencing pressures that impacted their confidence and general wellbeing. However, the impact of Covid-19 on the parental experiences shared in this study are hypothetical and uncertain. (See Appendix 28, Research Journal extract about Covid-19).

5.13 Contributions to Practice

5.13.1 Implications for EP Work

This research adopted an exploratory approach that did not seek to generalise or look to develop theory. Instead, the researcher hoped to make a difference. EPs in Burnham's (2013) study primarily defined their role as "mediators of useful outcome" (Burnham, 2013, p.25). The author argues that EP practice should be responsive to the needs of the communities in which they work in a negotiated and cooperative manner (Burnham, 2013). The findings in this research are relevant to EP practice on an individual and wider community level.

Firstly, parents in this study found it helpful when practitioners working with their child came alongside and met the parent where they were in terms of their constructions of their child's autism. For example, parents in this study were able to employ both medical and social models of disability; this suggests a role for EPs to support CYP and families in a non-stigmatising way to remove barriers and improve outcomes.

Secondly, the findings illustrate that parents are willing to work with professionals. Parents often found it helpful to talk with professionals rather than family members or friends. This was apparent for some parents in this study, especially in the initial stages of the diagnosis process. EPs are well placed, working across systems to challenge stereotypical notions that South Asian families are insular and display a preference for support from their own community rather than external professionals. This could be a wider community-level orientated work, similar to that advocated by Theara and Abbott (2015).

The majority of EPS service delivery models utilise a consultation model. This would be an appropriate opportunity to consider with parents the support structures that the family currently has and services that may be appropriate to meet family needs. EPs can play a pivotal role in building relationships with parents and encouraging their participation with services. Parents in this study were on their own unique journey; each displayed a need and readiness for support at different points. EPs can work closely with school settings to ensure that parents felt suitably supported to reach for support when they thought it was appropriate; for example, some parents in this study needed to absorb the diagnosis for several years before they displayed readiness for support. In addition, some parents were more comfortable than others advocating for their child in educational settings. EPs can play a role in advocating for families to have their voices heard and included during meetings where decisions are made by professionals about the CYP.

Finally, EPs are considered evidence-based practitioners (Boyle & Kelly, 2017) and agents of change across our core functions of consultation, assessment, intervention, training and practitioner research (Birch et al., 2015). EPs can be described as 'consumers' of research findings (Boyle & Kelly, 2017) and as such, we are often positioned and position ourselves as the conduit for contemporary knowledge. Along with our professional standards and frameworks (BPS. HCPC, DECP), we are required to maintain the knowledge base associated with our profession and find ways to ensure this is utilised in our everyday practice. Given that every parent in this study described the need for greater awareness and understanding of autism in the Bangladeshi community, it follows that EPs can use findings from this study to enrich the understanding of professionals that support parents. Mim's story illustrates the power of community workshops in educational settings.

Additionally, EPs can collaborate with diagnostic pathways to deliver training and facilitate culturally responsive support groups. For example, promoting intergenerational awareness. Family members' understanding and acceptance was a prominent factor in how supported families felt in this study.

5.13.2 Dissemination of Research

The researcher is keen to share the key findings with those that were part of the research process. The majority of the parents commented that they would like to see the research results; each parent expressed a hope that their participation would raise the profile of autism in the Bangladeshi community.

Both the LA that initially supported the research and the EPs where the researcher is on placement would like the researcher to share an overview of the study and its findings. In the placement LA, a team of professionals provide autism outreach support to schools interested in providing culturally sensitive support, so it is anticipated that the research will play a role in a future CPD day for that team. This researcher has secured future employment in an EPS where the population characteristics mean that this research is particularly pertinent to the context. The researcher is hopeful that this research will also be disseminated in this LA.

Lastly, the university that the researcher attends holds an annual end-of-year research day, where the findings will be shared with the tutor team, lecturers and link EPs in LA practice that support the training programme. In terms of the wider context, the researcher hopes to submit an article for future publication.

5.13.3 Implications for Further Research

This study is relatively small in size, consisting of five parents. A larger sample size would provide a wider range of experiences, with further insights and experiences of Bangladeshi parents. By widening the number, it would be hoped that both mothers and fathers would take part and increase the likelihood of parents who were first-generation migrants to the UK to also feature in the research. These were the voices that did not feature in the research and would mean that this was a more varied group of parents.

Building on some of the themes that parents discussed, broadening the research base to include wider family members and CYP who is autistic to gain a greater appreciation of the experiences of the family members involved. Perhaps looking at the family narratives that make up the experience would provide further insights into the intergenerational aspects of family life that parents shared in this present study.

Another way to develop this research further is to consider interviewing parents over time. Jegatheesan et al. (2010a, 2010b) and Jegatheesan's (2011) ethnographic study was conducted over several months in naturalistic situations, which allowed for relationship building with the participant, which in turn provided the thick descriptions that is a feature of qualitative research.

5.13.4 Learning taken from the Research

I started this research study with the aim of investigating the experiences of a minority ethnic group to which I also belong. My goal was to give voice to this underrepresented group. I saw this research as part of bringing those Bangladeshi parental experiences to the fore so they can be examined, reflected on, and the lessons learned applied for the benefit of that community. As I progressed through the research, I became increasingly uncomfortable with the idea of 'giving voice'. This made me consider the implications of 'giving voice' Whose voice was I privileging? Who gains from this telling? These are not questions that I have been fully resolved, however, I recognise that critical reflection is an integral part of anti-oppressive practice.

A criticism levelled at research that seeks to give voice to a minority group is that it can reinforce ideas of oppression that it seeks to challenge; for example, it assumes that the group that you seek to 'speak for' has no voice and is need of someone else to step in and provide that voice (Ashby, 2011).

Furthermore, qualitative research brings with it the inherent interpretation of the researcher. So, despite attempting to amplify the voice of research participants, the values and beliefs of the researcher will inevitably have some bearing on the findings; this challenges the emancipatory ideals professed by the researcher.

I came to consider whether the experiences of Bangladeshi parents with a child diagnosed with autism were inherently different to that of non-Bangladeshi parents. The stated aim of this study has the potential to ‘other’ the minoritised ethnic group it seeks to make more visible. In addition, should the research result in a strictly deficit view of this minority ethnic group of parents, the research would further disadvantage the very group it was purporting to advocate for. Articulating these thoughts in my research journal prompted some uncertainty and introspection around the language used by the researcher and how they would ensure that the minoritised ethnic group would remain at the centre of this study.

Finding and using Tillman's (2002) framework for culturally sensitive research (See appendix 29) reassured me that I was using research approaches to amplify voices that are not heard in the literature. Therefore, my approach aligned with the exploratory, emancipatory goals set out at the commencement of this research.

5.14 Conclusion

This study has contributed to the body of knowledge regarding South Asian parents with children who have a diagnosis of autism. The findings, while interesting and relevant, did not provide a definitive answer to the research question. Rather, this study provided insights and detailed descriptions and interpretations that enabled a better understanding of Bangladeshi parents' experiences of parenting a child with autism.

This chapter has discussed some of the key findings from the research. The need for raising awareness and understanding in the community featured prominently. Parents expressed a desire to navigate parenting their child with autism without the critical gaze of others. The findings illustrate the emotional impact of parenting a child with autism, but also a sense of hope for the future as parents became more confident and comfortable recognising and adapting their lives to the needs of their child. Each parent's journey was an evolving one and unique to them, but every parent displayed a willingness and a growing competence to enact change.

The parents in this study not only gave generously of their time but also shared an invaluable insight into what it means to be a Bengali parent of a child with autism. It is, therefore, fitting that we end with a quote from one of the parents in this study describing how she felt after attending a workshop about autism that she found impactful.

"I have a child who has autism, and it's fine, it's OK….It doesn't mean you know the end of the world. It doesn't mean that there's something wrong with me or my family, my child. Uhm, that emotional bit, accepting, I think, the hardest thing for a parent family to accept, and be OK with. That yes, I have a child who has autism, and it's absolutely fine. There is nothing wrong, and there will be nothing wrong, ever" (Mim, line 499-503)

References

American Psychiatric Association. (1987). Diagnostic and statistical manual of mental disorders (4th ed.). American Psychiatric Publishing.

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). American Psychiatric Association.

Andrews, T. (2012). What is social constructionism? *The Grounded Theory Review*, 11 (1). 39-46.

Ashby, C. E. (2011). Whose 'Voice' is it Anyway? Giving Voice and Qualitative Research Involving Individuals that Type to Communicate. *Disability Studies Quarterly*, *31*(4). https://doi.org/10.18061/dsq.v31i4.1723

Berry, J. W. (n.d.). Immigration, acculturation, and adaptation. *Applied Psychology: An International Review, 46*(1), 5–68. https://doi/org/10.1080/026999497378467

Birch, S., Fredrickson, N., & Miller, A. (2015). Educational Psychology. In *Educational Psychology* (2nd ed., pp. 3–30). Routledge.

Blaikie, N. (2009). Designing Social Research: The Logic of Anticipation (2nd ed.). Cambridge: Polity.

Bolton, G. (2009). Write to Learn: Reflective Practice Writing. *InnovAiT*, *2*(12), 752–754. https://doi.org/10.1093/innovait/inp105

Booth, A., Sutton, A., & Papaioannou, D. (2016). *Assessing the evidence base. In Systematic approaches to a successful literature review* (Second). SAGE Publications.

Boyle, J., & Kelly, B. (2017). The Role of Evidence in Educational Psychology. In *Frameworks for Practice in Educational Psychology, Second Edition: A Textbook for Trainees and Practitioners* (2nd ed., pp. 29–43). Jessica Kingsley Publishers.

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners*. SAGE Publications Ltd; First edition. https://read.kortext.com/reader/epub/268645?page=

Braun, V., & Clarke, V. (2021). *Thematic Analysis: A Practical Guide* (1st ed.). SAGE Publications Ltd.

Bryman A. (1984). The Debate about Quantitative and Qualitative Research: A Question of Method or Epistemology? The British Journal of Sociology, 35(1), 75-92.

Burnham, S. (2013). Realists or pragmatists? “Reliable evidence” and the role of the educational psychologist. *Educational Psychology in Practice Theory, Research and Practice in Educational Psychology*, *29*(1), 19–35. https://www.tandfonline.com/doi/pdf/10.1080/02667363.2012.734277?needAccess=true

Burr, V. (2003). *Social Constructionism*. Psychology Press.

Burr, V. (2015). *Social Constructionism*. Psychology Press.

Clandinin, D.J. and Connelly, F.M. (2000) Narrative Inquiry: Experience and Story in Qualitative Research. Jossey-Bass, San Francisco.

Connelly, F. M., & Clandinin, D. J. (1990). Stories of Experience and Narrative Inquiry. *Educational Researcher*, *19*(5), 2–14. https://doi.org/10.2307/1176100

Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. *The University of Chicago Legal Forum*, *140*, 139–167.

Creswell, J. W. (2006). Qualitative Inquiry and Research Design: Choosing Among Five Approaches (2nd ed.). London: Sage.

Creswell, J. W., & Miller, D. (2000). Getting good qualitative data to improve. *Theory into Practice*, *39*(3), 124–130.

Creswell, J. W., & Poth, C. (2013). *Qualitative inquiry & research design*. SAGE Publications.

Creswell, J. W., Hanson, W. E., Clark Plano, V. L., & Morales, A. (2007). Qualitative Research Designs: Selection and Implementation. *The Counseling Psychologist*, *35*(2), 236–264. https://doi.org/10.1177/0011000006287390

Creswell, J. W., & Poth, C. (2018). *Qualitative Inquiry and Research Design: Choosing among Five Approaches*. Thousand Oaks, USA SAGE Publications.

Critical Appraisal Skills Programme. (2018). https://casp-uk.net/casp-tools-checklists/

Croot, E., Grant, G., Mathers, N., & Cooper, C. (2012). Coping strategies used by Pakistani parents living in the United Kingdom and caring for a severely disabled child. *Disability and Rehabilitation*, *34*(18), 1540–1549.

Czarniawska, B. (2004). Introducing qualitative methods: Narratives in social science research. London: SAGE Publications. https://doi.org/10.4135/9781849209502

Davenport, M., Mazurek, M., Brown, A., & McCollom, E. (2018). A systematic review of cultural considerations and adaptation of social skills interventions for individuals with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *52*, 23–33. https://psycnet.apa.org/doi/10.1016/j.rasd.2018.05.003

Dewey, J. (1963). Experience and education. New York: Collier.

Didion, J. (1968). On Self-Respect. In *Slouching Towards Bethlehem: Essays*. HarperCollins Publishers.

Doig, S. (2012). *An exploration of the experience of Bangladeshi parents of children who have been diagnosed with an Autistic Spectrum Disorder* [Unpublished thesis, University of East London]. https://repository.uel.ac.uk/item/85z0z

Elliott, J. (2005). *Using Narrative in Social Research*. SAGE Publications Ltd. https://doi.org/10.4135/9780857020246

Etherington, K (2006) Chicken or egg? An exploration of the relationships between physical and psychological symptoms with a woman diagnosed with Tourette's syndrome. In Counselling and Psychotherapy Research. vol. 6, no. 2, pp138-146.

Finlay, L. (2002). “Outing” the researcher: The provenance, process, and practice of reflexivity. Qualitative Health Research, 12(4), 531–545. https://doi.org/10.1177/104973202129120052

Fombonne, E. (2009). Epidemiology of Pervasive Developmental Disorders. *Paediatric Research*, *65*(6), 591–598.

Fox, M. (2015). ‘What sort of person ought I to be?’ – Repositioning EPs in light of the Children and Families Bill (2013). *Educational Psychology in Practice*, *31*(4), 382–396.

Gallagher, D. (2004). The Importance of Constructivism and Constructivist Pedagogy for Disability Studies in Education. Disability Studies Quarterly, 24(2), 1-15.

Gergen, K. (1985). The Social Constructionist Movement in Modern Psychology. American Psychologist, 40, 266-275. https://doi.org/10.1037/0003-066X.40.3.266

Gergen, K.J. (1999). An invitation to social constructionism. London: Sage.

Glaser, B., & Strauss, A. L. (1967). The discovery of grounded theory: Strategies for qualitative research. New York, NY: Hawthorne

Glaser, B. G., & Strauss, A. L. (2017). *The discovery of grounded theory: Strategies for qualitative research*. Routledge.

Glesne, C., & Peshkin, P. (1992). Becoming qualitative researcher: An introduction. New York: Longman.

Gough, D. (2007). Weight of Evidence: A framework for the appraisal of the quality and relevance of evidence. *Research Papers in Education*, *22*(2), 213–228.

Guba & Lincoln. (1985). *Naturalistic inquiry*. Sage.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In *Handbook of qualitative research,* (2nd ed., pp. 163–194). https://miguelangelmartinez.net/IMG/pdf/1994_Guba_Lincoln_Paradigms_Quali_Research_chapter.pdf

Guba, E.G. and Lincoln, Y.S. (2005) Paradigmatic Controversies, Contradictions, and Emerging Confluences. In: Denzin, N.K. and Lincoln, Y.S., Eds., The Sage Handbook of Qualitative Research, 3rd Edition, Sage, Thousand Oaks, 191-215.

Habib, S., Prendeville, P., Abdussabur, A., & Kinsella, W. (2017). Pakistani mothers' experiences of parenting a child with autism spectrum disorder (ASD) in Ireland. *Educational & Child Psychology*, *34*(2), 67–79.

Hannes, K. (2011). Chapter 4: Critical appraisal of qualitative research. In *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions*. https://methods.cochrane.org/qi/supplemental-handbook-guidance

Harré, R., Moghaddam, F. M., Cairnie, T. P., Rothbart, D., & Sabat, S. R. (2009). Recent advances in positioning theory. Theory & Psychology, 19(1), 5–31. https://doi.org/10.1177/0959354308101417

Henrich, J., Heine, S. J., & Norenzayan, A. (2010). The weirdest people in the world? *Behavioral and Brain Sciences*, *33*(2–3), 61–83. https://doi.org/10.1017/S0140525X0999152X

Hiles, D. R., Čermák, I., & Chrz, V. (2010). Exploring narrative intelligence with NOI. In D. Robinson., P. Fisher., T. Yeadon Lee., S.J. Robinson., & P. Woodcock (Eds). Narrative and memory (pp. 33-41). University of Huddersfield Press.

Hiles, D., & Cermák, I. (2008). Narrative psychology. In C. Willig & W. Stainton-Rogers, *The SAGE Handbook of Qualitative Research in Psychology* (pp. 147–164). https://doi.org/10.4135/9781848607927.n9

Hoekstra, R. A., Girma, F., & Tekola, B. (2018). Nothing about us without us: The importance of local collaboration and engagement in the global study of autism. *British Journal of Psychiatry*, *15*(2), 40–43.https://doi.org/doi: 10.1192/bji.2017.26

Hurst, A. (2008). A healing echo: Methodological reflections of a working-class Researcher on Class. *The Qualitative Report*, *13*(3), 334–352.

Hutton, A. M., & Caron, S. L. (2005). Experiences of families with children with autism in rural New England. Focus on Autism and Other Developmental Disabilities, 20(3), 180-189.

Jegatheesan, B. (2011). Multilingual Development in Children with Autism: Perspectives of South Asian Muslim Immigrant Parents on Raising a Child with a Communicative Disorder in Multilingual Contexts. *Bilingual Research Journal*, *34*(2), 185–200. https://doi.org/10.1080/15235882.2011.597824

Jegatheesan, B., Fowler, S., & Miller, P. (2010a). From symptom recognition to services: How South Asian Muslim immigrant families navigate autism. *Disability & Society*, *25*, 797–811. https://doi.org/10.1080/09687599.2010.520894

Jegatheesan, B., Miller, P. J., & Fowler, S. A. (2010b). Autism From a Religious Perspective: A Study of Parental Beliefs in South Asian Muslim Immigrant Families. *Focus on Autism and Other Developmental Disabilities*, *25*(2), 98–109. https://doi.org/10.1177/1088357610361344

Kramp, M. K. (2004). Exploring Life and Experience Through Narrative Inquiry. In. K. B. deMarrais & S. D. Lapan (Eds.), Foundations of Research: Methods of Inquiry in Education and the Social Sciences (pp. 103-122). New York: Lawrence Erlbaum Associates.

Lally, C. (2020). *Impact of COVID-19 on different ethnic minority groups* (Rapid Response:) [The Parliamentary Office of Science and Technology]. UK

Parliament. https://post.parliament.uk/impact-of-covid-19-on-different-ethnic-minority-groups/

Lahman, M. K. E.,C, K. L., Moses, L., Griffin, K. M., Mendoza, B. M., & Yacoub, W. (2015). A rose by any other name is still a rose? Problematizing pseudonyms in research. Qualitative Inquiry, 21(5), 445–453. https://doi.org/10.1177/1077800415572391

Lieblich, A., Tuval-Mashiach, R., & Zilber, T. (1998). Narrative research: reading, analysis and interpretation. SAGE Publications, Inc.

