Research Thesis Title

"Autism doesn't come with a manual, it comes with a parent who never gives up": A Family Resilience Perspective to Exploring the Views of Black and Minority Ethnic Parents of Children with Autism

By

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A thesis submitted in partial fulfilment of the requirements of the University of East London for the Professional Doctorate in Educational and Child Psychology

Abstract

This research sought to adopt a family resilience perspective to exploring the views of Black and Ethnic Minority (BME) parents of children with autism. Semi-structured interviews were carried out with ten parents with the aim to elicit what was meaningful to parents.

The purpose of this research was to adopt a strength-based approach to investigate the views of BME parents of children with autism as they negotiate their way through the education system. The existing literature concentrates principally on a largely problem-focussed narrative around parents' experiences of raising a child with autism. Therefore, the purpose of the study was to emphasise a family's strengths and resources, using a family resilience framework to explore processes that enable families to thrive.

The data was analysed using thematic analysis with themes emerging around family and relationships, values and beliefs and response to diagnosis. Overall, the findings illustrated a diverse range of experiences, values and beliefs that contributed to the resilience demonstrated by all the families. The main findings indicate overwhelming support for the positive aspects of raising a child with autism that are embedded with values and beliefs across individual, family and cultural contexts. The qualities of resilience demonstrated by families enabled them to function and remain optimistic in challenging situations.

The research reflects implications for Educational Psychologists with respect to adopting culturally sensitive and strength-based approaches to working with families from diverse backgrounds. The qualitative paradigm has provided insight into understanding parents' views and values on raising a child with autism, and their hopes for the future.

Key words: Family resilience; autism; culture; exploratory.

Declaration

University of East London School of Psychology

Doctorate in Educational and Child Psychology

This research is being submitted in partial fulfilment of the requirements of the Doctorate in Educational and Child Psychology.

This thesis is the result of my own work and investigation, except where otherwise states. Other sources are acknowledged by explicit references in the text. A full reference list is provided.

Rosabel Ng

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List of Abbreviations

ADHD – Attention Deficit Hyperactivity Disorder

APA - American Psychological Association

ASC - Autistic Spectrum Condition

ASD - Autistic Spectrum Disorder

BME - Black and Minority Ethnic

BPS - British Psychological Society

CYP - Children and Young People

DECP - Division of Educational and Child Psychology

DSM-V - Diagnostic and Statistical Manual of Mental Disorders, 5th Edition

DfE - Department for Education

EP - Educational Psychologist

EPS – Educational Psychology Service

GDPR - General Data Protection Regulation

GP – General Practitioner

HCPC - Health and Care Professions Council

IPA - Interpretative Phenomenological Analysis

JSNA - Joint Strategies Needs Assessment

LA – Local Authority

NAS - National Autistic Society

NHS - National Health Service

ONS - Office of National Statistics

PTA – Parent and Teacher's Association

SEMH - Social Emotional and mental health

SEND - Special Educational Needs and Disabilities

SENDCo - Special Educational Needs and Disabilities Coordinator

SSI - Semi-Structured Interviews

TA - Thematic Analysis

UEL – University of East London

Chapter One: Introduction

1.1 Chapter Overview

The purpose of this chapter is to introduce the research by presenting the area under investigation in this thesis. In doing so, the researcher will clarify specific terminologies by providing definitions of the terms employed. The rationale for focussing on the chosen population will be explained by presenting the context and background for the research. With these contexts in mind, the researcher will then proceed to explain the rationale for the research. Next, the chapter will identify the researcher's position, which will later be considered in relation to the theoretical, conceptual and epistemological frameworks for the research. The chapter will conclude with the aim of the study and the research question.

1.2 Terminology

A number of complex terms have been used in the current study, which the author considered merit some clarification. They are autism, culture, ethnicity and family resilience, and are briefly explained below. Along with these, 'children and young people' (CYP) was used interchangeably with 'young people', referring to individuals who are 25 years or under.

1.2.1 Autism

Autism, also frequently referred to as Autism Spectrum Disorder (ASD) or Autism Spectrum Condition (ASC), can be defined as a complex developmental disability that appears in early childhood, having long-lasting impacts on individuals and their families (Ravindran & Myers, 2012). For the purpose of this research, "autism" was chosen to incorporate any autism diagnosed condition, including ASD, ASC and Asperger's syndrome.