Maxwell, J. (1992). Understanding and Validity in Qualitative Research. Harvard Educational Review, 62(3), 279–301.

Maxwell, J. (1992). Understanding and Validity in Qualitative Research. Harvard Educational Review, 62(3), 279–301.

Mertens, D. (2010). Research and evaluation in educational and psychology: Integrating diversity with quantitative, qualitative, and mix- methods approaches. Thousand Oaks, CA: Sage.

Murray, M. (2015). Narrative psychology. In J. A. Smith (Ed.), Qualitative psychology: A practical guide to research methods (3rd ed.) (pp. 85–107). Sage.

Murray, M. (2015). Narrative psychology. In J. A. Smith (Ed.), Qualitative psychology: A practical guide to research methods (3rd ed.) (pp. 85–107). Sage.

Nair, S. (2015). *A study of the experiences and perceptions of parents of Black and Minority Ethnic pupils statemented with autism in relation to the educational support provided for their children and for themselves.* [Thesis, Cardiff Metropolitan University]. https://repository.cardiffmet.ac.uk/handle/10369/7538

National Autistic Society. (n.d.). *National Autistic Society*. Retrieved 4 April 2022, from https://www.autism.org.uk/advice-and-guidance/what-is-autism

Office of National Statistics. (2020). *Child poverty and education outcomes by ethnicity*. Census https://www.ons.gov.uk/economy/nationalaccounts/uksectoraccounts/compendium/economicreview/february2020/childpovertyandeducationoutcomesbyethnicity#authors

Ollerenshaw, J. A., & Creswell, J. W. (2002). Narrative research: A comparison of two restorying data analysis approaches. Qualitative Inquiry, 8(3), 329–347. https://doi.org/10.1177/10778004008003008

Ollerenshaw, J. A., & Creswell, J. W. (2002). Narrative research: A comparison of two restorying data analysis approaches. Qualitative Inquiry, 8(3), 329–347. https://doi.org/10.1177/10778004008003008

Paez, A. (2017). Grey literature: An important resource in systematic reviews. *Journal of Evidence-Based Medicine*. https://doi.org/10.1111/jebm.12265

Perepa, P. (2007). ‘Are ASD services for minority ethnic communities accessible?’ *Good Autism Practice*, *8*(2), 3–8.

Perepa, P. (2014). Cultural basis of social ‘deficits’ in autism spectrum disorders. *European Journal of Special Needs Education*, *29*(3), 313–326. https://doi.org/10.1080/08856257.2014.908024

Perepa. (2019). *Autism, Ethnicity and Culture Working with Children and Families from Minority Communities*. London Jessica Kingsley Publishers. https://ebookcentral.proquest.com/lib/uel/reader.action?docID=5743719

Pietkiewicz, I. and Smith, J.A. (2014) A Practical Guide to Using Interpretative Phenomenological Analysis in Qualitative Research Psychology. Psychological Journal, 20, 7-14.

Pinnegar, S., & Daynes, J. G. (2007). Locating narrative inquiry historically: Thematics in the turn to narrative. In Handbook of Narrative Inquiry: Mapping a Methodology (pp. 3– 34). Thousand Oaks, California: SAGE Publications Inc.

Polkinghorne, D. E. (1988). Narrative knowing and the human sciences. New York: State University of New York Press.

Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. International Journal of Qualitative Studies in Education, 8(1), 5–23. https://doi.org/10.1080/0951839950080103

Polkinghorne, D. E. (2007). Validity issues in narrative research. Qualitative Inquiry, 13(4), 471–486. https://doi.org/10.1177/1077800406297670

Polkinghorne, D. E. (2010). The practice of narrative. Narrative Inquiry, 20(2), 392–396.

Ratto, A., Reznick, S. and Turner-Brown, L. (2016) ‘Cultural effects on the diagnosis of autism spectrum disorder among Latinos.’ Focus on Autism and Other Developmental Disabilities 31 (4), 275– 283. https://doi.org/10.1177%2F1088357615587501

Reay, D. (2004). Education and cultural capital: The implications of changing trends in education policies. *Cultural Trends*, *13*(2), 73–86. https://doi.org/10.1080/0954896042000267161

Riessman, C., Kohler. (2008). *Narrative methods for the human sciences*. SAGE Publications, Inc.

Rizvi, S. (2017). Exploring British Pakistani mothers' perception of their child with disability: Insights from a UK context. *Journal of Research in Special Educational Needs.*, *17*(2), 87–97. https://doi.org/10.1111/1471-3802.12111

Rizvi, S. (2021). *Undoing Whiteness in Disability Studies: The Special Education System and British South Asian Mothers*. Cham, SWITZERLAND Palgrave Macmillan.

Robson, C. (2002). Real world research: a resource for users of social research methods in applied settings. Chichester: Wiley.

Robson, C., & McCartan, K. (2016). *Real World Research* (4th ed.). Wiley.

Sabharwal, R. (2021). *Mothers' experiences of raising a child with autism spectrum disorder in Indian and Bangladeshi intergenerational families* [Unpublished doctoral dissertation, Alliant International University Emeryville]. https://www.proquest.com/openview/d7c284fb34cc0b70bd026f68c3e2383f/1?pq-origsite=gscholar&cbl=18750&diss=y

Scheurich, J. J., & Young, M. D. (1997). Coloring Epistemologies: Are Our Research Epistemologies Racially Biased? *American Educational Research Association*, *26*(4), 4–16.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63–75. https://doi.org/10.3233/EFI-2004-22201

Squire, C., Andrews, M., & Tamboukou, M. (2008). *Doing narrative research*. SAGE Publications.

Strand, S., & Lindsay, G. (2012). Ethnic disproportionality in the identification of speech language and communication needs (SLCN) and autism spectrum disorders (ASD): 2005-2011. *Department of Education*, 63.

Tebes, J. K. (2005). Community science, philosophy of science, and the practice of research. *American Journal of Community Psychology, 35*, 213–230.

Theara, G., & Abbott, D. (2015). Understanding the experiences of South Asian parents who have a child with autism. *Educational and Child Psychology*, *32*(2), 47–56.

The Law Society. (2022). *A guide to race and ethnicity terminology and language*. The Law Socety. https://www.lawsociety.org.uk/en/topics/ethnic-minority-lawyers/a-guide-to-race-and-ethnicity-terminology-and-language

Tillman, L. C. (2002). Culturally Sensitive Research Approaches: An African-American Perspective. *Educational Researcher*, *31*(9), 3–12. https://doi.org/10.3102/0013189X031009003

Timimi, S. (2010). The McDonaldization of childhood: Children’s mental health in neo-liberal market cultures. *Transcultural Psychiatry*, *47*(5), 686–706. https://doi.org/10.1177/1363461510381158

Warner, R. (1999). Research Section: The Views of Bangladeshi Parents on the Special School Attended by their Young Children with Severe Learning Difficulties. *British Journal of Special Education*, *26*(4), 218–223. https://doi.org/10.1111/1467-8527.00142

Watt, D. (2007). On Becoming a Qualitative Researcher: The Value of Reflexivity. The Qualitative Report, 12(1), 82-101.

Weiner, B. (2018). The legacy of an attribution approach to motivation and emotion: A no-crisis zone. Motivation Science, 4, 4–14.10.1037/bul0000042

White, C., & Barrowclough, C. (1998). Depressed and non-depressed mothers with problematic preschoolers: Attributions for child behaviours. British Journal of Clinical Psychology, 37(4), https://www.deepdyve.com/lp/wiley/depressed-and-non-depressed-mothers-with-problematic-preschoolers-XPODyZTS04

Wilson, S., Cunningham-Burley, S., Bancroft, A., Backett-Milburn, K., & Masters, H. (2007). Young people, biographical narratives and the life grid: Young people's accounts of parental substance use. Qualitative Research, 7(1), 135–151. https://doi.org/10.1177/1468794107071427

Appendix 1: Gough’s (2007) Weight of Evidence, Evaluation and Outcome:

A: A generic evaluation of the quality of the execution of the study, the Critical Appraisal Skills Programme (CASP) UK (2018) appraisal tool reviews studies for transparency, accessibility, and specificity (see Appendix 1, for a descriptive overview of research papers included in the literature review, including critical appraisal using the CASP UK, 2018).

B: Review the appropriateness of the research design. Each paper was assessed for suitability in method and usefulness in answering the review question.

C: Review the specific issues pertinent to the focus of the review. Each paper was evaluated to consider its relevance to answering the question posed in this review.

D: The overall WoE score assigned. Each paper included in the final literature review was allocated an overall WoE rating reached from the A, B and C scores.

Table 5

Weight of Evidence

Study	A: A generic evaluation of the quality of the execution of the study	B: Review the appropriateness of the research design	C: Review the specific issues pertinent to the focus of the review.	D: The overall WoE score assigned
(Habib et al., 2017)	Medium	High	High	Medium / High
(Theara & Abbott, 2015)	High	High	High	High
(Nair, 2015)	High	High	High	High
(Perepa, 2014)	High	High	High	High
(Doig, 2012)	High	High	High	High
(Jegatheesan, 2011)	Medium	High	High	Medium / High
(Jegatheesan et al., 2010a)	Medium	High	High	Medium / High
(Jegatheesan et al., 2010b)	Medium	High	High	Medium / High
(Warner, 1999)	Medium	High	High	Medium / High

Appendix 2: A Summary of Each Article Identified in the Literature Search

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
An exploration of the experience of Bangladeshi parents of children who have been diagnosed with an Autistic Spectrum Disorder (2012) Doig, S. Unpublished thesis UEL repository UK	Explore Bangladeshi parents' subjective experiences of the assessment, diagnostic and intervention process.	2 fathers 7 mothers of Bangladeshi origin	Phenomenological approach IPA Smith et al. (2009)	The role of culture and acculturation was addressed as a contributing factor to parental engagement with services. Participants described feeling a degree of affiliation to Bangladeshi culture, but also rejecting parts of that identity that did not fit them and are outdated. This means parents will filter the parts of culture they value and encourage in child with ASD. Culture has an impact on considering the cause and impact on diagnosis. Genetic /medical model offers an alternative to feeling responsible or blamed for diagnosis, this was something mothers spoke of. Ability to control / influence close members of the families	Researcher reflects own experience as a researcher and how she is perceived by the participants. Ethical issues are explored and considered but not addressed. Small sample Areas for future research is discussed. The analysis process is outlined – no mention of cross validation or triangulation.

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
				understanding of autism diagnosis. More difficult with wider family. Accepting of ASD diagnosis challenging, physical disability is easier to understand and explain to self and wider community. Not having the language to explain autism presents difficulties. Being a ‘bit behind’ suggests that the CYP will catch up with intervention. Several parents used a religious framework to make sense of their child’s difficulties. Faith as a coping mechanism Religion as a source of comfort / strength / resources Families spoke about a community-based support system available in Bangladesh (in comparison to the UK) Anticipatory worry about their child’s future - parents hoped that	

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
				their child would talk, that their child would 'grow out' of having ASD. Families were appreciative of support offered by professional services, however many parents commented that they benefited from informal support from wider family, religious leaders and other people who had gone through a similar process.	

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
Pakistani mothers' experiences of parenting a child with autism spectrum disorder (ASD) in Ireland (2017) Habib, S. Prendeville,	Explore the parental experiences of Pakistani mothers living in Ireland who have a child with autism spectrum disorder	7 mothers of chn with ASD	Semi structured interviews Thematic Analysis	Three themes emerged from the data: 1.Satisfaction and feeling content - Positive experiences of education - meeting the educational needs of their child - Communication - need for regular contact with school / speaking English is key	Researcher did not critically examine her own role, potential bias and influence during formulation No evidence of triangulation / member checking

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
P. Abdussaur. Kinsella, W. Educational and Child Psychology Ireland				component to participating in IEP - Positive impact of parenting a child with ASD - mothers were proactive in accessing support for their CYP and felt empowered as a result. 2.Challenges of raising a child with ASD - Access to services - waiting list to access services prior and post diagnosis - cause of stress - Challenges in education (lack of resources in mainstream schools) 3. Immigrant experience of raising a child with ASD - Life in the wider community - need for support from own community / isolation in EYs / living in a different culture - Life within the family (religious beliefs were a strong protective factor) - Cultural factors- being a Muslim in a Western world - Perception of autism in Pakistan were considered	Minor modification in question order after pilot interview Some limited discussion of contradictory data was examined Methods used for data storage were not discussed No discussion around saturation of data Did identify new areas for research, through discussion of limitation of the study

Study title **Year** **Author(s)** **Journal** **Context**	**Research purpose/aims**	**Participants**	**Design and methodology**	**Main Findings**	**Critical appraisal using the CASP framework**
From Symptom Recognition to Services: How South Asian Muslim Immigrant Families Navigate Autism (2010a) Jegatheesan, B., Fowler, S and Miller, P. Disability and Society	Experiences of 3 South Asian Muslim families navigating the assessment and cross-cultural conceptualization of their child's ASD diagnosis	3 multilingual S. Asian Muslim families (Pakistani / Bangladeshi background)	Grounded Theory Model Inductive thematic analysis Corbin and Strauss (2008) Qualitative Research with 3 Families Ethnographic / longitudinal research over 17 months	Cultural factors, interpersonal skills & diffs accessing services impact parent & proff interaction during diagnosis / post diagnosis time Parents used a cultural lens to make sense of parenting a child with ASD – this will be diff to that used by proffs working with the family	Critical Appraisal of all 3 papers: Small sample size Data collected in ways that addressed the research issue. Some descriptions of the way participants were recruited. No attempt to discuss ethical issues that might arise for researcher or participant. Data analysis was explored, and consideration was made of overall themes and differences across families. New areas of research were discussed. Application to other
Autism From a Religious Perspective: A Study of Parental Beliefs in South Asian Muslim Immigrant Families (2010b) Jegatheesan, B., Miller, P and Fowler, S. Focus on Autism and Other Developmental Disabilities	Exploring how the religious faith of 3 South Asian Musim families is incorporated in their sense making of their child's autism diagnosis.			South Asian Muslim parents expected the full inclusion of their child with autism in social life. Mix with wider family, partake in religious activities, speak different languages so that they are included in wider family and community life. Children were considered a gift from Allah. Having a child with autism was an opportunity to practice their faith.	

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
				God had chosen to give them this child as a test of their spiritual and moral faith. Complaining about the difficulties is in some respects similar to challenging the will of God.	populations were not explored as this was a small

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
Multilingual Development in Children with Autism: Perspectives of South Asian Muslim Immigrant Parents on Raising a Child with a Communicative Disorder in Multilingual Contexts (2011) Jegatheesan, B. Bilingual Research Journal	Perceptions of three South Asian Muslim families on multilingual development in their children with autism.			Multiple language acquisition considered important to maintaining normalcy in their children's lives. Immersion in multilingual contexts enriched social and familial relationships. Parents shared that professionals did not support the maintenance of native-language use at home. Parents were distrustful of professionals that gave advice that were perceived to hinder their child's social and cultural integration. For example, professional advice to speak one language at home. Children who demonstrated language impairments during initial ethnographic observations showed significant progress in their multiple-language development toward the end of the study.	

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
A study of the experiences and perceptions of parents of Black and Minority Ethnic pupils statemented with autism in relation to the educational support provided for their children and for themselves Nair, S. (2015) Unpublished thesis Cardiff University Repository Unpublished Thesis	Explores the experiences and perceptions of parents of BME pupils who have: a diagnosis of autism and an EHCP On the support they receive(d) for their child in education and themselves.	11 BME parents of which: 5 mothers & 1 father of Pakistani background Relevant stakeholders 11 Education personal 5 key personal from support organisations. 3 Elite interviews with individuals of authority who had experience and expertise in supporting pupils with autism and their families.	Qualitative case study approach Semi structured interview Interpretivist approach Thematic analysis	BME parents receive support from the providers within education rather than from their own ethnic communities. Showed a preference for mainstream schooling. Culture, religion, education and socio-economic backgrounds influence BME parents access and use services. Parents feel that the education system is essentially 'colour blind' and does not take into account their cultural needs and ethnicity. Parents expressed an expectation that society should provide them with more support.	Case study approach does not lend itself to generalisations. Diversity within ethnic minority ethnic groups means research about a particular ethnic group cannot be generalised. Researcher acknowledges her own role in the research process. Evidence of reflexivity. The researcher piloted the interview schedules and adjusted questions accordingly. Questions are shared in the appendix. Purposive sampling approach – utilising university lecturers

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
					contacts with schools in a specific LA in Wales. Ethical considerations are discussed and addressed in the setting up of the
Study title Year Author(s) Journal Context	**Research purpose/aims**	**Participants**	**Design and methodology**	**Main Findings**	**Critical appraisal using the CASP framework**
Cultural basis of social 'deficits' in autism spectrum disorders. (2014) Perepa, P. European Journal of Special Needs Education UK	Investigating the cultural influence on what constitutes appropriate social behaviour by parents of children with ASD.	63 parents of children who were on the autistic spectrum belonging to four different ethnic communities White British: 29 Somali: 6 Afro /Carib: 16 South Asian: 12	Semi structured interviews Episodic interviews (Flick, 2002) Combination of episodic narrative as well as asking the participant to provide opinions and definitions	There were cultural variations to the importance given to six social skills behaviours. The researcher goes on to explore potential reasons for these differences of opinion.Both gender and culture were found to explain variations in social skills importance. Cultural differences in the importance associated with certain social skills such as; understanding of facial expressions.	The aims of the aims of the research were clear and the methodology adopted was appropriate. Participants contacted through parent support group – engaged and aware of support services. What about excluded other groups, how representative?

Study title Year Author(s) Journal Context	**Research purpose/aims**	**Participants**	**Design and methodology**	**Main Findings**	**Critical appraisal using the CASP framework**
			(semantic knowledge) around specific situations (social behaviour)	Gender based differences around personal space and eye contact was noted. Parental choice of social skills were based the different models of disability parents used to explain their child's ASD diagnosis. For example, if a particular skill was seen as a deficit, I.e eye contact then parents identified this as a social skill their child would need to develop. If it was a felt that a skill was not of value – then parents did not encourage it to be supported. Power relations around being White British – meant this group did not display the need to 'fit in' and acquire skills considered socially desirable, more about what is comfortable for the child. Acculturation within western society influences the value	Recruitment strategy was outlined, and adaptations were explained and justified. Saturation of data was not discussed as sample sized for some ethnic groups were relatively small due to difficulty in recruitment. Relationship between researcher and participant were not explored. Some discussion around informed consent and simplifying language to make it accessible for participants that are not fluent English speakers, which raises some potential concerns around data collected.

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
				parents placed on certain social skills.	Some description of data analysis, findings were backed up with descriptive quotes. Findings were discussed in relation to the original research questions and possible reasons were outlined, for example 'acculturation'. Researcher considers the limitations of the study but draws attention to ways research may be used in the future. Findings cannot be generalised to wider population.
Understanding the experiences of South Asian parents	Explore the experiences of South Asian Parents living in	9 parents Semi – structured	Grounded Theory Model	Parents privileged 'medical model perspectives'	The main aims of the research are made clear and the methodology is

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
who have a child with autism (2015) Theara, G. Abbott, D. Educational and Child Psychology UK	the UK who have a child with autism. Learn, how disability Intersect with culture and consider how parents themselves understand that experience. (Intersectionality, Crenshaw)	interviews	Inductive thematic analysis Corbin and Strauss (2008)	Diagnosis process was considered a 'medical examination' something parents perceived as being removed from. Acceptance of medical model led to ideas that the autism 'curable', so information sought by parents reinforced the idea that autism a medical condition. Parents often wanted to help their child to get over the condition, in the interim to manage the condition and avoid the long term labelling of their CYP. Variability of how ASD presents left many parents discrediting the term. Result - parents had very little input from non-medical or educational practitioners. Cultural values and beliefs that underpin the construction of autism.	suitable to explore the research goal. The researcher made the method explicit; pilot study was conducted. Adjustments to questions were made based on areas that seemed to need more exploring. In line with Grounded Theory. A theoretical model was created but not explored with a wider group of parents to see if it held explanatory power. No acknowledgment of the researcher presence in the research. Details around; recruitment,

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
				'Medical model' is highly thought of back in their country of origin. Public sector support / social networks are not established in me the same way. So parents did not expect support from outside services and were comfortable utilising medical knowledge. Succeeding / economically - driving force for a community which has roots in developing countries. Having a child with a disability can be considered as a threat to such a belief. The link between successes of your child and how this has the potential to impact the social hierarchy on families. (autism, seen as a potential threat to overcome) Emphasis on the role of the family has having more importance than that of the state. Nearly all parents stated a preference to deal with	participants, interview duration, setting and transcription were included. Ethical approval was granted. Small sample

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
				things in their own preferred manner. Ideas around concealing disability, based on worries around fear and prejudice. Perhaps explain why there may be a preference for a medical understanding of autism. Dominant theme was one of feeling isolated. Some parents showed a preference to ‘mask’ their difficulties. Reluctance to share diagnosis with family, for not wanting to upset /concern family members. Mothers described feeling more isolated than fathers Not comfortable with engaging with professionals from support services. Strong focus on changing things, working hard for a better future for their child, so they could overcome the autism label they had been prescribed.	

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
				Public sector professionals likely to bring a social model construction of autism and parents are operating with a medical model. This disparity is likely to be feeding into the disconnect / disengagement that professionals working with S Asian families. Parents construction of their child's disability should in the first instance be the starting point for professionals working with families. EPs with their community level orientation could work with communities not just individuals, could bring long term change. Although parents displayed an overall acceptance of the medical model. There was a desire from parents that their child succeed academically. Significant role for schools and EPs, to support child in a non-stigmatising way.	

Study title Year Author(s) Journal Context	**Research purpose/aims**	**Participants**	**Design and methodology**	**Main Findings**	**Critical appraisal using the CASP framework**
				EPs can make a significant contribution because they bring psychological theories to their work. Positive psychology offers a helpful way to reframe dominant medical or deficit view of autism.	
Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
The views of Bangladeshi parents on the special school attended by their young children with severe learning difficulties Rachel Warner (1999) British Journal of Special Education UK	Bangladeshi parents' views on the educational provision received by their child in a specialist provision for SLD.	7 parents were interviewed in their own homes Using a Sylheti speaking interpreter.	Single - semi structured interviews using an interpreter Phenomenological approach	Parents of children with autism had very different views to those of children with SLD. . Parents responses indicated that they did not fully understand what the meaning of autism and the severity / nature of their child's 'disability. Possible reason - child's later diagnosis and not having a frame of reference as it not a condition that is widely known in developing countries. Parents wanted their child to walk, talk and learn self-help skills as well as to be educated.	Small sample - researcher does not seek to make generalisations. Participants recruited from a single school, no details about how they were encouraged to take part. Researcher does not mention their own role in the research. Study mentions using a translator and 'consecutive interpreting', some limitation in

Study title Year Author(s) Journal Context	Research purpose/aims	Participants	Design and methodology	Main Findings	Critical appraisal using the CASP framework
				High value was placed on the staff at school and the care they provided for their child. Communication was considered important between home and school. Parents took it upon themselves to utilise support networks at home and wider family to understand communication with the school. Other than parents of autistic CYP, all parents hoped their CYP, would become 'less handicapped' by attending the SLD school. Parents did not see school as somewhere their child needed to gain culture, religion or language from. This was considered a home responsibility.	using an interpreter is acknowledged.

Appendix 3: Thematic Breakdown of Literature

Paper	Identified themes (author)	Identified subthemes (author)
Habib et al., (2017)	Feelings of Satisfaction and Content	• Positive experiences of education • The need for good communication with school • Positive impact of parenting a child with autism
	Challenges of raising a child with autism	• Difficulties accessing services • Lack of resources in mainstream settings
	Immigrant experience of raising a child with autism	• Life in the wider Pakistani community • Life within the immediate family • Being Muslim in a Western world • Perceptions of autism in family members living in Pakistan
Nair (2015)	Support	• Some BME parents felt more supported by education provider than own ethnic community • Parents expect more proff support than they receive
	Access of services	• Culture, religion, education, socio-economic class influences BME parents access / use of services
	Education	• Preference for mainstream schooling • Educational settings are ‘colour blind’
Theara & Abbott (2015)	Parents privileged medical model perspective	• Diagnosis – supports deficit - ASD as curable • Variability in in ASD presentation – many parents discredited term

Paper	Identified themes (author)	Identified subthemes (author)
	Emphasis on the role of the family	• Parents wanted to deal with things in their own way • Parents did not expect support from outside services
	Parents wanted their child to succeed academically	• Immigration is related to accessing resources and improving current situation. • Autism seen as a potential threat to overcome
Perepa (2014)	A variety of importance attributed to social skills behaviours	• Cultural variations to the importance given to social skills behaviours • Gender based difference around personal space and eye contact • White British – did not display same the same need to ‘fit in’ and acquire ‘socially desirable skills’ • Acculturation within western society impacted value placed on certain skills
	Parents employed different models of disability	• Deficit model of disability meant that parents sought to develop that particular social skill
Doig (2012)	Acculturation	• Levels of acculturation contributed to he level of parental engagement with services • Parents felt a degree of affiliation to Bangladeshi culture • Parents describe asserting a Muslim identity was more progressive / inclusive
	Models of disability	• Genetic / medical model of disability alleviated feeling of guilt / blame (mothers)

Paper	Identified themes (author)	Identified subthemes (author)
		- Medical model helps parents make sense of their child's diagnosis - Medical model was useful way to share understanding with close members of family - Hoping that their child will 'grow out' of autism
	Not having the language to explain autism	- Using the language of 'delay' suggests that the child will 'catch up'
	Frameworks for understanding	- Faith based understanding of autism is helpful for parents - Faith based understandings offers comfort / source of resilience
	Sources of support	- Families were appreciative of support by professional services - Families benefited from the informal support of wider family. - Families felt particularly helped by meeting people who had gone through similar experiences.
	Parent and professional interaction	- Cultural factors can be a barrier between parent and professionals - Interpersonal skills of the professional - Difficulties associated with accessing services during / after diagnosis
	Meaning making	- Parents employ a different lens to professionals - Professionals employ a different lens to parents

Paper	Identified themes (author)	Identified subthemes (author)
Jagatheesan et al., (2010b)	Parents expected full inclusion of their child with autism	• Parents expected religious inclusion • Parents expected social inclusion in wider family / community life
	Religious meaning making of autism	• Child as gift from Allah • Having a child with autism is an opportunity practice faith in action
Jagatheesan (2011)	Multilngualism	• Parents felt professionals did not support maintenance of home language • Parents felt maintenance of home language was important for inclusion in wider family • Parents were distrustful of professionals that employed deficit language about their child
Warner (1999)	Parents did not fully understand the meaning of autism	• No frame of reference / unknown back in developing countries
	Education	• High value on the role of staff and care provided to child • All parents hope that child would become 'less handicapped' by attending educational settings • Preference for mainstream provision • Developing culture / religion is considered home responsibility (not school)

Appendix 4: Thematic Matrix

Theme	Paper								
	Habib et al., (2017)	Nair (2015)	Theara & Abbott (2015)	Perepa (2014)	Doig (2012)	Jagatheesan (2011)	Jagatheesan et al., (2010a)	Jagatheesan et al., (2010b)	Warner (1999)
Privileging the Medical Model and Implications			Parents privileged medical model perspective	Deficit model of disability meant that parents sought to develop that particular social skill	Genetic / medical model of disability alleviated feeling of guilt / blame (mothers) Medical model helps parents make sense of their child's diagnosis Medical model was useful way to share understanding with close members of family				
Differences around the understanding child's diagnosis			Diagnosis – supports deficit - ASD as curable	Cultural variations to the importance given to	Hoping that their child will 'grow out' of autism				No frame of reference

Theme	Paper								
	Habib et al., (2017)	Nair (2015)	Theara & Abbott (2015)	Perepa (2014)	Doig (2012)	Jagatheesan (2011)	Jagatheesan et al., (2010a)	Jagatheesan et al., (2010b)	Warner (1999)
			Variability in in ASD presentation – many parents discredited term	social skills behaviours Cultural variations to the importance given to social skills behaviours Gender based difference around personal space and eye contact White British – did not display same the same need to 'fit in' and acquire 'socially desirable skills'	Using the language of 'delay' suggests that the child will 'catch up' Faith based understanding of autism is helpful for parents Faith based understandings offers comfort / source of resilience				

Theme	Paper								
	Habib et al., (2017)	Nair (2015)	Theara & Abbott (2015)	Perepa (2014)	Doig (2012)	Jagatheesan (2011)	Jagatheesan et al., (2010a)	Jagatheesan et al., (2010b)	Warner (1999)
The Impact of Acculturation	Being Muslim in a Western world Perceptions of autism in family members living in Pakistan	Culture, religion, education, socio-economic class influences BME parents access / use of services	Immigration is related to accessing resources and improving current situation. Autism seen as a potential threat to overcome	Acculturation within western society impacted value placed on certain skills	Levels of acculturation contributed to he level of parental engagement with services Parents felt a degree of affiliation to Bangladeshi culture Parents describe asserting a Muslim identity was more progressive / inclusive				
Impact of Autism on Family Life	Positive impact of parenting a child with autism Life in the wider Pakistani community	Some BME parents felt more supported by education provider than own ethnic community	Parents wanted to deal with things in their own way		Families benefited from the informal support of wider family.				

Theme	Paper								
	Habib et al., (2017)	Nair (2015)	Theara & Abbott (2015)	Perepa (2014)	Doig (2012)	Jagatheesan (2011)	Jagatheesan et al., (2010a)	Jagatheesan et al., (2010b)	Warner (1999)
	Life within the immediate family		Parents did not expect support from outside services						
Parental Experiences / Parental Needs	Need for good communication with school Positive experiences of education Difficulties accessing services Lack of resources in mainstream settings	Parents expect of more professional support than they receive Preference for mainstream schooling Educational settings are 'colour blind'			Families were appreciative of support by professional services Families felt particularly helped by meeting people who had gone through similar experiences. Parent and professional interaction dependent on inteperson Difficulties associated with accessing services during				

Theme	Paper								
	Habib et al., (2017)	Nair (2015)	Theara & Abbott (2015)	Perepa (2014)	Doig (2012)	Jagatheesan (2011)	Jagatheesan et al., (2010a)	Jagatheesan et al., (2010b)	Warner (1999)
					/ after diagnosis				
Multilingualism, Perceptions and Experiences					Parents felt professionals did not support maintenance of home language Parents felt maintenance of home language was important for inclusion in wider family Parents were distrustful of professionals that employed deficit language about their child				

Appendix 5: Timeline for Research Phases

Date	Research Phase and Activity
June 2021	**Recruitment** • Contacting EPS • Contacting disability support services
September 2021	**Recruitment** • Parent flyers sent out to LA specialist schools support workers • Parent flyers sent out to SENDIASS
October 2021	**Recruitment** • Attended in person SENDIASS parent support group
November 2021	**Recruitment / Data collection** • Pilot study conducted • First participant was recruited and interviewed
December 2021	**Recruitment / Data collection** • Switched to online recruitment • 4 parents were interviewed online
December 2021 - February 2022	**Data analysis** • Transcription • First phase of data analysis (including sharing excerpts of restorying with supervisor, and storied narrative with participants)
February 2022-March 2022	**Data analysis** • Second phase of data analysis
March 2022 – April 2022	**Completing thesis write up**

Appendix 6a: Research Flyer

Are you a **Bangladeshi** parent of a child with **autism?**

I would like to know more about **your** experiences of **raising** a child with **autism**

There is very little research looking at Bangladeshi parents who are raising a child with autism.

My research will provide an opportunity for you to share your experiences and views in an **anonymous** and **confidential** way

I hope the information you share will be helpful to you, the wider Bangladeshi community and professionals that work with parents.

you are of Bangladeshi heritage
r child has received a diagnosis of
ism, please get in touch.

If you are happy to take participate please send an email to U1524390@uel.ac.uk or the school can do that for you. We will then arrange a convenient time to talk more about the research

Appendix 6b: Information Sheet for Parents

What is the Research?

- The aim of this research is to explore the experiences of Bangladeshi parents of raising a child with autism.
- I am particularly interested in understanding how you make sense of your child's autism and how this has impacted your parenting and wider relationships with community and school.
- It might be useful to consider how you perceive your journey towards diagnosis, how you see yourself managing now and looking towards the future for you and your child.
- I am interested in how your experience of parenting an autistic child is both similar and different to the challenges faced by other parents

Why is it Important?

- There is some research around South Asian parents and their experiences of parenting a child with autism
- There is **very limited research into Bangladeshi parents** who are parenting a child with autism
- This research would provide opportunities to share your experiences and views
- I hope to use this information to help professionals work with parents in a culturally inclusive and responsive way

The Researcher

I am Rasna, I am a Trainee on the Doctoral course in Educational and Child Psychology at the University of East London.

I am very interested in exploring the ideas and experiences of Bangladeshi parents as they navigate parenting a child with autism

Who are the participants?

I am interested in speaking to:

- English speaking Bangladeshi parents
- Whose child has received a diagnosis of autism.

All images copyright free from "Vecteezy.com"

What will the research involve?

- If you agree to participate in this research, I will send you a consent form to say you are willing to take part in the research.

- Once I receive these, I will organise a time that is mutually convenient so I can explain what the research is about and what it will entail.

- Following on from this I will arrange an online discussion between you and myself, this will be online and recorded. It is envisaged that this will last between 30-60 minutes

- I will organise a third and final session with you, so I can check my understanding of your experiences with you. This will be at least a month after our online discussion.

Session 2 (interview) will be recorded and later transcribed by the researcher.

Confidentiality

Data will be anonymised, and pseudonyms will be chosen by you or allocated by me. All recording and transcriptions will be kept stored securely on a password protected laptop and then uploaded to a secure encrypted online storage space. The information gathered will be kept centrally in a secure data base at the university for 5 years.

All information will remain confidential unless you disclose information which might suggest that you or anyone around you is at risk of harm. In which case I will need to pass on the information to the relevant authorities.

Supervision and ethical approval

Ethical approval has been granted by the University Research Ethics Committee at the University of East London

My supervisor is Dr Mary Robinson and she can be contacted in the following ways: Dr Mary Robinson. School of Psychology, University of East London, Water Lane, London E15 4LZ,

Email: M.Robinson@uel.ac.uk

What should I do now?

If you have any further questions, please feel free to contact me on my email U1524390@uel.ac.uk. If you are happy to take participate please send the attached consent form to me via email.

Disclaimer

You are not obliged to take part in the study and are free to withdraw at any time. Should you decide to withdraw from the research you are able to do so without being placed at disadvantage and without obligation or reason.

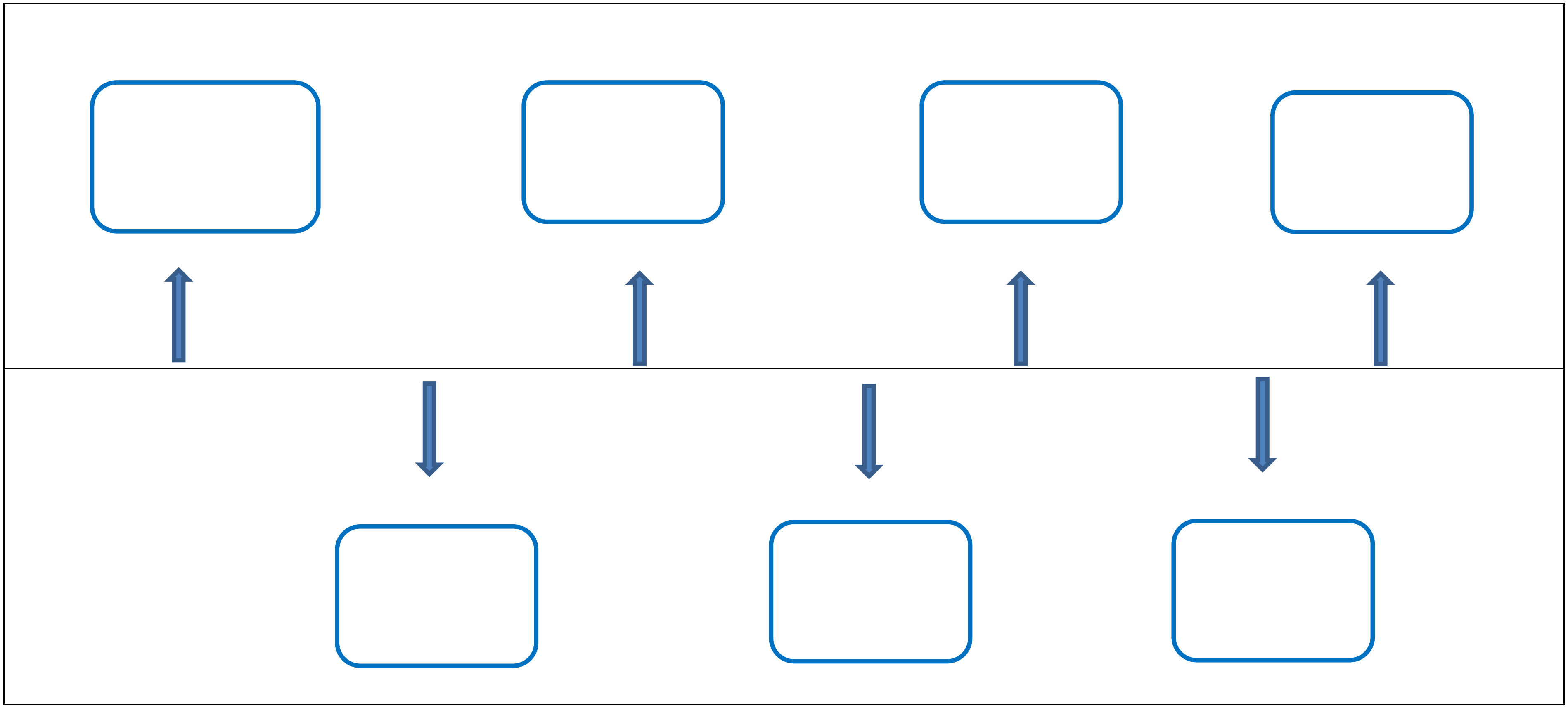
Thank you for your time, Rasna Begum Email: U1524390@uel.ac.uk

Appendix 7: Life Story Grid (with prompt)

Introducing Timeline

To help you tell me your story, we can use the timeline to help plan what you would like to tell me about your experiences of being a Bengali and a parent of a child with autism.