According to the DSM-V (APA, 2013), autism is defined by the presence of behaviours over three domains: difficulties in social interaction, communication, and restricted, repetitive interests of behaviours. Autism is understood to be along a spectrum, of which individuals might have varying strengths and difficulties across these areas. The diagnosis of autism is predominantly based on descriptions and observations about behaviours (Lord & Bishop, 2010).

As for the prevalence of autism, it is no longer a rare occurrence (MacKay, Greig & Connolly, 2017) but widely cited as affecting over 695,000 people in the U.K (ONS,

2011) regardless of culture, community or social economic status (Tincani, Travers, & Boutot, 2009).

1.2.2 Culture and Ethnicity

The definition of culture adopted in this research refers to culture as a dynamic yet stable set of goals, beliefs and attitudes that are shared by a group of people (Matsumoto, 2001). It frames our worldview and helps us to make sense of what is known. This definition is deemed appropriate as it encompasses sociological and psychological factors (Ravindran & Myers, 2012). Ethnicity, on the other hand, refers to one's identity within a group or race and is a biological and genetic concept (Turner, 2000). Ethnicity can also be referred to as a perceived membership or belonging to a social group, hence the term Black and Minority Ethnic (BME) is a collective terminology used to refer to ethnic minority groups (Aspinall, 2002). Both a person's sense of ethnic and cultural identity is complex as they can be fluid and highly personal (Slade, 2014).

1.2.3 Family resilience

Family resilience was approached from a strength-orientated perspective, falling within the realm of positive psychology (Simon, Murphy & Smith, 2005) which informs strength-based approaches in educational psychology practice (Wilding & Griffey, 2015). From this stance, resilience is a complex evolving construct, associated with the recognition of risk and protective factors (McCubbin & McCubbin, 2005). It can also be defined as the "ability to withstand and rebound from serious life challenges" (Walsh, 2016, p.4).

Extending beyond the contextual view of individual resilience, family resilience focusses on shared beliefs and positive narratives that capture a sense of cohesion, collaboration, competence and confidence (Walsh, 1996). From a systemic viewpoint, family resilience is an interactional process driven by an evolving ecological context that strengthens a family unit over time. It has been argued that a family systems approach to practice appears to resonate with ethnic minority families because of the emphasis on interconnection and reciprocity (Kumpfer, Alvarado, Smith & Bellamy, 2002). As such, there has been interest in shifting perspective from family deficits to understanding family processes that generate growth over time and across contexts.

1.3 Context

1.3.1 National Context

Over the past few decades, Britain has been transformed into a diverse society that is rapidly changing in line with increased worldwide mobility and ethnic diversity (Frederickson & Cline, 2015). BME communities comprise ethnic minority groups who are Asian/Asian British, Black/African/Caribbean/Black British, Mixed/Multiple Ethnic Groups and Other Ethnic Groups, making up 14 per cent of the U.K population and 83 per cent of the population in some London boroughs (ONS, 2011). As a result of the increase in diversity, debates have emerged nationally around culture and national identity (Williams, Weerasinghe & Hobbs, 2015), further impacting the lived experiences and engagement of BME families

There are views that believe cultural issues have given rise to 'ethnic disproportionality', which is particularly relevant to the field of autism (Strand & Lindsay, 2012). Interestingly, information available suggests certain ethnic groups are often over-represented within groups of CYP with whom educational psychologists work with, or under-represented when accessing services and support. For example, Lindsay, Dockrell, Law and Roulstone (2012) found that the prevalence of language and communication needs in Black pupils were twice as high as those of White British pupils. Meanwhile, Lindsay et al (2012) identified that autism diagnoses for CYP from an Asian heritage were half the prevalence of those of White British pupils. In response to exploring reasons for such imbalance, it has been a national priority to improve the effectiveness of engaging BME families by attempts to make services more culturally sensitive (NHS, 2009). However, to date, there has been scarce evidence of such improvements between services and BME families (Lloyd & Rafferty, 2006).

1.3.2 Local Context

The notion of 'ethnic disproportionality' is reflected in the local context of the current research that included participants from four inner London Local Authorities (LA), all of which are considered economically and ethnically diverse. The researcher worked in one of these LAs, in which 60 per cent of the local population was of ethnic minority (ONS, 2011). Based on the data available on the four LAs, the majority of children from BME families have a diagnosis of autism (JSNA, 2017; Annual Equality Report, 2016; ONS, 2011).