The idea is that each box represents a significant event or life experience that occurred and plays an important part in your story. The beginning of your story goes in the first box of the timeline and the most recent part of the story goes in the last box.



Appendix 8: Consent Form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Research focus: Exploring the narratives of Bangladeshi parents who have a child with autism

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher in the study will have access to identifying data.

It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after three week of the interview taken place after which the analysis of the data will have begun and withdrawal will no longer be possible.

Some of the things you have shared (anonymised extracts from the transcripts) will be included in my thesis and may be included in a published article in an academic journal in the future.

Do you give consent for me to include anonymous extracts from your interview in an academic journal in the future?

Participant's Name (BLOCK CAPITALS)

……………………………………………………………………………………

Participant's Signature

……………………………………………………………………………………..

Researcher's Name (BLOCK CAPITALS)

RASNA BEGUM

Researcher's Signature

R Begum

………………………………………………………………………………………

Date: ……………………..…

Appendix 9: Debrief Letter

PARTICIPANT DEBRIEF LETTER

University of
East London

Thank you for participating in my research study exploring the views and experiences of Bangladeshi parents who are parenting a child with autism. This letter offers information that may be relevant in light of you having now taken part.

What will happen to the information that you have provided?

The following steps will be taken to ensure the confidentiality and integrity of the data you have provided:

Your privacy will be upheld at all times. Any information which may identify yourself or anyone else will be anonymised and audio recordings of the interview can only be accessed by the researcher. Any information which could potentially identify yourself or anyone else will be anonymised using pseudonyms before the data analysis. Personal contact details will be stored on my password protected OneDrive Microsoft account and will be kept separately from the interview data. Consent forms, interview recordings and interview transcripts will also be stored securely on my OneDrive account for a year, at which point they will be destroyed.

My research findings will be shared with my university tutors and colleagues at Enfield Educational Psychology Service but in a format that is fully anonymised. It may also become available on academic journals online. Your interview recording will be transcribed within 4 weeks of the interview taking place, upon which it will be deleted. Anonymised data such as interview transcripts will be kept securely in the University of East London data repository for 5 years, upon which it will be destroyed.

You may also request to withdraw your data even after you have participated, provided that this request is made within 3 weeks of the data being collected (after which point the data analysis will begin, and withdrawal will not be possible).

What if you have been adversely affected by taking part?

It is not anticipated that you will have been adversely affected by taking part in the research, and all reasonable steps have been taken to minimise potential harm. Nevertheless, it is still possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected in any of those ways you may find the following resources/services helpful in relation to obtaining information and support:

Child Autism
HELPLINE
If you need advice or
support just call
01344 882248

Child
Autism UK
releasing potential

https://www.childautism.org.uk/for-families/parent-to-parent-support/

National Autistic Society

Parent to Parent Emotional Support Helpline

https://www.autism.org.uk/what-we-do/help-and-support/parent-to-parent

Telephone: 0808 800 4106

You are also very welcome to contact me or my research supervisor if you have specific questions or concerns.

Contact Details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Rasna Begum Email U1944291@uel.ac.uk

If you have any questions or concerns about how the research has been conducted, please contact the research supervisor Dr Mary Robinson. School of Psychology, University of East London, Water Lane, London E15 4LZ,
Email: M.Robinson@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Ian Tucker, School of Psychology, University of East London, Water Lane, London E15 4LZ Email: i.tucker@uel.ac

Appendix 10: Copy of UEL Ethical Approval

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Icram Serroukh

SUPERVISOR: Mary Robinson

STUDENT: Rasna Begum

Course: Prof Doc in Educational and Child Psychology

DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The

revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

(Please indicate the decision according to one of the 3 options above)

Approved, but minor amendments are required before the research

Minor amendments required *(for reviewer)*:

4.2 – I would advise anonymising at point of transcription, rather than at the analysis stage. This way, as the entire transcript is anonymised, this will significantly minimise the potential of anyone but the researcher ever finding out the identity of the participant.

The researcher will anonymise all identifying features at transcription stage. This is to minimise the potential for anyone but the researcher being able to identify the participant.

If the researcher is planning to publish findings, as stated in section 4.5, it would be wise to include a clause in the consent form which explicitly states that the participant consents to excerpts from their interview being published.

Add to consent form:

Some of the things you have shared (anonymised extracts from the transcripts) will be included in my thesis and may be included in a published article in an academic journal in the future.

Do you give consent for me to include anonymous extracts from your interview in an academic journal in the future?

Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students)*:

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):* Rasna Begum

Student number: U1524390

Date: 20.05.2021

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

[✓ YES] / NO

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: Dr Icram Serroukh

Date: 19/05/2021

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

Appendix 11: Copy of LA Ethical Approval

Rasna Begum
[redacted]

[redacted]

25
August
2022

[redacted]

[redacted]

Reference: CERGF262

RGF Application Approval

Dear Rasna

Research Title: Exploring the narratives of Bangladeshi parents that have a child with autism

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

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

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

I wish you well in your research study.

[redacted]

[redacted]

[redacted]

Appendix 12: Amended Ethical Approval

UNIVERSITY OF EAST LONDON

School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Trishna Patel (Deputy Research Director/Chair of School Research Ethics Committee).

HOW TO COMPLETE & SUBMIT THE REQUEST

Complete the request form electronically and accurately.

Type your name in the 'student's signature' section (page 2).

When submitting this request form, ensure that all necessary documents are attached (see below).

Using your UEL email address, email the completed request form along with associated documents to: Dr Trishna Patel at t.patel@uel.ac.uk

Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.

Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.

Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.

A copy of the approval of your initial ethics application.

Name of applicant: Rasna Begum

Programme of study: Professional Doctorate Educational and Child Psychology

Title of research: What are the experiences of Bangladeshi parents with a child who has a diagnosis of autism?

Name of supervisor: Mary Robinson

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
The following amendments are being requested which will impact on: **3.4 Participants** I wish to **withdraw** the following statement – *Each participant will have had at least 3 since the participant's child has received their diagnosis of autism. The thinking behind this inclusion criteria is to allow the parent a reasonable period of time to have elapsed post diagnosis. In this time period, it is hoped that they will have absorbed /come to terms with the implications of the diagnosis (past). Also, to be in a place to consider their 'present' and possibly begin to look towards the 'future'. 3 years was considered to be a reasonable period of time for the participant to be able to recall that time, but also not to feel unduly distressed by their recollections.*	

Remove criteria '3 years post autism 'diagnosis to allow for a wider pool of parents to be recruited.	The focus of the research is Bangladeshi parental experiences of parenting a child with a diagnosis of autism. By extending the recruitment criteria, it will enable those recently gone through the diagnosis procedure to take part and widen the research pool of participants.

The following amendments are being requested which will impact on:

3.5 Recruitment:

This is statement is **now added** to original ethics form –

Should this method of recruiting participants not provide the required number of intended participants, then the researcher will consider approaching additional London Boroughs for their support. Only Local Authorities that ***do not*** *require additional ethical approval form their own ethics board will be approached. The Educational Psychology Service in each of these additional local authorities will be approached. It is envisaged that this will enable me to contact each authority's specialist autism support service. This service will then help the researcher identify schools and clients that they have supported, who meet inclusion criteria. Schools identified with the support of the autism support service will be approached via email. In addition, Educational Psychologists will be asked to consider clients that will meet the inclusion criteria. The information leaflet (Appendix A) will be shared with the additional London Boroughs.*

Change the recruitment method to allow recruitment in local authorities outside of Tower Hamlets.	The desired sample is hard to reach and it has not been possible to recruit the desired number of participants (5) in Tower Hamlets. Therefore, by widening the recruitment method, hopefully the researcher will have access to a wider research pool and find it easier to identify and recruit participants as parents will be able to choose to take part.

The following amendments are being requested which will impact on: **3.5 Recruitment:** This is statement is **now added** to original ethics form – *In addition, I would like to recruit through social media platforms such as Facebook and Twitter, the accounts used would only identify me as a trainee educational psychologist studying at UEL. I would share my participant poster and ask interested participants to get in touch via my university email. Participants that met inclusion criteria would be asked to participate. Once the desired participant number was achieved (5) then I would stop using this platform to recruit.*	
Changing the recruitment method to allow online recruitment.	The desired sample is hard to reach, the current recruitment method, through the Educational Psychology Service, schools and parent support groups has not been successful. To date, it has been possible to recruit 1 of the 5 participants needed for the study. Therefore, by widening the recruitment method, hopefully the researcher will have access to a wider research pool and find it easier to identify and recruit participants as parents will be able to choose to take part.
5.18 Parents will be provided with a £10 digital Amazon voucher to thank them for participating with their child.	This is in recognition of the time that parents will take to meet with me.

Please tick	YES	NO
Is your supervisor aware of your proposed amendment(s) and agree to them?	X	

Student’s signature (please type your name): Rasna Begum

Date: 10/11/21

TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		

Reviewer: Trishna Patel

Date: 11/11/2021

Appendix 13: Data Management Plan

Appendix 14: Example of Transcript

Example of Nila’s Interview Transcript

(Excerpt of Nila’s transcript, numbers refer to line numbers in the original transcript)

INT: Yeah.

Yeah, and. So then she said that her nephew has it and and then she started giving me .... So there's a children centere nearby that is for special needs children and she said I would like you to go there and and see how he does there? So that's when I went, and and I met the most amazing people that helped me get his diagnosis. And at that time, I'm still hopeful they've got it wrong. You know he's gonna start talking. Because at the same time

Nila: : that I was doing this I was talking to my family, talking to my in laws and all of them are saying the same thing to me. He's a boy. He's slower. You know he'll pick it up and so and so spoke at three so and so you know.

INT: Yeah.

Nila: : So, I'm dealing with all of that, and then I'm dealing with. I had two kind of different lives with him and so then I'm kinda doing his diagnosis, and I knew by the time I had done all my research I knew this is what he's got. Every single trait, he’s got it?

INT: Umm.

Nila: : And and then when we got the diagnosis, they're still telling me, both families. Oh, you know that's fine. Just just pray. Just pray, maybe go haj. Maybe go ummrah, he'll be fine. You know they're kind of seeing it as an illness.

INT: OK.

Appendix 15: Example of Colour Coded Stanza According to the Elements of the Three-Dimensional Framework

(Excerpt of Mim's colour coded stanza, numbers refer to line numbers in the original transcript)

Key to Colour Coding:					
Interaction		Continuity			Situation
Personal	Social	Past	Present	Future	Context

161 **Mim:** And so I attended this (.) Uhm this seminar at my child's local school where they invited a
162 speaker and you know I sort of went along just just for information really just to see what's out
163 there(.) And this speaker came along and you know he's he was talking about how he will, he says
164 over freelance advisor for schools(.) To help support children with needs, particularly with autism(.)
165 And then he spoke really, really well(.) You know, very articulate, very knowledgeable, and you
166 know(.) And then you know at the end of it he was(.) He said, you know, he was himself autistic, and
167 you know he went on to speak about his family, his wife, his kids(.) And then when he starts started
168 to speak about all of that, I I don't know what happened, but I just sort of got this(.) Relief from you
169 know, and this connection I suppose(.) Maybe with him as well, like as in I just, you know(.) Honestly
170 I was just like wow(.) He has autism and he's here(.) He's married(.) He has children, his living(.) He's
171 working(.) It was all of that(.) All these you know things questions and know things in my head like it
172 was on it was like one of those light bulb moments for me it was like(.) OK, life can be OK for people
173 who have autism and they can survive and they can do this(.) And I mean you know he was really I
174 mean an inspirational speaker as well(.) He spoke so well and he the things that he spoke about, how
175 you know his life had been, you know he was saying he grew up in the 70s and early 80s and you
176 know at that time there was no events like this and you know his mom had to sort of drag him to
177 school he's crying and screaming and he would you know have his head in his lap all the way through
178 the school and all of that(.) And you know, it sort of really reassured me put my fears(.) And I felt a
179 sense of relief that actually this doesn't mean that you know a person cannot survive in the world
180 and you know(.) There is life with autism if you like(.) And and I think on that day I saw you know, it
181 was(.) I came away from that seminar(.) You know, really feeling empowered, you know, and I'm
182 thinking that's it, OK(.) I'm not going to, you know, be so worrying(.) And you know how, how would
183 this(.)There are things that then I'm going to go out there and educate myself(.) And really, you
184 know(.) Live a better life now(.) A better quality of life for myself and my children for my family as
185 well and go out there and not(.) You know, think that Oh my gosh, my child has autism and you
186 know I have to sort of(.) Carry it like a burden(.) If you're like, really(.)

Appendix 16: Example of Completed Three-Dimensional Framework

Example of Completed Three-Dimensional Framework

(Excerpt of Mim's Three-Dimensional Framework, numbers in brackets refer to line numbers in the original transcript)

Interaction		Continuity			Situation
Personal	Social	Past	Present	Future	Context
'I I don't know what happened, but I just sort of got this(.) Relief from you know, and this connection I suppose(.) Maybe with him as well, like as in I just, you know(.) Honestly I was just like wow(.) He has autism and he's here(.)' (168, 169, 170) And you know, it sort of really reassured me put my fears(.) And I felt a sense of relief that actually this doesn't mean that you know a person cannot survive in the world and you know(.) There is life with	'(.)He has autism and he's here(.) He's married(.) He has children, his living(.) He's working(.) It was all of that(.) All these you know things questions and know things in my head like it was on it was like one of those light bulb moments for me it was like(.) OK, life can be OK for people who have autism and they can survive and they can do this(.) ' (172-173) 'And then he spoke really, really well(.) You know, very articulate, very	'he was saying he grew up in the 70s and early 80s and you know at that time there was no events like this and you know his mom had to sort of drag him to school he's crying and screaming and he would you know have his head in his lap all the way through the school and all of that(.)' (175, 176,177,178)	'A better quality of life for myself and my children for my family as well and go out there and not(.) You know, think that Oh my gosh, my child has autism and you know I have to sort of(.) Carry it like a burden(.) If you're like, really(.) ' (184, 185, 186)	'And and I think on that day I saw you know, it was(.) I came away from that seminar(.) You know, really feeling empowered, you know, and I'm thinking that's it, OK(.)' (180, 181,182) 'And you know how, how would this(.)There are things that then I'm going to go out there and educate myself(.) And really, you know(.) Live a better life now(.)' (182-184)	'And so I attended this (.) Uhm this seminar at my child's local school where they invited a speaker and you know I sort of went along just just for information(.)' (161,162)

Interaction		Continuity			Situation
Personal	Social	Past	Present	Future	Context
autism if you like(.) (178, 179,180) I'm not going to, you know, be so worrying(.) (182)	knowledgeable, and you know(.) And then you know at the end of it he was(.) He said, you know, he was himself autistic’ (165, 166)				

Appendix 17: Example Illustrating the process of creating Interim Narratives and using these to create Storied Narratives

(Excerpt from Mim's interim narrative, numbers in brackets refer to line numbers in original transcript)

Interim Narrative	***Storied Narrative***
Feeling empowered / wow moment I attended this (.) Uhm this seminar at my child's local school where they invited a speaker and you know I sort of went along just just for information. (161, 162) He's married(.) He has children, his living(.) He's working(.) It was all of that(.) All these you know things questions and know things in my head like it was on it was like one of those light bulb moments for me it was like(.) OK, life can be OK for people who have autism and they can survive and they can do this(.) *(172-173)* I I don't know what happened, but I just sort of got this(.) Relief from you know, and this connection I suppose(.) Maybe with him as well, like as in I just, you know(.) Honestly I was just like wow(.) He has autism and he's here(.)(168, 169, 170) I'm going to go out there and educate myself(.) And really, you know(.) Live a better life now(.)(182-184) And and I think on that day I saw you know, it was(.) I came away from that seminar(.) You know, really feeling empowered, you know, and I'm thinking that's it, OK(.) (180, 181,182) I'm not going to, you know, be so worrying(.) (182)	***Feeling empowered /wow moment*** Mim attended a workshop at Riz's school, the guest speaker shared his experiences of being an autistic child. Mim had a light bulb moment where she realised that people can be autistic, work and have a family. This really reassured Mim and she felt a sense of relief and made a decision not to worry. Mim described feeling empowered by listening to the speaker and decided she was going to educate herself. Mim decided not to carry her son's diagnosis of autism like a burden and wanted to go out there and ensure a better quality of life for her family. (161-186)

A better quality of life for myself and my children for my family as well and go out there and not(.) You know, think that Oh my gosh, my child has autism and you know I have to sort of(.) Carry it like a burden(.) If you're like, really(.) (184, 185, 186)	

Appendix 18: Overview of Narrative's Thematic Stanza's Across Storied Narratives

Colour Codes for Shared Storyline in Parent Narratives	
Trying to understand and make changes	What others say / do?
Feelings / Emotional World	Explaining to others
Impact on family life	How I have helped myself
Fitting in	Hopes and worries for the future

Raina	**Nila**	**Tahira**	**Mim**	**Aliya**
Every autistic child is unique	Lack of understanding from the Bengali community	Early days – very sensitive and very attached	Early days	Being Bengali is being social and family orientated
Explaining to the older generation	Needing to constantly educate the Bengali community	Early upheaval – explained behaviour	First assessment	Not caring if they upset someone (learning not to care)
Comments that she is spoiling him	Feeling like your autistic child is invisible to others	Struggle to cope with her son's behaviour.	Time in-between	Early signs / speech delay
Knowledge and understanding in Bengali community is limited	Excluded from family gatherings	Initial surprise - CAMHS referral / diagnosis – High Functioning Autism	Second assessment	Emotional toll
People from the outside think it's easier than it is	Family expectations that don't take into account the child's needs	Autism is not something you can 'fix' - you need to adapt.	Relief and worry	Initially rejecting the diagnosis
A typical day	Competitive comparisons	Adapting and managing his behaviour	Wow moment	Infant school / Junior school experiences
Language delay	'But he is so handsome'	Difficulties around change and new experiences	Taking risks - make changes	Putting things in place to support needs

Raina	**Nila**	**Tahira**	**Mim**	**Aliya**
Denial	Change his name – things will change	Not being able to do things that other parents do.	Networking online – learning through the experience of others	Needs change as he develops
Looking for causes	Reasons for his condition: Jinn (spirits) /shaiytan (devil)	Sensitivities – hard for others to accept	To share or not to share diagnosis? Stigma	People don't always understand him
Not knowing that autism has abroad spectrum	Medical problem, therefore curable	The need for stability and routines	Managing her own anxieties	Masking looks different for boys and girls
Increase in the number of cases of autism	'Their heart is in the right place'	Not being able to explain in a way that others understand	Filling his gaps is not the answer Uncertainty	Sharing the diagnosis selectively
Not knowing about the help that is on offer from professionals	People find it hard to make adaptations (disappointment)	Parents see her son as being very sensitive – don't understand this autism idea.	Important to remain positive	Autism is not something that can be 'fixed' it needs to be managed
Diagnosis helps make sense of behaviour	Asserting the choice for a special school	Son's sensitivities that parents don't understand.	Adjusting to Riz	Her son was labelled as 'naughty'
Sharing the diagnosis with other people	Lack of awareness means people don't make accommodations	Not speaking Bengali can be a good thing	Wanting to raise the profile of the Bengali experience.	Standing out – having routines
R's family have been supportive	Lack of community education	Wish for grandparents to understand her son	Parents who might need more help than others.	Impact on wellbeing
Knowing what his triggers are	Having your parenting skills questioned	Comparison's with extended family members	Early help / support is important	Unable to do normal parent things
Learning from the experience of others.	Younger generation seem to understand (Hope)	Positives about your child	Seeing the possibility of a positive fulfilled life	Reading about the experience of others has been helpful.

Raina	**Nila**	**Tahira**	**Mim**	**Aliya**
The need for understanding about autism	Parental guilt– autism something you caused.	School is oppressive and stifling	Advocating for your child (swimming / haircuts)	The need to be constantly vigilant / police
Feeling criticized when you are out with your child.	Not knowing about autism – the unknown	Needing to do things in his own way	Being ok with the idea that your child has autism	Having other children
A special kind of love	Living two separate lives – external world where autism exists, community - 'He will grow out of it'	Feeling frustrated with her son	'Why me?' Mentality	Siblings meant he had to be independent.
'normal' parenting aspirations	Dealing with diagnosis as a father	Raising awareness in the Bengali community	Language barriers to explaining about autism	Parenting as a mother, parenting as a father.
Difference should be celebrated	Dealing with diagnosis as a mother	Tahira is managing	Explaining how your child is different can help explain what autism is	Second generation Bengali's understand
	Looking back – how things were	The benefit of emotional support	Post diagnosis. Now what?	Awareness about autism is growing
	How things are now		Cultural identity. Heritage language	Hidden disability
	My autistic child is invisible		Eating with his hands (fitting in)	Managing friendships
	Forcefully making your own family understand		Faith – celebrating successes	Needing to be a well-informed parent
	Being assertive - situations bring it out in you.		Learning about faith in his own way – lifelong journey	Worries and hopes for the future
	Challenging Bengali women – who describe her son as 'naughty'		The need for knowledge and awareness in the Bengali community.	Teaching skills for life
	Homeschooling her other children		Empowerment = advocating for your child	

Raina	Nila	Tahira	Mim	Aliya
	Support and understanding that comes from people who have CYP with similar needs.			
	Language differences - MH issue			
	Constantly having to explain – credibility – they know better.			

Appendix 19: Summary of Identified Narrative Themes and Corresponding Sub-themes

Narrative theme	Sub theme
A: Parental Meaning Making	- Autism as an Unknown - Making sense of the Causes - Accepting the Diagnosis - Gendered Experiences - Adapting to the Child
B: The Emotional Impact of Parenting a Child with Autism	- Emotional Pressures - Pressures around Food - Feelings of Isolations and Disconnection
C: Extended Family Relationships and Wider Support	- Understanding and support
D: Extended Family Understandings and Responses	- Alternate Faith Based Understandings - Autism as Something that can be 'fixed' - Bad Parenting and Blame
E: Lack of Understanding from the Older Generation	- Sharing the Diagnosis - Not having the Language to Explain in a Meaningful Way - Sensory Difficulties are Hard to Explain and Understand
F: Connections that Support a Cultural Identity	- Connection through Food - Language and Identity - Connection through Religious Faith
G: "then and now"	- Nila then, and Nila now - Mim's "Wow" Moment - Not Caring / Rejecting Traditional Roles - Advocating for your Child with Professionals
H: The Future	- The Potential Barriers and Raising Awareness - Hopes and Worries about the Future - The Future is Not Without Hope

Appendix 20: Nila's Story

Nila and her son Musa

Lack of Understanding from the Bengali Community

Nila describes having to educate a lot of people about autism, it's something she continues to do to this day, even though it has been 3 years since her son's diagnosis. With some people she would say they have come a long way, but with others they are still at the beginning. The constant battle has made them isolated as a family from the wider community.

Experiences within the Family

A lot of people don't see her son as another being, he is often ignored, and people will ask about her daughters. But the questions about her son, Musa are intrusive. When it comes to getting to know Musa, they think it best just to leave it. This is something Nila and her husband have an issue with and now they only mix with a select few people. As a result, the family don't bother anymore with social gatherings very much.

Nila has left quite a few houses and weddings crying because she can see the experience has been like torture for her son. The family don't bother anymore with social gatherings. Now with the isolation (for Covid-19) they just don't get invited to a lot of places because they just don't want to cater to his needs and would rather take him out of the equation altogether. This has been Nila's experience of the Bengali community.

Recently Nila's brother in-law got married and it was a sad experience as Musa wasn't invited to the wedding. Nila had asked the family to make accommodations about the timing of the event so that Musa could attend, and she was encouraged to get her family to look after him instead. Nila doesn't think the family realised how deeply hurtful she found this. Her son, their grandson / nephew does not get a mention. People assume he is not even going to notice, but he kind of does. Musa knows who really loves him and when people are wary of him and he kind of stays back from them.

The family went to an evening dawat (dinner party) not long ago, it was at her husband's aunt's house. The family live nearby so they agreed to go. Musa found sweets everywhere, so he was high on sugar and over tired, it was all too much for him and by the end of the evening he was sat in the cat bed. Nila waited until the men were fed around 10 o'clock and then wanted leave as Musa was going crazy.

That evening, four different women told her off for leaving without having eaten the hosts food, this was considered very rude, and she was painted as the bad guy. Nila is used to this kind of response and doesn't let it phase her anymore. People can be silly, making a specific request for her and her family to attend and then not cater for her children. Nila would like people to understand that her son is her priority, and not make things harder for her.

Family's Lack of Understanding

Nila has heard a lot of competitive comparisons; people don’t realise that every child with autism is unique. Often Nila will hear that so and so’s child is out of nappies and they have autism, or so and so can speak now. They put it down to her or her husband's bad parenting.

When NIla takes her son anywhere, women will often say “But his face is so normal” or “But he’s so handsome”. As if this has anything to do with anything. Nila finds this so offensive; she will often have to take time to explain about Downs Syndrome and then autism.

Nila’s son Musa is named after a prominent prophet in the Qur’an. This prophet is known for not having clear speech, lots of people have told Nila to change her son’s name. Nila considers this to be mumbo jumbo, but it hasn’t stopped people telling her that she should choose a name that will bring calmness to her son.

Family members keep saying superstitious things to NIla. A relative from America called and shared that someone had gone to a particular imam (religious leader), he blew over their son and he can now talk. Although Nila has respect for her mum’s relatives, she thinks they are talking absolutely rubbish. People want a cure for Musa, something she’s not looking for. So can become snappy with family depending on who they are.

NIla’s mother-in-law is looking desperately for a cure. They think what Musa has is curable. They have suggested she explore CBD oil, Chinese herbal medicine and Indian spices. Autism is not a curable condition; it’s something that the Bengali community need to learn more about.

Nila feels that the Bengali community feel her son’s condition is either curable or Jinn related. People have told Nila she needs to do Ruqyah (Qur'anic verses are said over a person for protection and healing) on her son, because they think some Jinn or shaitan (the devil) has hurt my child. Not long ago, her mother-in-law asked her to come over to meet someone. When she arrived, a man was there and wanted to speak with her. He told Nila that her son is afflicted, and autism is created by Jinns (supernatural spirit, below the level of angels or devils).

To Nila, this is not even someone who believes in God, because she feels that Allah (God) has given her a son with autism. There is benefit for her form being in this situation and she needs to look for it. For Nila, her son is a blessing. He is very special to her and brings so much joy to her home. When he smiles, everyone around him just stops and smiles with him.

At the time she felt strongly that this man was not allowed to see Musa, no one is allowed to see her son if they think his autism is because of XYZ. Previously NIla would have felt pressured and given it a go. NIla now, was deeply offended and left the house. Later on, women from the extended family called her and tried to persuade her that there was no harm in trying what the man was suggesting. It just left her fuming and made her blood boil. She recognises that they are not bad people, and they really honestly think that they are trying to be helpful. Instead, Nila would like to see them read a book, or take notice of the things she forwards on to them about autism or just educate themselves about it. To Nila, that would be the most helpful thing they could do.

Wanting to be Understood

In the past, Nila has phoned her mother-in-law to make the house child friendly before the family visit. When the family get there, they will still find sewing scissors or deodorant sprays lying around. Explaining what they can do to best help Nila and her family visit, just doesn't seem to work. Now they have taken a step back and only go to visit houses that are willing to help them and accommodate Musa. Nila's mother-in-law, now comes to her house to see the kids. It's sad that people won't put these helpful things into place to enable the family visit. People just don't understand the effort that goes into looking after children who are not neurotypical. So, they forget.

Musa attends a special needs school in an area where not many Bengali's live. Nila's friendship circle includes parents from the school her son attends. She describes the group as closer than some family members because they all understand each other and accommodate each other and their child's needs. They can see that adapting for a child can make a child happy, and they do it. Nila has been in situations where family members have wanted to watch what they want on TV and refuse to make changes for her son. It's been deeply hurtful and upsetting.

Nila believes this happens because members of the Bengali community are not educated enough. They almost don't really want to know, if it doesn't affect them within their household, they kind of don't want to know.

There was a huge uproar from family when Nila decided to send her son to a special needs school, they felt strongly that he would look at all the other kids in mainstream school and become normal. This became a talking point for a lot of people. It was felt that by making this decision, Nila was institutionalising Musa and it would only make him worse. Nila knew that he would be terrified of the numbers of children in a mainstream class, and he wouldn't be able to do their routines.

People have always questioned Nila's parenting skills, this scrutiny extended to her two daughters, but even more so for her son. The younger generation seem to understand, but anyone older than 45 don't seem to get these things.

Journey to diagnosis

Back to the Beginning

Nila had two daughters and then her son Musa. She remembers that the girls hit their milestones really quickly. With her son, she would take him to the health visitor, and they would say “He’ll get there”, “He's a little bit slow”. There was no mention of the word autism. It wasn’t until they got to his 2-year-old review that they mentioned that there was something wrong. Nila recalls that the health visitor used a questionnaire and there was not one single thing that Musa could do. The nurse made Nila feel bad for not taking her son to play groups. With three children under three years of age it just hadn’t been possible. The experience left Nila feeling bad and tearful.

Eventually as the older children went to Nursery and Reception, Nila went along to children's groups with her son. Whilst all the other children were playing, Musa would just sit there and cry. One day he just started hitting his head against a bookshelf, NIla remembers he was really hurting himself and she could see all the mums staring. She took Musa to the toilet and was trying to soothe him when a worker from the Children’s Centre came in and offered her a cup of tea and a chat. Nila didn’t take her up on the offer, she put Musa in the stroller and recalls crying all the way home.

Nila’s husband didn’t think it was a good idea to go back again and Nila was fine with that too. The Children’s Centre worker phoned Nila and wanted her to come in and talk further. Autism was not something Nila knew much about, she had heard about it in passing so when she was asked if she thought her son might have autism, it felt unknown. The worker told her about her own nephew who had autism and gave her information about a children’s center that was for special needs children. Nila met the most amazing people at the children’s center and they helped Musa get his diagnosis.

At the same time Nila was still hopeful that the professionals were wrong, and that Musa was going to start talking. Her own family and in-laws were offering different reasons why Musa was the way he was. It felt like she had two different lives with Musa. Her family were saying that “He’s was a boy, he's slower”. “You know he will pick it up” and “ So and so spoke when they were three”. After doing her own research, Nila realised that Musa had every single trait of autism that she had ever read about. Even after the diagnosis, both families were telling Nila that everything would be fine, and she just had to pray and go to ummrah and hajj (both different types of pilgrimages to Mecca). They saw his diagnosis as an illness. This is something that still gets to Nila to this day.

Dealing with the Diagnosis as a Father

Musa’s father will often spend time explaining to family members that what Musa has is not an illness, it is something that he was born with and it’s a part of his son. NIla remembers that he wasn’t always so passionate about Musa. After 2 daughters and now a son, his family was complete. He imagined that Musa would play football with him, and they would go to the mosque together. Looking back, Nila saw that he had all these ideas of how he wanted his son to be. So, it took a long time to warm up to the idea of Musa and he grieved for the son Musa was not.

Dealing with the Diagnosis as a Mother

In contrast, Nila as a mum had to make do with whatever was thrown at her, she was dealing with him 24 hours a day, 7 days a week. Musa would never sleep, he would wake his dad and that would disturb his work, as a result he would be angry. Nila's husband ended up sleeping in a different room and she was left to deal with her son on her own. So, for Nila, she had to accept things straight away and get on with things herself.

Looking Back, Then and Now

One thing that stuck with Nila is that people will always ask about the girls, not her son. This upsets her to this day. Nila is closer to her own family than her in-laws and she can see that they are much more aware. Lots of conversations have been had about Musa's speech, where family members have told her not to worry, he will grow out of it. Nila recognises she has in the past put up with a lot of rubbish people say. Now days, she will tell people that if her son doesn't talk, that's ok. He will communicate in other ways.

With her own family she has been much more vocal. Making a point that this is autism, watch this documentary, read this book, get to know it. It's not going away. This has changed her own family's perceptions and they've made adjustments that make her more comfortable to visit. Nila accepts that her approach with her own family is different to that with her in laws, she can scream and make her point with her family, something she can't do with her in-laws.

Nila Three Years Ago, Nila Now

An experience in a park during Ramadan made Nila reflect on how her approach had changed. The family had taken her son to a park, it was lockdown, and he needed his physical activity. Musa had run towards the riverside, Nila and her and her husband were picking him off the floor and putting him in his stroller. Musa finds transitioning between activities hard and will lie on the floor and cry. Whilst this was happening a lady walked past giving them a very dirty look. Musa's dad knew what was coming, Nila was much stronger than she had been before. She recalls asking her husband to deal with her son and she ran up to the woman. Nila made the woman know she had noticed her watching and explained that her son has autism, is nonverbal and has sensory processing needs. He was finding it difficult to transition back into the car. The woman's face dropped, and she walked away. Later, at the car, the same lady approached the family and Nila thought she was coming to start a fight and to her surprise the woman apologised. Nila felt it important for the woman to know about her son's needs, his crying can make people think they are hurting him. To Nila, if passers-by do actually think that she is are hurting her child, then they should proactively get involved and ask what’s happening. Instead, people just stare in a really dirty way.

After the incident, Nila’s husband looked at her in a different way. He was used to seeing her as this little lady who never says anything. But she had just yelled at a woman and got her to apologise. Looking back, Nila is in two minds about whether she should have yelled at the woman as she was fasting (abstaining from food and drink, during Ramadan – trying to maintain a spiritual spirit in daily interactions). She realises it was probably the adrenaline that made her get those words out. But it gave her a confidence boost, she can now speak to anyone and everyone about her son, she is not ashamed. In recent times, Nila has found herself challenging even Bengali women who are calling her son naughty. Nila has told them that her son is exempt and does not have to adhere to their rules and he is free to do whatever he wants, she's sorry, but is going to basically let him do what he needs to do.

Looking back, it's almost like Nila is a different person dealing with it now. Home schooling her daughters has been important for NIla. Initially, they would all come home from school and in the afternoon, there would be this rush and she could never spend any quality time with any of them unless her husband was there. Nila never imagined she would home school her children, but two years ago Nila made the decision to home school her two daughters. An important experience for Nila was meeting a fellow special needs mum. In conversation, she had shared that her other children did not feel she had had enough time for them. Everything was always about their sibling with special needs. Nila never wanted her children to grow up and say that to her. She wanted to make time to do normal parent things with her daughters and home schooling them has allowed her to do that.

Support of Special Needs Mum Friends

Nila feels she has used the interview to rant, she has her special needs mum friends that meet every week for coffee. They take it in turns to just rant. In describing all the small parts of her life, she realises how incredibly hard it's been. Having lived it, it feels like a lifetime ago, but the family continue to live it every day, so it feels kind of bizarre.

Explaining to Family Members

Language Differences

Nila has been trying to explain to family members about what autism is, it's been really hard, the word autism means nothing to them. They think it's some kind of mental health problem. Looking back, she realises that you would hear someone had a child or a sibling in a residential home, it was classified as a mental health problem when actually they had autism. The word autism was never in their vocabulary so people would just class everyone under one box.

‘But that’s Bengali’s for you’

Musa’s dad’s Bengali is much better than Nila’s, she describes herself as using lots of English terminology, whereas her husband will take more time and patiently explain that children are born this way. Soon after Musa was born his dad decided he wanted to train to be a doctor and is now in his final year. Nila sees that now he is about to qualify (Insha-Allah, God willing) people take his words more seriously than they would have in the past. Even though he has taken time to explain in a way that they might understand, the next time they visit, he has to go through the same explanation all over again. So, it just feels like repetitive explanations, again and again but that’s what the older Bengali generation are like.

Appendix 21: Mim's Story

Mim and her son Riz

Early days

Mim remembers that there were no concerns or issues when Riz was born. Looking back, she recalls he spoke a little bit late and probably walked a little bit late. It was only when he went to preschool that a few things were shared with Mim; she was told he liked to play on his own and wouldn't really interact much with people around him. Mim remembers thinking he was a little bit shy; he'd grow up and catch up with everyone else.

Primary School

A similar thing happened when Riz started nursery at primary school. He again attended a couple of hours each day. The early years lead met with Mim and told her about the things Riz didn't like to do. He didn't like crowds and wanted to be on his own. Riz wasn't interested in interacting with adults or children around him. If he needed something, he would get it himself. Playing with Lego and water fascinated him; he spent a long time playing with these on his own. At the time, Mim remembers thinking that if Riz needed additional help, it was fine for the school to look into things further.

First Assessment

Mim didn't know much about autism, just what she had heard hyped up about autism and the MMR vaccine in the media. That was it, really. After initially feeling a bit reluctant but wanting what was best for Riz, Mim agreed to a referral to a consultant who specialised in diagnosing children with autism. The consultant was very thorough, and she was finally given the verdict. The consultant said Riz was very young, and he was still developing, and she wasn't 100% about the diagnosis. Riz was hitting the borderline benchmark for diagnosis. The consultant thought it best to wait another year or so.

Mim felt relieved that he wasn't given a diagnosis. She had been worried and wasn't sure what a diagnosis would mean for Riz. Mim came away that day feeling glad that it wasn't autism, whatever that was.