With this local picture in mind, it is therefore recognised that such diversity will impact the quality and effectiveness of service delivery. There is now a considerable amount of research that recognises how diversity has affected the conceptualisation of Special Educational Needs and Disabilities (SEND). In particular, this includes the recognition of how this conceptualisation of SEND is influenced by family organisation, patterns of change, and how such perceptions of SEND evolve with culture, family and organisational systems (Frederickson & Cline, 2015).

1.3.3 Legislation

Listening to the views of parents from BME backgrounds and focussing on strength related concepts is underpinned by legal perspectives. According to the Equalities Act (2010), professionals have a responsibility to remain aware of the prevalence and recognition of SEND in ethnic minority groups. By listening to the views of parents, the research also considers principles outlined in the SEND Code of Practice (DfE, 2015) and the Children and Families Act (2014) which gives power to parents, providing them with increased autonomy over the support offered to their child. In summary, legislation illustrates the importance of family centred approaches, informed by policy, formulation and evidence-based practice.

1.3.4 Professional Context: The role of the Educational Psychologist

Educational psychologists (EPs) are professionals who offer an array of support to CYP, families and professionals across a range of settings (BPS, 2015). They work with others to identify and build on strengths and relieve difficulties or barriers to learning.

EPs are required to adopt a holistic approach to practice which considers the context around children and young people (BPS, 2015). In relation to the prevalence of autism, there is a need to foster positive educational and social experiences for young people, which is considered an important goal for parents, professionals and EPs (MacKay et al., 2017). In doing so, EPs can build up a positive working relationship with parents by obtaining their views (BPS, 2015). They are particularly well placed to work with schools, multi-disciplinary professionals and families to achieve positive outcomes for young people.

EPs have an important responsibility to have an awareness of the impact of culture and diversity, and adapt practice to meet the needs of different individuals (HCPC, 2015; BPS, 2017). Even within Educational Psychology training programmes, multicultural

competence has been given special attention (Lopez & Bursztyn, 2013), as well as cultural awareness being persistently reflected in Standards for Educational Psychology training (BPS, 2015).

Working within schools and at the individual and family level, EPs are in a strong position to identify shared core values which promote empowerment in communities (Dickson, 2012). The researcher, also a trainee EP, has considered the application of the research beyond the research context. The research can benefit the BME community by raising cultural awareness and sensitivity to practice in schools and Educational Psychology Services.

1.3.5 Theoretical context

The research is underpinned by principles from positive psychology which refers to the exploration of positive emotions, positive character traits and enabling functions (Seligman, Steen, Park & Peterson, 2005). The shift in focus from deficit to strength-based models seeks to go beyond recognising positive emotions and positive thinking; rather, it focusses on what might make individuals become resilient and flourish (Hefferon & Boniwell, 2011).

The realm has received some criticism for replacing what might be known of human suffering and deficit (Seligman et al., 2005), but the field intends to supplement, not remotely replace, challenges one may encounter. Thus, intentions are to have a more balanced scientific understanding of human experiences. As a result, the field has attracted attention over the past decade, especially in relation to cross-cultural findings revealing an ubiquity of strengths and virtues (Seligman et al., 2005). The fundamental principles of positive psychology underpin the concept of family resilience that behove the researcher, utilising the concept as a framework within the research.

1.4 Researcher Position

The current study adopts a relativist ontological position which rejects the notion that we can ascertain the 'true' nature of reality (Braun & Clarke, 2013). Informing a socially constructionist epistemological paradigm, knowledge is discovered through experiences, which are socially constructed across time and contexts (Ponterotto, 2005). Presenting the researcher's position acknowledges that prior experience and pre-conceived assumptions were intertwined during this process of discovery and difficult to avoid.

1.4.1 Reflexivity

The researcher accepted their role as a subjective researcher, which assumed their presence and involvement with participants elicited data that represents the complex nature of human interactions (Frost, 2016).

The researcher adopted an explicitly self-aware position throughout the research, where exploration led to reflexivity (Drake & Heath, 2011). By including the 'self' throughout the process (Etherington, 2007), reflexivity recognised that personal insights and engagement were an important part of understanding the phenomenon (Patton, 2002). Reflexivity was important as the researcher had to be sensitive to their own influence on the research process in relation to their identity, experience, cultural background and personal values that impacted the study and its findings.

1.4.2 Personal background

The researcher was previously a teacher and taught in inner London schools. Having taught in a mainstream primary school, as well as a secondary special school for CYP with a range of Social and Communication difficulties and Social Emotional and Mental Health (SEMH) difficulties, the researcher has experience of working with children and families from a range of diverse backgrounds. Before starting the professional doctorate training, the researcher valued the importance of culture, strength-based approaches and working collaboratively with parents. The research process provided opportunities to further explore this valuable area and contribute to a limited evidence base.

Although the researcher is not a parent, the researcher is from a BME background and therefore shares aspects of an insider's perspective which has enriched the nature of the research. This provided a better understanding of BME families' experiences. Such aspects of shared knowledge and understandings were implied when interviewing parents, which provided opportunities for collaboration and reciprocity in eliciting their voice (Tillmann-Healy, 2003). However, it is also recognised that although this might facilitate a culturally sensitive approach to conducting the research, the researcher was also aware of potential biases that might be placed upon participants.

1.5 Research Rationale

1.5.1 Strength-based approach

The aforementioned background and context to the research provided a rationale to extend the researcher's curiosity in this area. Namely, this was to adopt a strength-based approach to investigating the views of BME parents of children with autism as they negotiate their way through the education system. While there is a historically recognised paucity of research into BME families affected by children with autism (Corbett & Perepa, 2007), the existing literature concentrates principally on a largely problem-focussed narrative around parents' experiences of raising a child with autism. The rationale behind studies in this area has been around recognising the stressors of raising a child with autism from an immigrant family.

In contrast, by emphasising a family's strengths and resources, family resilience was a useful conceptual framework for identifying the key processes that enabled families to thrive (Walsh, 2003). The notion of family resilience also called for professional practice to be attuned to the challenges of families within their sociocultural contexts (Walsh, 2016). However, in doing so, the researcher needed to explore processes that fostered family resilience, while being mindful of cultural diversity and the potential challenges of raising a child with autism. By not focussing on one particular ethnic group, the researcher recognised that there were multiple viewpoints on what was defined as healthy family functioning.

1.5.2 Addressing the gap in literature

The current study sought to address the gap in the existing literature on numerous levels. Existing research explores problem-focussed deficit models; this study by contrast focuses on positive psychological approaches, offering ways of reframing negative views of autism within cultures (Theara & Abbott, 2015). Parents have reported valuing a strength-based approach in educational psychology practice that focus on the importance on positives, resources and qualities (Bozic, Lawthom & Murray, 2017; Hogg, Hart & Collins, 2014). Furthermore, Harris and Glasberg (2003) explained that some families of children with autism demonstrated strength and resilience in their experiences of raising their children.

The rationale of this research is also largely prompted by the lack of qualitative research in this area. The research has methodological significance as it contributes to a limited amount of small-scale qualitative research in the area of culture and autism

(MacKay et al., 2017). Surprisingly, studies on family resilience have predominantly adopted a quantitative methodology, despite the fact that qualitative methodologies are found to hold great potential for exploring family belief systems (Walsh, 1996).

1.5.3 Theoretical contribution

The study also offers a contribution to the field of culture and autism by providing new conceptual understandings of the area. It was an explicit aim of this research to adopt a strength-based approach as, until now, there has been no direct exploration of the views of BME parents of children with autism with a family resilience framework in mind. The research also achieved practical significance by empowering participants in the research process. In turn the researcher, as a practising trainee EP, developed skills in consultation by working collaboratively with parents.

1.5.4 Developing cultural competence

It has been documented that professionals need to develop their cultural competence in order to best meet the needs of BME communities (Slade, 2014). Therefore, it is important that educational psychology practice continues to revisit the value of diversity in communities. Research in this area warrants further attention, particularly when working with ethnic minority groups whose cultural beliefs differ significantly from one's own.

The researcher was interested in gaining insight into parents' views which can be related to a wider theoretical context. In considering ethical best practice (Larner, 2004), the aim was to draw on evidence-based approaches that responded to the unique stories shared across a range of cultural and family contexts. The researcher recognised that 'views' referred to perceptions, views and opinions but also included experiences (Braun & Clarke, 2013). The purpose of the study was to explore these aspects and identify patterns and ideas, rather than to test hypotheses.

1.6 Research Aim

With the above in mind, the research aim for this study was to adopt a family resilience perspective to exploring the views of BME parents on raising a child with autism. Through the use of semi-structured interviews, the study was planned to elicit what was meaningful to parents.

1.7 The Research Question

A semi-structured interview was designed to address the following exploratory question:

From a family resilience perspective, what are the views of BME parents on raising a child with autism?