Time In-Between

The time between the two assessments was probably about a year and a half. Mim felt relieved that it wasn't what they had discussed but also felt selfish for feeling this way. Soon after school started, Mim started noticing little things, getting progress reports from school, and these small moments accumulated to what might be described as something big. Mim described how it would hit her all over again, that there were little things, signs that she couldn't reject; she did not want to be blindsided by this. Things that Riz was not able to do, his mannerisms made her think it was still there. Just because the consultant had said he was borderline didn't mean it had gone. Her attempts to lock this out wasn't working, and she approached the second assessment with an open mind.

Second Assessment

Time passed, and a year and a half later, Mim was asked to go through the same process again, but this time with more information from herself and the school. In the meantime, Mim had started her own research and had started to pick up on things at home. Mim saw the same consultant as she saw last time; again, she was asked if she wanted to take the diagnosis. Riz had just hit the mark where he would be given a diagnosis. The consultant was very knowledgeable and sat with her and gave some worldly advice. Taking the diagnosis would only help Riz; as he grew, he would probably struggle in life and probably academically too. Taking the diagnosis would mean Riz had access to extra funding, and it would be helpful in other parts of his life. The consultant went into great detail and talked at length about how things might be going forward for Riz as a child and for Riz as an adult. So, having a diagnosis was not a bad thing. Mim found the discussion with the consultant very helpful and realised that getting the diagnosis was OK and not the end of the world. Having a second appointment helped Mim get her head around her emotions and be more accepting of the diagnosis.

Relief and Worry

Mim felt some relief from accepting the diagnosis, knowing that there were other parents out there, and she wasn't the only one.

However, Mim did start to worry about what was next. She began doing her own research and attending classes, and these helped her to focus on what she could do to help Riz. Mim wanted to be proactive and equip herself with information about what was out there. She wanted to make sure that Riz was getting everything that he should be getting.

Mim realised that even though she was born and brought up here, she couldn't help but feel some social stigma. But even more, worrying for Mim was how was life going to be like for her child. She found herself concerned about how he would survive in the real world, cook for himself, manage money, get a job, an education and how others would treat her son.

Even with these worries, Mim was adamant that she was going to provide Riz with the tools and knowledge, so he could be as well informed as he could be growing up. Mim does not want to use the word ‘normal’ but wants Riz to live as a general being able to manage in the real world.

Feeling Empowered / Wow Moment

Mim had an important significant event that happened that really shifted her worries by a long way. Mim attended a workshop at Riz's school; at the end, the guest speaker shared his experiences of being an autistic child. Mim had a light bulb moment where she realised that people could be autistic, work and have a family. This really reassured Mim, and she felt a sense of relief and decided not to worry. Mim felt empowered by listening to the speaker and decided she was going to educate herself and would not carry her son's diagnosis around like a burden. Instead, she wanted to go out there and ensure a better quality of life for her family.

Certain Times Were Hard

Certain times were especially hard, especially when Riz was younger, going out to eat, attending family functions where there were a lot of people. Riz would cry; he did not like being there, particularly when it was a big family gathering. Mim remembers going to a family wedding, and Riz absolutely didn't like it; he cried and covered his ears all the way through. Riz has always had quite sensitive hearing. So, for quite a while, Mim avoided these types of gatherings, not wanting to distress him more than necessary.

Actually, Quite Adventurous Now

Mim made some changes, and things started to fall into place. Mim would take Riz out just by herself or with the family at quieter times. Taking Riz out at his comfort level, getting him used to being in restaurants initially and slowly, more family gatherings seemed to work. They would go to family gatherings for short times, leaving as soon as Riz got upset. Doing things like this made Riz calmer, and as a result, she felt calmer. Doing these things helped Mim do more things with the family and wider extended family, allowing him and the family to experience as normal a family life as possible. They have even managed to take him on an aeroplane for a family holiday; he absolutely loved it. Riz is actually quite adventurous now.

Find Out More – Make Changes

Mim decided to do her own homework and equip herself with information about the things that Riz would encounter in his life. She wanted to know what she should do and move forward. Mim sought advice from the SENCo in school. Most of all, she read a lot, looking at websites for self-help tools on overcoming tantrums and overcoming anxieties.

It just wasn't fair to put Riz in situations that would cause him to have meltdowns and tantrums. Mim would take managed risks and test how Riz would be in different environments.

Online Networking

Mim found it useful to join online self-help support groups through Facebook. For Mim, it was powerful to be able to reach out and connect with other parents with autistic children, reading about their experiences and ideas about what is going on out there. For mums, it's particularly important to reach out and engage.

To Share or Not to Share

Initially, Mim kept the diagnosis to herself and did not want to discuss it with anybody; not wanting people to look at Riz differently, saying it out loud somehow made the diagnosis more real. Mim described meeting other parents and attending seminars, classes and courses, basically gaining information and seeing how others were dealing with similar situations. Mim's worries and fears were being addressed by gaining more information.

Initially, Mim started by sharing with their immediate families. Both families were fine, and they had no problems with what she shared, especially her own siblings. Slowly, Mim began to share with her friends but still wouldn't say her son was autistic. She reflected that she wasn't sure why that was.

"A Good Talking To"

Mim did not want to be one of those people who wanted to avoid autism because of worries about social stigma but reflects that, in some ways, this must have been something that subconsciously played on her mind. Mim described seeing the impact of the stigma and seeing other people dealing with it. When situations like this would get to her, she would sit down and give herself a good talking to. For Mim, it wasn't what others would think; he was her child; this was her anxiety. Mim recalls sitting down and talking to herself about it. Coming to realise it was fine, this was her family, her child, and she didn't care what other people have to say.

The Important Things

It has been important not to look at everything through doom and gloom spectacles. It was important that Mim not just label Riz and just talk about autism all of the time. Whatever he was achieving academically, they celebrated that and made it feel like he had achieved.

When it came to choosing Riz's secondary school, she looked for a nearby school that had a really good SEN provision as well. Mim lives in a highly populated Bangladeshi community, so having people that are of the same ethnic background as Riz so that he could identify with those around him was important to her. They are a close-knit family, so having family in the area was also something Mim looked for in a school. Growing up around an extended family would mean that they would be able to help Riz in times of need.

Adjusting to Riz

Mim described how Riz has always had something about stairs, particularly when he was younger. Whenever the family went somewhere, to his grandparent's or other families' houses, he would sit on the stairs and play; he would often take his Lego with him everywhere he went. It actually helped Riz to stay calm and be OK, so Mim didn't mind. These little things helped Riz manage situations; it helped him to be part of family gatherings or go out to eat. These were things he needed to help him to be in that space.

Riz is well-spoken, and he doesn't stand out in social gatherings. Children, especially older children, often notice Riz's differences or make comments like, "Why doesn't he come and play with us?". After a 5-minute interaction, Riz would go off on his own and happily play for hours. Things are much harder for parents whose children are non-verbal or have other issues. When a need is much more visible, people will automatically look and think, what's wrong? The feedback from family and friends was that Riz's needs were not that visible.

Reflections on being a Bangladeshi parent of a child with autism / Raising awareness of the Bengali experience

Mim does not describe her journey of being a Bangladeshi parent of a child with autism as being unique. There are hundreds and thousands who have children with needs of varying scales. But she feels strongly that the journey needs to be known. Bangladeshi parents need information and guidance. For Mim, the need for awareness is absolutely paramount to helping children with needs and autism.

Parents Who Might Need More Help

For her, it's taken 12 years from diagnosis, meeting other parents and gaining knowledge about her son's needs. What about other parents who speak English as an additional language? Particularly Bangladeshi mums, probably a lot of dads too. Stigma or shaming in the community can still be a big issue, even in this day and age. Even if parents have been born and brought up, educated in this country, they might not want to go out into the world with their child. They worry that their child is not behaving; they worry about tantrums, or breakdowns, or meltdowns. At the moment, awareness around autism is non-existent in the Bengali community; there is hardly anything out there. All the information that Mim has read about autism has been about the non-Bengali community; for her, this has been OK, but she realises not every Bengali parent will see things in the same way.

Mim now works with children and families; she sees how Bengali parents don't wish to speak or know about needs their child possibly might have. When she has approached parents to discuss these matters, they will often say that the child is very young, and they will grow out of it. Parents will often brush it under the carpet, not want to talk about it or say they know of someone who has grown out of a similar problem.

Mim thinks that it would be helpful to have more information out there for parents, and the earlier that earlier diagnosis is made, the better. If your child has a need, it should be normalised, and parents shouldn't feel like it is the end of the world; you can go on and live a fulfilled life.

Helpful for Parents to see Positive Possibilities

For Mim. the time when she physically met a breathing, walking, talking person with autism in real life was very impactful. This opportunity helped her visualise and understand that her child or any child with needs would be all right. This is probably something that a lot of parents might actually benefit from, helping them see that it's OK and their child can lead a happy, fulfilled life. This experience left Mim with the possibility that Riz can achieve everything that any other person can achieve. In turn, this realisation also helped her along her journey and come to terms with many things.

Can you Cater for my Needs?

Mim describes dealing with things in her own way but says she realises although she still finds some things hard, people describe her as being quite strong emotionally. Perhaps this explains why she has gone out there and got what her son needed. It is a hidden disability, so Mim feels she has had to explain why certain things need to be in place. For example, she describes wanting to take her son to the movies and finding a quieter time so he can still go.

Riz hates haircuts and absolutely hates them. Mim had to find somewhere where it was quiet and somebody who was sensitive to Riz's needs. Recently she has found an absolutely amazing hairdresser. When she called to make the appointment, she described what he needed, and the barber was accommodating, and Riz was absolutely fine. A couple of years ago, Mim would not have asked; if you ask for it, you can get things. It's not all doom and gloom out there.

Worries for the Future

Mim does wonder how Riz will survive in the real world, "How do children with vulnerabilities survive in the real world?", "Can children like Riz make friends?" or ask a stranger for help if they need it. These thoughts particularly worried Mim. Like most children with autism, Riz doesn't have a physical disability that you can see. People looking at Riz wouldn't think there was anything wrong or that he might need their help.

Mim has come to realise that no one can predict the future, and there was no point in her killing herself worrying about what might happen. Just going along with things has been the only way to manage these underlying worries and anxieties. In addition to putting financial things in place for Riz's future, Mim wants to equip him with the tools and skills that prepare him for whatever may come his way, whether she is here to support him or not.

Emotional Journey - Being OK with Autism

Mim described her parenting journey with Riz as an emotional one. She realises she can only speak for herself, but talking with other parents and going to workshops has been eye-opening and has helped her accept that she has a child with autism. That it is not the end of the world and doesn't mean there is something wrong with me, my family or my child. The hardest bit for any family is to accept and be OK with it. Mim accepts she has a child with autism, there is nothing wrong, and there will be nothing wrong, ever.

Mim does not want to dwell on things, focusing on "Why me?". In her experience, that is what parents in the Bangladeshi community are doing. It was important to her that she was OK with her son's autism. She accepts things mentally, emotionally, physically, psychologically – being OK in every sense.

Sharing the Diagnosis with Family

Our language doesn't have the words, so many terms like the word cripple are used to describe children with needs. Trying to find the right words to make her parents understand about Riz's needs was one of the hardest things she's had to do. Mim told her mum initially and then later her dad. She hasn't used the word autism, instead describing how Riz was and that there was a name for how he was. Mim's mum was curious about the diagnosis meant for Riz and if they could give him something for it. She explained it as something they couldn’t see or do anything about.

Using examples of how Riz plays and how he is to explain the difference between him and other children has been one way of explaining. There wasn't much anyone could do about it. Adults needed to fit around Riz, rather than trying to make him fit around them, their version of normal if you like. Mim's mum was quite educated in Bangladesh, which made things a bit easier.

Mim's dad is from a generation where these things are not spoken about. She recalls explaining about Riz; he took it in and didn't have too many questions. Mim isn't sure if he understood the full extent of what she was telling him and what it means, but because of how Riz presents –she imagines that that is why her parents have not expressed any concerns.

Diagnosis – Now what?

Mim described how it took her a long time to be OK to tell someone other than professionals working with Riz. Looking back, Mim realises she was thinking about how they and her son would be perceived and needed to take time to come to terms with it herself. Everybody knew that there were a few things here and there, and he wasn't your average child.

Sharing Riz's diagnosis did bring Mim a sense of relief; it was out there now. Everyone knows and has no issues with it, and everyone always asks about him, and he's very popular in the family. For a short time, Mim did let what society thinks enter her mind. There wasn't much out there for her or her family after his initial diagnosis. "What next?". They were quite frank with Mim, simply stating that this was a diagnosis and nothing else. Mim was a little surprised by this and left with questions about what to do next for her child.

The school took the next steps to put provisions in place and let the LA know about his diagnosis. The GP was notified, but there was nothing else for Mim in the community. This felt like being put on a boat without a sail, not knowing where to go after the diagnosis. So, for Mim going out there, finding out information for herself, attending the seminar and workshops and gaining information was crucial to her.

Maintaining a Cultural Identity

Heritage language

Mim related how her heritage was important to her and wanted Riz to know about his ethnic background. She would like Riz to identify with his heritage and the language that the family speak. Riz only speaks a few words of Bengali here and there; this is important to Mim. Professionals working with Riz when he was very young asked Mim what language she would like Riz to speak? At the time, she remembers feeling in two minds about which language she wanted for Riz. Mim worried that he would not learn to speak and did not want to confuse him, so she spoke to him in English only. Looking back now, she wishes that she had been better informed about it. The realisation came to her recently through her work that having a solid home language is more important than any other language that they learn later. Her other two children speak their native language very well, and Riz doesn't.

Mim wants to carry on encouraging Riz to know about his cultural identity through his language, food and celebrations. It's important that he know his place in the world, being a British Bangladeshi. Mim thinks Riz is capable of understanding about this, and it's just a normal part of family life, something she will help him to understand.

Riz Eating with his Hands

Certain cultural things that are really important to Mim; they are part of her heritage. Eating with your hands is one of those things. This is something Riz is now very good at. Mim's mother was very proud and praised Riz for eating rice and fish with his hands. His grandmother commented that this is something she had never expected he'd be able to do, with or without needs.

Faith

Mim described her faith as being paramount in her and her family’s lives. This is something she has made sure Riz knows about as well.

After trying various weekend Madrasa (Islamic educational institutions) with varying degrees of success, Mim has now found a local teacher who uses a soft approach, where things are calm, quiet and on Riz's level. Even though she would like him to do better and much more, she is OK with Riz learning about the Qur'an and their faith in his own way. She is not fixated on him learning everything, as she imagines he will learn in his own way as he grows up.

Mim described how Riz kept all of his fasts last year and the year before that as well. He fasted out of his own free will; he said he wanted to do them and would be fine. Mim describes this as a joyous moment for her, it was his free will, and he completed them. The family celebrated really big, and they gave him treats as well. Importantly for Mim, it helped her put things into perspective; things were getting better if he was to restrict himself from food and water for a full day, go to school and do everything else at the age of 11 and 12, then she realised that he was strong physically and psychologically. The integrity behind that act blew her away. Mim celebrates the successes when they happen.

Speaking about her Son

This interview was the first time she had been really asked about her experiences with her son. Things have come up that she hadn't thought about in years. Mim now works with parents and can see the fears and anxieties that were in her mind reflected in other parents too. In teaching someone about something, you also learn yourself. Her role now means she talks to parents about making a referral to other professionals. It is helpful to talk in-depth with parents about their worries, even if they don't always seem ready. At the back of her mind is the thought that this is actually helping them deal with their fears but also her own as well.

Mim recalls that initially, after her son's diagnosis, she tried to close herself from the world; she now knows that there is life beyond her son's situation, and it does not dictate how life will be. There is also a realisation that if it wasn't this need, it could have been something different, but it's all OK. These thoughts reassure her and help her be present in her and her children's life. Mim's journey has been about her child and his needs and wants and what she can do for them, not about herself.

The Need for Knowledge in the Bengali Community

Mim reflected that her journey has shown how paramount knowledge and information is for parents and their ability to cope with difficulties. The Bangladeshi community have a high percentage of parents whose first language is not English. The community might say a child is delayed or absolutely horrendous words like ‘phagol’ (crazy), but Mim feels that you can't bash them down for thinking like that. It's high time that the Bengali community pulled themselves up and accepts that this is not a problem that happens in other cultures. This could happen to you, me, anybody at any given time. The community should be empowered; they should be out there helping, bringing it into the open by talking about it and normalising it. This would help parents dealing with things feel like they are not alone. Publicising, awareness weeks, sharing information about organisations that are out there to help parents and give them support. Parents of children who are really high on the spectrum might need a night off and need to feel that they are not suffering alone; respite support is not something many parents know about.

The more a parent is empowered, they will know things out there, and they can ask for help. Having a cry or talking to someone about having a really bad day is crucial. Mim thinks mums in the Bengali community take the brunt of things; dads go out. It's a cultural rather than a man thing. Dads are often like a brick wall; they say things are OK, they don't want to talk about it or deal with it and just carry on. Just because people are not talking about it doesn't mean these difficulties are not there.

Appendix 22: Raina's Story

Raina and her son Taha

Every Autistic Child is Unique

Raina would say that parenting a child with autism is about taking it day by day. She wouldn't say that any parent has an in-depth knowledge, because every child seems to be different. So, parents can only relay some of their experiences to other parents, but most of the time these children are very different in their behaviours, likes, dislikes and their language.

Talking to the Older Generation

As a Bangladeshi parent, the thing that Raina has found difficult is that the older generation find it difficult to grasp the idea of autism. For Raina, Bangladeshi people are all about feeding, you need to be constantly feeding your child or you are not a good parent. Raina has been told that she should be feeding her son Taha rice, "Have you tried it like this?" Or "You should be giving him such and such food". For Raina, it doesn't work that way, and it is frustrating that the older Bengali generation don't seem to understand this. Instead, what people see and comment on is that Taha dictates what he eats and when he eats it. Raina would rather Taha be happy and calm, rather than follow what is considered normal behaviour. For Raina, when you have an autistic child, you just can't live like that. instead, she has to take her cues from Taha and that's what she has found that works.

"Knowledge about Autism in the Bengali Community is Very, Very Small"

When Riana takes Taha out, she has to be very careful. People don't want to talk about autism, it's like a taboo topic for them. When she talks about Taha and his needs with people, they often think she is complaining and criticising him for the things he can't do. There are times when someone talked to him and he hasn't responded, they think he's being rude. They don't seem to understand that he doesn't like speaking with strangers. Constantly having to explain yourself is very difficult. Its down to knowledge about autism in the Bengali community being very very small. People think a lot of it is down to parenting, rather than behavioural challenges within the child, but they don't understand that Taha is not comprehending the world the way we or other children do. Unless someone has experienced it for themselves, they don't understand it and the Bengali community can be very narrow minded.