With three sub-questions:

1. What are the views on the role of family and relationships?
2. What are the views on the role of values and beliefs?
3. What are their experiences on their response to the diagnosis?

1.8 Chapter Summary

This chapter introduced the current research by outlining specific terminologies and explained the context and background for the research. Following this, the rationale for the research was presented which briefly identified the need for further investigation. The chapter concludes with reflections on the role of the researcher and ends with the specific aim of the research and the overarching research question with sub-questions. This leads to the following chapter which presents the Methodology and exploration of the theoretical, conceptual and epistemological framework underpinning the research.

Chapter Two: Literature Review

2.1 Chapter Overview

This chapter will provide a comprehensive and systematic review of the relevant research to the area under investigation. The chapter will cover details of the systematic search process, followed by a critical and systematic analysis of the research findings. The sections discussing areas of the literature will be organised under different themes and critically analysed, along with the research design. The research findings will be placed and discussed within the theoretical area. To conclude, a summary of the literature will be provided.

2.2. Literature Review Process

Aspects of a systemic literature review were carried out using the relevant terms and identifying key themes. The main purpose of the review was to engage with the literature and explore the intellectual boundaries for the current research project. It also considers how the literature informed the rationale for the research and the research design. This will justify that there is a gap in the literature for a strength-based approach to exploring parents' views on raising a child with autism, culture and family resilience.

Aspects of a systematic literature review was carried out using the following databases: Academic Search Complete, British Education Index, Child Development and Adolescent Studies, Education Abstracts (H. W. Wilson), Education Research Complete, Educational Administration Abstracts, ERIC, PsycINFO, PsycARTICLES, Teacher Reference Center, Scopus (for citation searches) and Science Direct. To ensure sufficient scoping of the literature, the following search strategies were used: key word search across databases; thesaurus searches (controlled vocabulary produced by database indexers) and citation searches for identified pearl papers (key papers considered highly relevant to the current research) (Booth, Sutton & Papaioannou, 2016). Guidance was also sought from a specialist librarian on how to conduct aspects of the systematic literature review. The researcher engaged in a process of reviewing and re-viewing the searches by screening the literature at several stages. Further details and the full process of the literature identification can be found in Appendix I – VII.

To engage fully with the literature, the following stages were referred to in order to provide shape to the engagement process: summarise, synthesise, analyse and authorise (Trafford & Leshem, 2008). The final stage allowed the researcher to locate the current

study alongside or within the existing literature and therefore to authorise her position held towards the current research.

An initial literature search was conducted using all terms relevant to the study and their synonyms: parent views, autism, culture and family resilience. However, this produced no results and the author proceeded forward by using combinations of these terms and by extending and dividing the search into three main strands. The literature was then explored within each of the three strands: parent views, autism and culture; family resilience and autism; family resilience, autism and culture. Figure 2.1 illustrates these areas, with the number of relevant studies identified added in brackets.

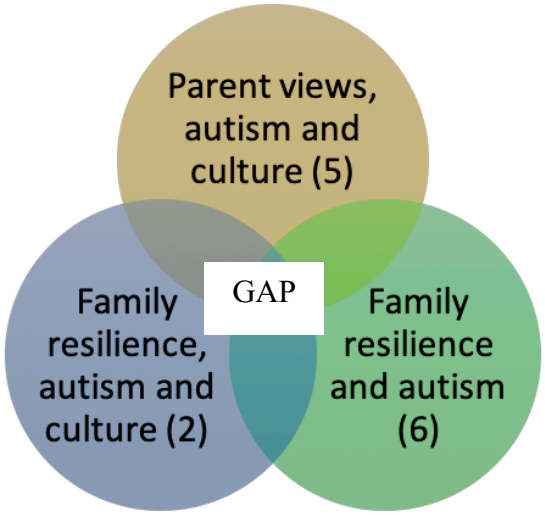

Figure 2.1. The strands of the systematic literature review.

The following sections will critically engage with the literature in the three main areas investigated. The sections are organised thematically and discussions will consider theoretical underpinnings, epistemology and main findings. Alongside this, the research design will be discussed including the methodology, participants, data collection, and analysis. Consideration will be given to how the findings enhance the researcher's understanding of the area under exploration. Conclusions will then be drawn about the significance of the studies to the current research. The chapter will conclude with the research aim and questions.