"People from Outside Think it's A Lot Easier Than It Is"

The school that Raina's son attends is very conscious of healthy meals, Taha's packed lunch typically consists of a packet of crisps and a small bag of cookies. Raina can see that the school have made compromises, they realise that Taha eating some food is better than no food. When relatives offer advice about Taha's food and eating, there is only so much as a parent that can do. Dealing with Taha on a day-to-day basis is exhausting enough, without feeling the added pressure to try new foods as well.

Perhaps if Taha was her first child, perhaps if she had been younger she would have had the energy to try to give him all these new experiences, take him to new places. From the outside people thinks it’s a lot easier than it actually is, sometimes it’s exhausting.

A Standard Day for Taha

Raina’s day will often start with her fighting with him to get him to school. She knows deep down that he actually does like school, but he doesn’t like the idea of going to school. She will often struggle to dress him and has to be firm, or he will push her boundaries. Taha won’t eat any breakfast at home before he leaves for school. The school have been very accommodating and let him have a later start as they could see he was finding the playground overwhelming in the mornings. Raina didn’t have to ask them, they just did it and she has found that very helpful.

Raina can see that the school know how to make him learn in his own way. They have used pirates and stickers to encourage him. He responds better and when he sees things he likes, and the teachers use things like that in school. Raina will follow Taha’s routines, and they help keep him calm. At home he likes to mimic things he watches on TV, and Taha has been doing that for as long as Raina can remember. Taha needs Raina to lay down next to him to help him sleep and he will refuse to sleep before 11 each day. This is a standard day for Taha.

Journey to Diagnosis

Raina’s son had glue ear, so they thought that this explained the speech delay. A child psychologist saw him soon after to see if there was anything that could be done to help. It was at that initial meeting that autism was first mentioned. Around three more meetings took place over the period of about two years before it was officially confirmed as autism. Some time passed between initial discussion and final diagnosis; this gave the family time to wrap their heads around the idea a bit better.

Initially Raina was in complete denial, as was the school. Her son didn’t display all of the traits, such as walking on tip toes, avoiding eye contact or being unsociable around people. The one trait he had was speech delay. The family felt that this was purely down to his glue ear, as he couldn’t develop language if he wasn’t hearing everything clearly.

Making Sense of Autism

Although Raina knows you shouldn’t believe everything you read on social media, some scientists have made a link between MMR and some childhood autism. Raina didn’t vaccinate Taha for his MMR until quite late, so she has sometimes thought back to how his behaviour was before he had the vaccine. Other than his speech, he was a perfectly normal child. Something else Raina has read is that autism is genetic. Although, she has no real way of knowing, understanding how Taha has come to have autism would give her a sense of closure about his diagnosis.

Raina used to work in a special needs school, so she has some experience of autism, but it was very severe. All the children were nonverbal, very violent and antisocial. So, when the professionals said that Taha had autism, she immediately thought that this was what they were referring to. At the time Raina didn't understand that there was a broad spectrum, and many children display different traits.

Making Sense of the Help Out There

Raina now works as benefits advisor, and she can see that more and more people from the Bangladeshi community are coming to her needing disability forms to be filled in. More and more parents generally are coming to her with autistic children. This wasn't the case when she started the job around 15 years ago. Raina thinks that people have always had autistic children, but they didn't realise there was help available.

Raina has found that there is not a lot of help out there, as with any kind of disability it's not just about extra money. People need things like respite care, they need activities that are centred around children with special needs, and it's just not available. If more people had support groups, they would, learn how to deal with the condition better, parents would be able support one another and they would know what to expect with their child. Every day with Taha is different, the certainty that parents can have with a child of a certain age just isn't there for parents with autistic children. With an autistic child you there is a lot of uncertainty about what the future holds. Raina has seen people through her work, that have grown up with autism and gone on to be more independent, and she hopes her son is going to be like that one day too. The uncertainty about the future is something that scares Raina. She can't help wondering if Taha "Will he get married?", "Will he ever have children?", "Will he live independently?"

After Diagnosis

Receiving the diagnosis officially has made a difference to the family. At the beginning, the family had no knowledge or experience of autism and were taking each day as it came. Taha was younger, so physically it was easier to deal with him. Mentally, it was still a strain. They struggled to make sense of his tantrums as they wouldn't know what triggered him. There were times when they had been out and he was fine and all of a sudden, he would have a meltdown. Raina wouldn't know why this had happened or what to say to people. Not knowing what to do to help him was hard. There were times she just didn't know what to do, and she felt as confused as Taha at that time. The family have become more aware of his needs now, and they have educated themselves on how to behave with him and deal with his behaviour.

Sharing the Diagnosis with People

The diagnosis took some time and by the time they had the official diagnosis, they had had a bit of time to get their head around it. Raina had started to tell family and friends that it was possible that Taha was autistic. This helped explain some of the behaviours he was showing when he was around them.

Raina's family have been great, they have all learnt about autism, and now understand that his unpredictable behaviour is down to his condition. So, in some ways the diagnosis has been helpful in explaining his meltdowns or when people are getting frustrated with him. In situations like that, being able to say he can't help it and he needs help to calm down can be useful. If people can be given a reason for Taha's behaviour it can makes it easier for people to accept him.

Raina recalls being afraid to take Taha places, purely because he might react, and they would need to come straight home. It was not practical to stay anywhere with a child that was screaming the house down, especially when there were other guests around. Nowadays, Raina will leave him at home because Taha is more comfortable and happier that way. Getting people to understand has been difficult and it does mean that Taha will often misses out on family gatherings.

Look at other people's experiences is always helpful, a recent documentary was on TV about a celebrity with three autistic children. It's interesting to see how other people cope.

Helping people understand it (autism) would make life a lot easier for parents. Raina recalls a time when time in a shop, Taha was wearing a harness and running around, and a woman commented that normally she didn't agree with harnesses but in Taha's case it was necessary. It's hard to know if this was a criticism or a compliment, it seemed to Raina that she was saying your child is uncontrollable and needs to be restrained like an animal. In that sense it is quite sad, but that's the hand Raina has been dealt with and she will make the best of it.

A Special Kind of Love

In comparison to her other children, Taha has a very special place in Raina's heart. It's not only because he is her son, but because he is different, because he has autism. Raina feels no shame or sadness about her boy. Talking about him is just like explaining about her experiences with any one of her children. (527-533) Taha will sometimes do the smallest thing any child who is seven years old might very easily do, but for Raina it feels like when a child first starts to talk, and they say funny things and you just have to share it with everybody. These times are awe inspiring, it's difficult to explain the depth of love she has for him.

Aspirations

As a parent, Raina wants the same things for her son as anybody else would want for any normal person. Raina also recognises that in saying normal she realises her son is not normal, but to her he is normal.

Raina knows that some people with disabilities feel like they should be treated like everybody else. She feels that sometimes she may be discriminating against him by saying he is not the same as other children. To Raina, this is a good thing. His differences should be celebrated, talked about, understood rather than being told he's different, and as a result he gets treated differently.

Raina does not want to seem narrow-minded or discriminatory, but the different treatment that her son needs in his everyday life is to make him appear 'normal' to other people. Raina understands her son and just hopes he can lead as normal a life as everybody else, he deserves that, anything less than that would be a disservice to Taha.

Appendix 23: Aliya's Story

Aliya and her son Kabir

Being Bangladeshi

Bangladeshi culture is very much about being social and family orientated so having an autistic child really impacts that. Alyia did not grow up with much extended family around her but both her husband her come from large families, and she lived in a multi-generational household after marriage. Her son Kabir spent his early life living with his grandparents, there would always be events going on.

Aliya remembers saying no to extended family weddings and gatherings, if it wasn't a sibling or her best friend's wedding, she did not take her son. For Aliya's own sister's wedding, her son Kabir stayed for a few pictures with the bride at her mendhi (henna) party. Then she sent him home with his other set of grandparents and stayed on without him.

In terms of Aliya's feelings at that time, she felt very isolated because she had to manage her son and therefore was not present in whatever was going on at the time.

When Kabir would play with other children, even if it was a structured game, once he would get involved, things would just break down. As a toddler he would end up lashing out or hitting another child. It was always Kabir being told off. As he got older, Aliya noticed that his outbursts were often a reaction to something, but Kabir's response would be louder, he stood out.

Aliya Can't Care Anymore.

Aliya recalls attending a family wedding with Kabir when he was nearly 4, the venue was near the riverside and there was no way of taking him outside. Kabir was being very high energy and Aliya was running around after him all dolled up in a saree, which was not very comfortable. Aliya remembers this as the experience that was the last straw. She made a conscious decision that she would no longer be part of these things.

She realised that she just did not care if this person or that person was going to upset that she did not go to this event or that event. Aliya found herself not caring if her in-laws expected certain duties from her as a daughter in law. Instead, she had to realise that Kabir was playing up in those situations because he was hypersensitive to the sounds and energies around him. Kabir was finding these situations stressful and for Aliya, it was not worth putting him in those situations.

Beginnings / How We Got here

Apart from watching programmes and reading books that mentioned autism, Aliya did not know anyone with a diagnosis. Looking back now, she did notice certain things about Kabir. He would line things up, he was very repetitive in his play. Aliya thinks that the reason she never picked up on his language was delay was because he memorised things really well. By the age of nine months, he was singing all the words to nursery rhymes. Aliya now thinks that she should have noticed that this was super early. He would also repeat things he had heard on TV like adverts, or monologues from TV programmes he had watched.

Aliya started to piece things together when nursery shared concerns speech delay, he was not formulating his own sentences. A referral was made by nursery for speech and language support, after 12 months it was felt he had caught up and he was discharged.

Discussions at Kabir's two-and-a-half-year review with the health visitor and this started the referral to the Child Development Centre, he had a 360 review for autism. They saw him in different setting and the review said that the way he behaved in school was totally different to how he behaved at home. This is one of the things that Aliya has really pushed on, Kabir never had any issues in school, no disruptive behaviour or outburst. The violent tantrums happened a lot at home. Looking back, Aliya was not dealing with it well, she would react by shouting at him and then feel bad. Some days Aliya would be in tears.

Diagnosis and Schooling Journey

After the reviews had happened, he diagnosed with high functioning autism. At the time Aliya decided not to take the diagnosis that he was offered. Having someone sit with him and help him did do his work was not how Aliya wanted Kabir to start his primary school years. She wanted him to feel like he could naturally do things himself, especially as she was told he was high functioning. They understood his needs well in primary school.

Things changed when Kabir moved to Junior School. This is when the social aspects of things really started playing up. There was an incident at school where a Year 6 child would push him and take his tuck shop money. This sort of stuff started happening and the Junior School SENCo pushed Aliya to get another review in place. It was 4 years since Kabir had been given the Asperger's diagnosis, the local authority was really overstretched in terms of appointments, even though he was on the system it took a long time for Kabir to get a follow up appointment, it just kept getting delayed and delayed. Once the family did get the appointment, Aliya decided to take the diagnosis. Previously, they were told that they don't like to diagnose Asperger's in toddlers as a lot of the behaviours could be toddler related. But now Kabir an 8-9 years old, this time they gave him the diagnosis, describing it as high functioning autism mostly on the social communication side of things.

Then Covid hit, and there was lockdown. Aliya was really worried about how Kabir would cope, but he did really well. He seemed to thrive on the feeling of having his own laptop and the responsibility of managing his own timetable. Kabir liked having structure of knowing what he needed to do and when he needed to complete it by. He really took charge of his learning.

Aliya thinks that he has this thing where, once he has started something, he needs to finish it, it’s like bish bash, bosh, it’s done. Kabir sat the 11+, passed and now attends a grammar school.

At the time Aliya worried about sending Kabir to a grammar school which was going to be quite high intensity, quite attainment orientated. Aliya now feels reassured and the highly structured environment seems to suit Kabir. One term in he seems to be happy. The school has provided face to face feedback to Aliya, this is more than Kabir had in his 4 years at Junior School.

Aliya’s Journey with her Son is Constantly Evolving

Every time Kabir hits a new developmental marker, Aliya has noticed he reacts differently. There was a long time where Aliya felt like he had oppositional defiance disorder. A lot of the markers really rang true, it was just constantly like a brick wall. Speaking to professionals really annoyed her, they read about him on paper and kept telling her to try this technique and try that technique. They had no idea what it was like to really live it. Aliya remembers trying one technique out 22 times in one single day. She found herself losing the will to try anything. All she could do was step back and let him get on with things. It was beginning to become detrimental to her relationship with her son. She began to feel like the policeman, if Kabir was being difficult with his food, Aliya was telling him off, if he was being difficult with his cleanliness, Aliya is telling him off, if he was not doing his work, Aliya was telling him off. Aliya felt all she did was tell him off.

Aliya feels that her journey with Kabir is constantly evolving. Where he has high functioning autism it makes the education side of things a lot easier. The social side is what worries Aliya. He could get into arguments with other boys at school.

Kabir in Social Gatherings

Kabir has had a lot of exposure to a lot of family growing up, Aliya has noticed that he is better at masking, something he has learned to do over time. He can do quite well now in different environments.

When he is at his grandparents, he can talk for 2 hours about football with the other men and boys. Aliya thinks its more acceptable for boys to talk about their interests for hours, she’s not sure the response would be the same if a girl sat there and spoke about rainbows for hours.

Things are easier for Kabir because his interests are to do with sports and computer games. So, he is able to find a common ground with most new people. It’s interesting to see how masking looks different for both boys and girls.

Aliya obviously knows him well and can see the connections he is making during conversations, but to someone else, he will just start talking about something totally unrelated to what they are talking about. It can seem like gibberish to people who don't know him well.

Sharing Kabir's Diagnosis

Aliya and her husband are totally on the same page about their son. Sometimes, especially in the Bengali community parents, mainly dads, they do not want to accept something like this. They will say things like he will grow out of it. Aliya's husband has accepted it and she can see that they both address it in the same way with family, and what they needed to put in place.

What did take time for him to accept was that the diagnosis was not something that could be fixed. Now days, she feels he is actually much better than Aliya in terms of his understanding. Aliya continues to be the 'bad cop', while her husband is the 'good cop'. She is glad for that. Kabir is probably a lot more affectionate with his dad, Aliya thinks it is good that he has that.

Aliya and her husband decided not to tell their parents in the early days. They were a lot older and would probably not understand. It was felt that they would think it was something to fix and would want to fix things.

Instead, they decided to share their son's diagnosis with a small group of people in each of their families. These people acted like respite care for Aliya. They were happy with the environment they provided for him. So, these people became the circle of people who knew in the early days.

Aliya's own father died when Kabir was a toddler, and her mother does not really speak English and probably would not understand if they tried to explain. With her husband's parents, she feels things are a bit more acceptable now, as they can see Kabir functions and functions fine. He has a few quirks, but he is generally ok, so they have been a bit more open about sharing as Kabir has gotten older.

Family Life

Looking back, Aliya realises that Kabir was considered 'naughty' in family gatherings, but her and her husband 'took that' as it was only for a few hours and when they went home, he was a lot calmer and things were easier. The family made a conscious effort to put in place structured routines around meals and sleeping, so whatever they did had to work around him. Aliya would take her own food so that she knew that it was ready, and he would eat what she brought with her. There was a stage where Kabir only ate beige food that did not touch each other. They were very strict about bedtimes too, so he would be in bed around 7pm. Aliya recognises that this was a bit of a point of ridicule amongst the family. Growing up for Aliya and her husband there was no such things as a bedtime, you rolled into your room and went to bed. There was no one to instil the concept of a bedtime routine, so it was a bit of a foreign thing to do.

Impact on Aliya’s Wellbeing

Aliya was at a point where she was struggling to live her day to day and feel like they weren’t alone. Kabir was Aliya’s first child; things were hard, and she was a young mum. She remembers wanting to do all sorts of things with her son, simple things like watching a movie or having play dates. Those things were not Aliya’s reality for a long time. Looking back, Kabir was around eight years old before they went to the cinema as a family.

Aliya wondered what things were going to be like further down the line. Reading about other people’s experiences helped Aliya. The focus on her son’s sleep routine had a lot to do with self-preservation. Kabir has always been a super early riser and she has not woken past six o’clock in the last 12 years of her life.

It was like being a ‘Duracell’ battery, being 100 % all the time, watching like a hawk, being on guard. Kabir was full of energy like a bunny all day until he went to sleep. The time after he slept became a time where Aliya would regroup herself. A lot of the time before his bedtime were absolutely awful, she would be exhausted and upset with Kabir and herself. She found herself questioning how she was going to manage to do this every day.

After her son’s bedtime Aliya would need some time to be alone, watch some TV or read a book. She just constantly wanted to be alone. She would find herself sitting and not talking, zoning out. She realises that Kabir’s sleeping schedule was needed as much for him as well as her. Also, her relationship with her husband became all about parenting her son they forgot about their relationship. Having that time in the evenings was also meant they were able to spend time with each other.

Having Other Children

Aliya spent some time basically trying to understand if it would be fair to have another child. There whole world was Kabir, he had all of their energy and attention. They asked themselves how fair it would be on him, the new child and the possibility of having another child with autism. So, after a five-year age gap, they felt having a sibling might enrich his life as well.

At the beginning there was quite a few worries about how Kabir would react to the baby. She felt like she had to watch him like a hawk, she realises that this was really bad but she was worried that he possibly might hurt her. Instead, she found he was very nurturing. The new baby also meant that Kabir had to be more independent and do things for himself. For example, giving him a spoon and encouraging him to eat by himself. Kabir’s motor skills were very behind so it was hard for him to change his clothes and wash himself. Aliya went on to have two more children, now they are a family of five.

Parenting as a Mother, Parenting as a Father

Although Aliya does not like the term normal, through her girls she has been able to experience parenting neurotypical children. It's a totally different dynamic. Aliya herself grew up with brothers, she feels more comfortable being a boy's mum. She likes sports, football and cipher. Parenting the girls has bought out a different side to her, inversely the girls have bought a different side to her husband. He is very tactile, affectionate and just a lot softer. When Kabir was a toddler, Aliya felt like she was the one constantly firefighting Kabir's reactions. Aliya would feel pressure to control Kabir so as not to stress out her husband. So, the pressure felt constant, and Aliya carried the weight of this on herself. Since having the girls, he's changed a lot as well. His perspective has changed, he's much more mellow and chill. Letting the kids just be kids. Aliya feels like her family unit of five, is now a lot more complete.

Knowledge about Autism is Growing

There has been a change, now there is like a second generation of people who have been through the education system here and are aware. Aliya has seen her own friends who understand autism a lot better and can see signs that it is no longer a taboo to get help and ask for interventions.

People are now much more aware of autism. Aliya thinks its previously been masked and has been explained as other things. As Aliya has begun to talk about her son, a lot of staff who know her in his school have approached her to say they had no idea Kabir has autism. Those kinds of comments can sometimes be a bit annoying. Aliya reflects, that perhaps this is why autism is considered to be an invisible disability.

Aliya considers Kabir to be an extrovert by nature but masks it very well. If you people know him well, they might notice that he doesn't hold eye contact very well and he looks away. When they get feedback from school about Kabir, Aliya just feels really proud. She knows it can't be easy for him to navigate school.

Needing to be a Well-Informed Parent

Aliya's husband calls her 'Dr Google' because she likes to diagnose everything. Aliya knows that she likes to be armed with lots of information. Aliya has found parent forums so much more relevant and useful than the official sources of information and guidance. It just felt much more relatable hearing from parents, rather than someone who has studied autism and is super learned about the science involved.

Sometimes when people don't speak English very well or their new immigrants, it can be easy to be fobbed off by the professionals to a certain extent.

She remembers saying to the teacher in Kabir's Junior School that she gets that the child who shouts, screams and throws a chair across the room gets the extra help. But what is not fair is that because Kabir does not react like that, he gets no sort of extra help or even understanding.

One-year, Kabir had an excellent teacher who understood his need for movement breaks and just incorporated them into the classroom. For Aliya it’s not simply about putting provisions in place to stifle Kabir, its more about understanding.

Aliya has found that unless she presents herself as being uber knowledgeable, it is really hard to assert yourself. When she goes into a room with professionals, she has to know autism, know isms, know what stimming is, know about thinking hats, be knowledgeable about interventions that will help Kabir. To be taken seriously, you need to be able to talk the jargon.

Worries and Hopes for the Future

For Aliya, in her mind, it’s been, what about the future? What about the possibility that Kabir as an adult might find himself in a scenario in which he gets in trouble for something he does not understand? Kabir’s understanding about personal boundaries might leave him vulnerable

Aliya has a cousin brother who quite clearly has spectrum disorder and finds it hard to manage relationships well. He has more in common with younger kids than he does with people his own age. Aliya hopes that Kabir learns enough on the social side of things to be able to function.

Another hope is that he finds someone who loves him, understands and accepts him for being him. Aliya knows first-hand how difficult it is to live with someone who has Asperger's, but she is a caregiver so will always be the person looking after him. In a relationship he needs to be person in a partnership and will need to spend time looking after the other person.

Aliya realises that Kabir cannot be taught skills empathetically, his brain does not work in that way. So, she focuses on teaching him physically the things he needs to do to look after himself and think about another person. For example, there is a plate in the sink, just because it’s not mine does not mean someone else should wash it. Aliya is using little things like this to teach Kabir skills for life and partnership. Her greatest hope is that he finds someone who loves and accepts him, and he is able to maintain a relationship.

Appendix 24: Tahira's Story

Tahira and her son Sameer

Journey to Diagnosis

How Things Started

Tahira recalls having difficulty with the social side of her Sameer's behaviour. He was displaying certain behaviours; he was very sensitive and very attached to her. These behaviours just wouldn't go away. He would have complete melt downs, if he wasn't able to do things he needed to do - he had habits. Tahira put it down to the upheaval he had experienced when he was younger, the family had moved around quite a lot.

Behaviours that Tahira Noticed

Sameer would be very focused, he couldn't cope with chopping and changing. He would need to see things all the way through to completion before he could move on to something else. These things were making it really difficult at home and it was a struggle to cope.

Initially, Tahira had thought that he would just get over it, or that it was just a phase, and he would grow out of it. Instead, things just got worse. Her brother suggested getting the GP involved and to her surprise he was referred to CAMHS. The children had experienced quite a difficult childhood and their dad no longer lives with them. So, in Tahira's mind Sameer's behaviours were connected with that experience..

After referral and assessment, they diagnosed Sameer with autism, high functioning autism. Tahira recalls not being happy with the diagnosis, but it did kind of shift her mentality. Autism was not something she could 'fix', instead she realised that she needed to know how to cope with it.

Managing him – Managing his Frustrations

Some of the behaviours that Sameer would show were quite upsetting. If he was frustrated, he would break things in the house or bang his head against the wall until she would need to pull him away. Now days, Tahira usually knows when it's going to get to that point and can diffuse that kind of situation. Whereas before, she would just become frustrated, and Sameer would a get frustrated, and it would just make things worse. They no longer have as many episodes as they used to. Educating herself has helped. Tahira knows the things that trigger him, things that he can't cope with. Moving things in his room, so that they are not where he left them is upsetting for him. Not following through with things is a problem for Sameer, so if you make a plan and something happens to change the plan, it is very hard to get him back on track.

Change and New Experiences

Tahira thought it would be nice to take both her sons to Camden last summer, get something to eat and look at the canals. The experience was too noisy for Sameer, it was crowded, and he didn't enjoy it. Another family visit to Soho and Chinatown was again too much for him. Sameer sat on a bench and put his hood up, not wanting to interact or try anything new. These experiences just weren't for him, and he just wanted to go home.

Sameer likes things to be the same, over and over again. The same food, the same cartoons over and over again. She knows he does not like the feeling of trying something new. Tahira knows that these are the kinds of 'quirkiness' that her parents find difficult to understand, they don't get this autism thing at all. It's been really difficult to get them on board.

The family are in the process of moving home. This will obviously cause a lot of anxiety for Sameer; Tahira doesn't know where they will be going yet. She won't start packing things up or move things around until she absolutely knows the day they are leaving. So, everything will be last minute, rather than a long dragged-out moving process. The hope is that by doing this it will minimise the fall out, and then slowly, slowly they will build things up for Sameer again.

Not Being Able to Explain in a Way Her Parents Understand

Tahira's parents find her son's habits difficult to understand. When Tahira is at work, they would look after him a lot. Sameer would have his little behaviours and they would kind of make fun of it a little bit. They couldn't see that this was making him even more upset or angry. To them, it was just a little bit of fun, and they thought that they were making things better by making light of things. Tahira's parents find him a bit weird. This is something Tahira struggles with in some sense quite a bit. She puts this down to them growing up in a different generation.

Tahira's parents see her son as a really sensitive boy and they kind of struggle to have a bond with him. He knows they find him odd and because of this he puts a bit of a wall up. Tahira has tried to explain to her parents that Sameer is not like this through choice. He finds everything a bit overwhelming and likes the security of his own little areas. These areas are like comfort zones for him. So, when he does lash out it's because he doesn't feel secure, and he needs a safe quiet spot.

Tahira thinks that they are coming round to it, but it's not something they fully understand, and she doesn't have the language herself to fully explain it to them. Tahira describes her Bengali as very broken and has asked her sister to explain it to them as her Bengali language skills are better. Tahira wishes there was some sort of Bengali literature out there for grandparents, particularly for her parents' generation. There are loads of leaflets and websites for English speakers.

Tahira’s children spend time at their grandparents a lot and she doesn’t want their experiences there to be negative all the time. She wants Sameer to like going there and feel that it's just an extension of his own house. That he can do whatever he wants there, that he can be in his own world there, just as safe as he is in his own home. Where no one is going to laugh at him or nit-pick at him for wearing that coat again. Tahira explains that she can see these things really wind Sameer up, but she doesn’t know how else to say it to her parents.

Sensitivities – that the Older Generation Don’t Understand

Clothing

Sameer fixates on certain clothing. He likes to wear polo necks; they seem to give him some sort of comfort. Currently, Sameer is wearing a coat that is two sizes too big for him. He wears the coat all day and likes to wrap it around himself and doesn’t want to take it off. He wears a heavy bag because it feels like something is hugging him from the back, he doesn’t like taking it off and will keep walking around with it on. Tahira has sometimes sent a text message to her sister asking the family not to say anything when Sameer goes over wearing his polo neck. Tahira finds herself guessing what might occur and then trying to minimise and manage things.

Haircuts

Tahira’s parents really hate it when boys have wild or unkempt hair. It takes a lot for Tahira to get Sameer to have a haircut, he just doesn’t like the feeling of the blade. So, often his hair will be very long and unkempt looking. Tahira finds herself explaining why her son finds this hard to her parents too.

Food

Everything about Sameer seems to bother Tahira’s parents. The way her son eats, the kinds of foods he eats. Sameer doesn't like food of a certain texture or consistency, it's not because he doesn't like the taste, it's more the consistency that bothers him. Mealtimes are often a battle at her parents' house, they will often bug him about his food. Tahira’s mum will ask him to try foods he doesn’t like, saying things like; “How can he know if he doesn’t like it, if he doesn’t try it?”. Packing food for him, so he can just take it out and eat, can sometimes make things easier. This is about them as grandparents wanting to feed their grandchildren, so it comes from a good place, but it is something that the family struggle with quite a lot.

Not Having the Language to Communicate can be a Good Thing.

Tahira’s parents will often ask how Sameer is doing at school, commenting that he must be thick or something like that. They will say in our language that he must be like this or must be like that. Tahira is glad that her children don’t understand Bengali too much, some of the comments that they make would really hurt and upset them. She explains that her children’s father isn’t Bengali, so they spoke English in the house, and they didn't pick up a lot of Bengali. A lot of stuff is said about Sameer that he doesn't understand, which Tahira thinks is a good thing. She wouldn't want her son to think that his grandparents were talking about him like that. There is no malice in the comments that his grandparents make, it is just down to a lack of understanding.

Grandparent's and their Lack of Understanding

The main hope for Tahira is that her parents understand Sameer, she understands him now but realises that there were times when she didn't. For her parents, there is a big gap in their understanding. They don't seem to accept autism as a condition. Tahira's parents think she should stop babying Sameer. They would like Tahira to give him a good talking to, to be tougher with him and that this would solve his issues and straighten him up. From Tahira's perspective, she is the same with both of her children, Sameer is just a lot more hard work.

They will often share examples of extended family members in Bangladesh who are like her son but managing fine. Tahira thinks that there is a lot more support in Bangladesh, where families lean on each other. If someone can't work or hold a job, there is always something for them to do. Here, in this country, there's a lot of pressure on children to do really well in school, in every single subject and then get a really good job. Later on, they should have a family. Tahira admits that she does not know if her son will ever be in a place where he can live independently and do all these things for himself. This is something that she does worry about.

Wanting to Follow his Own Interests

After getting Sameer's diagnosis she shared it with his school, and they put a few things in place. After changing schools, he had some help but because Sameer is high functioning, he does not seem eligible for the kind of support other autistic children might get.

Tahira's can see that Sameer is good at art, that is his strength. He just doesn't bother with any other subject. Every teacher in a recent parents evening described how Sameer will just sit and daydream, and that he can't seem to focus on what's being taught in school unless it's of interest to him. School has told her that when he does try, he does really well but he's just not interested. He just doesn't focus on anything else except for art. in art, he will sit still, focus and engross himself.

Tahira worries about what Sameer will be like if he gets a job, he barely gets through the school day. He doesn't like going. She has tried to explain how trying to do well in other areas will open doors for him in the future. It may just be a teenage boy thing, but Sameer is not thinking about the future at all. He is so engrossed in his art, that it's the only thing he wants to think about. He has his own sketch books and materials, and he will just paint and sketch.

Tahira would like to make a little studio for Sameer, so he could be in there and do as much art as he likes. It would help him feel less stressed and really help him to calm down. School routines and life don't suit Sameer at all. When Sameer was younger, he was home schooled for a little while and did not go to school until he was nearly 7. Sameer's always missed home schooling: he could do things at his own pace. He loved history, dinosaurs were a special interest, and he would just fixate and learn everything, every aspect of them, inside and out. It makes her sad that she can't give this to him again.

From school's perspective, Sameer is now more social at school than when he started. Tahira thinks it's just that he tolerates school better than he did before. As soon as he comes home, he's just so glad to be home. So glad it's all done, and done for another day, glad to be in his own space again.

Needing to do Things in his Own Way

Tahira herself goes through phases of just being really impatient with Sameer. Some things Sameer does really stress her out and she has to remind herself to take a breath. Some mornings they will be running late, but it doesn't matter to her son, he still needs to do the things he needs to do before he can walk out of the door. This makes Tahira wonder how he will get to work on time, manage people inputting their ideas on him when Sameer just likes to do things in his own way and that's that.

Way forward

Tahira hopes for more awareness in the Bengali community. There is nobody she knows who Bengali is and has autistic children. A couple of work colleagues do have autistic children, but they have very limited language, mobility and things like that. This means that they have a lot of help, school buses come and pick them up and things like that. It's hard for Tahira to relate to this, Sameer tests and challenges her in very different ways. It might be nice to have some people to talk to about her experiences with Sameer, it doesn't make for great conversation at home when you are a single parent. People can see that Tahira is coping and bumbling along and that's fine, she is managing. But what would be really helpful is some sort of literature for the older generation, translations of stuff in Bengali that is already out there for English speakers.

Making Sense of Sameer

Talking about her son, from the beginning has made Tahira remember how guilty she sometimes feels. Maybe it was her, maybe she has done something to make Sameer this way. He didn't have the best early start and there was a lot of conflict and things like that in the home.

When Tahira does talk to someone else about her son, she wants that person to understand him. She feels kind of protective over him, he's not just this boy who does weird things, she wants people to know all sides to him. Sameer is such a good boy, so affectionate and kind, and he loves animals. But in speaking about him, Tahira realises that he will always struggle in life more than most people. She recognises that everything is going to be more difficult for her son, so she just wants to help him as much as possible.

Appendix 25: Research Journal Extracts - Writing the storied Narratives

Writing the restoryed narratives: (09/01/2022)

As I write up the interim narratives, I wonder should I be writing X felt? Or X's story illustrated? I cannot possibly know how X felt. The decision to write the final storied narratives in third person, means I am writing from narrators perspective but this is a co-construction, I have a role in the creation of the narrative, how can I ensure that I express the thoughts, feelings and experiences from the parents viewpoint, not my own?

When I read back the storied narrative, I can hear the voice of the parent. I can see and read the words she used. Its almost like the parent is a character in her own story, separate but part of the story.

Sharing the storied narrative: (26/01/2022)

"like someone wrote a diary for me"

"I forgot, how much of a battle it has been"

Two parents, two comments. I worried about doing justice to parents' stories, to putting a mirror up to their experiences. I was worried about their responses. We often say things in conversation, we do not like to hear back. The responses tell me that they could see themselves in the stories shared. This is a huge relief; I have done justice to the stories they shared. What better compliment could there be. In the telling of their stories, some parents got a glimpse of the journey they have been on. Taking a moment to talk about your everyday challenges, promotes introspection and reflection. Ethically, morally I needed their approval to continue analysis – they have made me a custodian of their story.

Appendix 26: Research Journal Extracts - 'Our Language' 'Our Community'

As I restory the interviews, I can hear the nuances in language and expressions that several parents have used in the interviews. Often an unspoken understanding, 'you know' or 'our community' 'our language'. It was especially apparent when a parent was sharing that their child can eat quite well with their hands, its something his maternal grandmother commended him on. What might not appear significant, might be significant. As a Bengali researcher, I am aware about the cultural traditions associated with eating with your hand, and eating fish with your hands represents a cultural marker. It is these intimate details that make me a culturally sensitive researcher. The suggestion is not that the parent would not have shared this with a non Bengali researcher, the suggestion is more that there is a shared understanding that comes with insider credentials. It is in the smiles, the nods the awareness and understanding I can communicate through my body language and facial expressions. These are the dynamic participant / researcher interactions and rapport building that facilitate this type of collaborative understanding. These are the details, that make this research unique.

Equally, I am mindful that I do not let my biases and beliefs do not impose a meaning that is not apparent in the text. So the interpersonal experience of being in the interview needs to be backed up with evidence from the transcript, a feeling that situation described is important or emotive is not enough. The way to ensure it is not simply based on the interaction between the researcher and the parent is to use the parents own words to give weight to my understandings. This is why I decided to verify my meaning making by going back to the interview transcripts, rather than rely on the retorying. It gives a further layer of support to my arguments. I am fully aware that my being a Bengali researcher, researching the Bengali community, is a double edged sword. Not only does it give validity to the findings, but it could be the very thing that undermines the findings. This is narrative methodology, so in so many ways it is contextual, situational and temporal. This was how this parent felt on this day, time talking with me via a video link. I desire to be culturally sensitive but supported by the data collected.

Appendix 27: Research Journal Extracts – Comfortable talking with the researcher

Four out of the five participants about my interest in the topic and if I had a child with autism. The nature of the question made me consider what may have prompted parents to ask these questions and why it might be important to their participation in the research. It suggests to me that they felt comfortable talking to an interviewer from a similar background to them and that they were wondering how to position me as the researcher and my interest in the research topic. The recruitment flyer had both my name and picture. Therefore, at the outset, participants were aware that they would be talking to someone who had a name that identified them to be Bangladeshi and looked like a member of that community. It makes me consider if their decision to take part in the study was enhanced by the fact that I was Bengali. Prior to starting the research, I was conscious of the cultural stereotypes about stigma and shame, so I imagined that parents would not want to share their stories with someone from the community, in case we had connections in common now, or in the future. However, what I have noticed is a confidence to speak out, describe candidly about the impact on mental well being (Aliya), cultural roles (Nila), disappointment and sadness at not having receiving support from family members. I think either I had captured their trust, or they had trust in the research process.

Appendix 28: Research Journal Extracts – Covid-19

This research was conducted during the Covid-19 pandemic. Although English school closures were not in place during the start of the recruitment process in April 2021. The researcher was mindful that the schools and SENCo's were experiencing an uncertain and highly stressful time. All the initiatives described resulted in one parent's request to take part. Due to the limited time to recruit participants, the researcher decided to amend their ethics application and recruit online via social media, using platforms such as Facebook and Twitter; in an effort to maximise recruitment efforts, parents were offered a £10 voucher to thank them for their participation. Covid-19 had an impact on recruiting parents from one particular LA for the study and necessitated the recruitment through online platforms. Once the research was shared online, the researcher received over 11 requests of interest to participate; however, dues to the researcher's capacity, only the first five parents were chosen to take part.

The impact of Covid-19 on the parental experiences shared is uncertain. Many parents in the study expressed ideas around additional pressures and uncertain times

Appendix 29: Tillman’s (2002) Theoretical Framework for Culturally Sensitive Research

The researcher utilised Tillman's (2002) theoretical framework for culturally sensitive research and consider this in relation to this research study:

- Culturally congruent research method is the use of qualitative methods that capture and investigate the holistic context of a minority community in relation to their everyday lives. This researcher used narrative interviewing in this study to ensure that the parents shared what was meaningful about their experience.
- Culturally specific knowledge outlines the expectation that the researcher is both committed to and maintains the cultural integrity of data shared by parents. To these ends, this researcher maintained a reflective journal that considers the extent of their own cultural knowledge and the issues related to being both an insider and outsider to the research process (Appendix 20b).
- Cultural resistance to theoretical dominance, this stance encourages the researcher to consider that the cultural standpoints of those that experience the phenomenon under investigation is prioritised over those that are positioned outside of the experience being investigated. This fits with the social constructivist underpinnings in this study.
- Culturally sensitive data interpretations ask that culturally sensitive research analyse and present data in ways that are appropriate for the group being researched but carried out in ways that seek to address the power imbalances between researcher and researched by using co-construction methods. This study used data from narrative interviewing to create a storied narrative that was 'member checked' with individual parents.
- Culturally Informed theory and practice ask culturally sensitive researchers to maintain a focus on the perspective of participants and develop connections with espoused theories without privileging them.