2.3 Exploring the Literature on Parent Views, Autism and Culture

The identified studies within this strand use a qualitative research design to explore the views of BME parents on raising a child or children with autism. The databases and search terms for studies that explored parent views, autism and culture are presented in Table 2.1. Details of the inclusion and exclusion criteria and screening process can be found in Appendix I and Appendix II, with the final studies included presented in Appendix III.

<table>
<tr><th>Limiters</th><th>Databases</th><th>Search terms</th></tr>
<tr><td rowspan="4">Restricting the dates from 2002-2018

Restricting the age of the participants to below 25 years

Searching peer reviewed academic journals

Restricting the language to English.</td><td>Academic Search Complete, British Education Index, Child Development and Adolescent Studies, Education Abstracts (H. W. Wilson), Education Research Complete, Educational Administration Abstracts, ERIC, PsycINFO, PsycARTICLES, Teacher Reference Center</td><td rowspan="4">Parent experience OR parent perceptions OR parent opinion
AND
Autism OR asd OR autism spectrum disorder
AND
Culture OR cultural OR ethnicity OR identity or values

NB: the term views also refers to experiences, opinions, perceptions and understandings</td></tr>
<tr><td>Scopus</td></tr>
<tr><td>Science direct</td></tr>
</table>

Table 2.1 Search details for studies on parent views, autism and culture.

As Appendix III illustrates, of the five studies identified, three explored the views of South Asian parents (Theara & Abbott, 2015; Habib, Prendeville, Abdussabur & Kinsella, 2017; Jegatheesan, Miller & Fowler, 2010), one explored the views of Somali parents (Fox, Aabe, Turner, Redwoord & Rai, 2017) and one explored the views of Black African immigrant parents (Munroe, Kathryn, Hammond & Cole, 2016). Each of the studies elicited views using interviews and additionally, one also used observations (Jegatheesan, Miller & Fowler, 2010). The studies are predominantly underpinned by a constructivist

approach where realities are socially constructed through the person's experiences (Theara & Abbott, 2015; Habib et al., 2017; Munroe et al., 2016). However, one adopted a community-based participatory research approach (Fox et al., 2017) and another used an ethnographic approach (Jegatheesan et al., 2010).

2.3.1 Themes

Across the articles that explored parent views, autism and culture, the researcher identified themes of 'experiences', 'religion' and 'constructions of autism'. Each theme is discussed below, before proceeding to consideration of theoretical and conceptual frameworks, research design, researcher position and analysis.

2.3.1.1 Experiences

A majority of the studies report predominantly negative experiences of cultural aspects and raising a child with autism in a Western society. A prominent theme across the studies include feelings of stigma and isolation, with reasons varying across studies. Munroe et al. (2016) found that parents felt judged and blamed for their child's autism; the judgment infringed upon them meant they did not feel accepted by other parents in the local communities. Similarly, Theara and Abbott (2015) and Fox et al. (2017) identified that parents who expressed overwhelming feelings of isolation also refrained from engaging with professionals and services. Further, parents in Jagatheesan et al's (2010) study reported detailed negative experiences they had faced raising a child with autism which included discrimination by professionals.

In contrast to the negative experiences, Habib et al.'s (2017) study with Pakistani mothers revealed positive communication with services or professionals. Parents expressed how they felt empowered to proactively access services and therefore had established positive relationships with professionals. This was inconsistent with findings from Theara and Abbott's (2015) study, also on South Asian parents in the U.K, where parents reported experiences of loneliness and disengagement with services. A reason for this disparity could be the high education levels of mothers included in Habib et al.'s (2017) study - they were all working professionals who could easily access services and communicate confidently with professionals.

Although none of the studies sought to explore positive experiences of parents, some positive themes from the findings included parents adopting positive outlooks for the future (Theara & Abbott, 2015); references to acceptance and hope (Munroe et al., 2016;

Fox et al., 2017) and appreciation of strengths in their child (Habib et al., 2017). Contrasting findings were reported in Munroe et al.'s (2016) study where Black African immigrant parents described the experience of raising a child with autism as all-consuming and linked to physical and emotional exhaustion. An explanation for this finding could be the impact of migration and separation from social support systems. By comparison, families in the majority of the remaining studies had been in the country of residence for a prolonged period of time. Some methodological limitations might also account for this difference around the position of the researcher and the interpretative paradigm underpinning the research.

These studies also highlight that working with professionals is a key factor which impacts families' experiences of raising a child with autism. Findings illustrate there are varying constructions of autism across cultures, and on the whole, these do not discuss how professionals can adopt a more positive attitude towards working with families from different cultures.

2.3.1.2 Religion

A shared theme across the studies was that religion is a protective factor for families (Munroe et al., 2016; Fox et al., 2017; Habib et al., 2017). Religion offered meaning and hope to mothers (Munroe et al., 2016) and was a form of support that mothers could rely on consistently. Jegatheesan et al.'s (2010) study revealed that religion was so prominent in the families' lives that they felt blessed to be chosen by Allah to raise a child with autism. They therefore shared experiences of having greater compassion towards their child. The role of religion appeared to be a significant contribution to how families perceived their child's disability, in turn this impacted the meaning drawn from their experiences and how they viewed both past and future outlooks.

2.3.1.3 Constructions of autism

An interesting theme emerging from the studies is the parents' construction of autism. There are striking differences in how autism is constructed and perceived in South Asian parents in the U.S (Jegatheesan et al., 2010) compared to the U.K (Theara & Abbott, 2015). Positive connotations were reported by parents in Jegatheesan et al.'s (2010) study where autism was described as a gift from Allah. However, these parents were then more likely to reject dialogues with professionals around their child's deficits from a more medicalised model, causing the relationships with services to be strained.

Conflicting with these findings, a major theme from Theara and Abbott's (2015) study, also with South Asian parents, was that constructions of autism were from an overwhelmingly medical model perspective, but that this was readily accepted by parents. They therefore, sought clarity and information from a medical perspective and were resistant to alternative explanations. One explanation for this disparity is that parents may have been influenced by more medicalised and deficit models of autism . This raises the question of how constructions of autism vary across cultures and countries. According to Theara and Abbott (2015), public services in the U.K are more likely to bring a social model of construction of autism, which could conflict with medicalised beliefs around autism. The prominence of a medical model across cultures might also explain the stigma attached to the autism label, if it is seen as a medical or mental health disorder (Fox et al., 2017; Munroe et al., 2016). Regardless, it is evident that disparities in the construction of autism are likely to be contributing to the disengagement between families and services. Future research might consider clarity around families' constructions of autism, in order to reflect on how to strengthen relationships between services and communities.

2.3.2 Research Design

Due to the exploratory nature of the studies, all studies included small samples of participants, ranging from three (Jegatheesan et al., 2010) to fifteen (Fox et al., 2017). Three studies included both mothers and fathers with both boys and girls with autism (Fox et al., 2017; Theara & Abbott, 2015), and one included both parents, but only with sons with autism (Jegatheesan et al., 2010). Two studies included mothers (Munroe et al., 2016; Habib et al., 2017) and two included only parents of sons with autism (Munroe et al., 2016; Jegatheesan et al., 2010). Therefore, it is possible that gender could be a significant variable in shaping the findings. Due to the small samples and unique contexts, it is unlikely that the experiences are representative of wider areas or populations.

Of these studies, Habib et al. (2017) had the most homogenous sample as all mothers from Pakistani origins, were from professional families and therefore not representative of Pakistani families in Ireland. It is important to consider the impact this would have on findings as mothers reported positive experiences communicating with and seeking support from services. This differed from mothers who struggled to access services due to language barriers and an unfamiliarity with the education and health care system (Munroe et al., 2016; Fox et al., 2017). In addition, some of the studies included hard-to-reach families or those nested within small cultural communities, making findings

harder to readily generalise. Despite this, they have produced rich data and valuable insights into the specific population and context explored.

2.3.2.1 Data collection

All researchers elicited views using interviews which allowed the opportunity to explore in more detail and gain a deeper understanding of the parents' views. It meant that parents were able to openly articulate their opinions and likely felt empowered to do so. In studies where interviews were co-facilitated and analysed by another member of the same community, trustworthiness of the data was strengthened (Fox et al. 2017; Jegatheesan et al., 2010).

A well rounded and more complete view of the family as a whole was gathered in Jegatheesan et al.'s (2010) study through observations and the longitudinal aspects of the study. In this research, a unique interviewing style was adopted, where interviews were customised to the local communicative norms. The initial interviews were shaped by the first researcher's observations of the home and community, and this illuminated how parental religious beliefs informed child rearing understandings and practices.

Due to the highly contextualised approach to Jegatheesan et al's (2010) study, it is likely that findings cannot be generalised to other South Asian Muslim populations due to the intricate and unique nature of the data collection method. Interviews were also more informal, and carried out during normal daily routines which might have been disruptive to the flow of the conversation. Despite this, the longitudinal aspects meant a rapport was built with families, resulting in rich and culturally valid findings.

2.3.2.2. Data analysis

Most of the studies endured a rigorous process of triangulation which involved a team of individuals analysing the data. Methods of analysis included grounded theory (Theara & Abbott, 2015), thematic analysis (Habib et al., 2017; Fox et al., 2017), Interpretive Phenomenological Analysis (IPA) (Munroe at al., 2016), and multi-level analysis (Jegatheesan et al., 2010).

In some instances, researchers were able to confirm or disconfirm initial inferences before final interpretations were developed (Jegatheesan et al., 2010). On the other hand, for the participatory led research (Fox et al., 2017), it is unclear whether final themes from analysis were shared or checked with participants. However, the researchers did work closely with the community members to ensure the inductive analysis reflected the

participants' views and experiences. In line with the principles of participatory research, it would have been interesting to know how findings were disseminated to promote action and improvement within the Somali community.

2.3.2.3 Researcher's position

An interesting reflection point across studies is the authors' reference to their own ethnicity and potential impact this had on interpretations within the research. All the authors (Fox et al., 2017; Theara & Abbott., 2015; Jegatheesan et al., 2010; Habib et al., 2017), apart from one (Munroe et al., 2016), shared the same ethnic background as the participants. One researcher also had a child with autism (Habib et al., 2017) and referred to this as having a valuable insider's perspective that enriched the study by providing a better understanding of mothers' experiences. In contrast, the researcher in Munroe et al., (2016) was White-British from the U.K, compared to the participants who were Black African immigrants. This might have led to perceived power imbalances and would have required the researcher to maintain a reflexive stance throughout.

2.3.2.4 Theoretical and conceptual frameworks

Some studies were underpinned by theoretical and conceptual frameworks, impacting the research design and findings. As the focus of Jegatheesan et al.'s (2010) study was on religious aspects only, Islam provided a primary framework for the families in adapting to raising a child with autism. In turn, the authors also familiarised themselves with Islamic principles to engage with families and to facilitate the analysis process. As only three families were included, findings are unlikely to be generalisable to other Muslim families as the degree to which they follow Islam could vary considerably.

Similar principles of community engagement were adopted in Fox et al.'s (2017) study by working closely with Somali families. Both studies (Jegatheesan et al., 2010; Fox et al., 2017) had access to resources that made it possible to promote a collaborative approach to the study, yielding unique contributions to the field of exploratory research.

The social constructionist lens, underpinning Theara and Abbott (2015) and Munroe et al.'s (2016) research, allowed authors to explore how autism is to an extent, a social construction. Munroe at al. (2016) mapped themes within the findings onto Berry's (1997) process of acculturation which provided some explanation for the cultural and emotional dissonance experienced by mothers. In a similar way, Theara and Abbott (2015) used the concept of intersectionality to highlight how families raising a child with autism

can be shaped by the intersection of cultural beliefs and disability. Both studies arrived at shared findings around parents being more likely to hold a dominant medical model construction of autism. This was framed as being negative due to incompatible cultural beliefs between the minority culture and the Western model of disability.

The epistemological considerations and implications of findings from Theara and Abbott (2015) and Habib at al. (2017) relate directly to EP practice. Theara and Abbott (2015) reached a point of developing a theoretical model which has supported exploration of the implications of the findings; however, this is yet to be tested within the field. Both papers provide EPs and other professionals with greater awareness of cultural issues within educational settings in the U.K.

Overall, the studies demonstrate that there is value in exploring parents' views around raising a child with autism and cultural aspects. All studies gave an opportunity for parents to share their experiences of raising a child with autism from various cultural perspectives. Nonetheless, the cultural aspects that were highlighted have been predominantly negative. Further research could therefore be useful on how positive psychology can be applied in order to identify positive aspects of culture and communities.

2.4 Exploring the Literature on Parent Views, Autism and Family Resilience

In synthesising the aforementioned literature, this section will present studies which explored parent views, autism and family resilience. Combinations of the three main terms were used in the searches as illustrated in Table 2.2; as it was thought that exploration of literature in this way would enhance the researcher's understanding of the area under investigation. The databases and search terms for studies which explored parent views, autism and family resilience are presented in Table 2.2. Details of the inclusion and exclusion criteria and screening process can be found in Appendix IV and Appendix V, with the final studies included presented in Appendix VI.

Limiters	Databases	Search terms
Restricting the dates from 2002-2018 Restricting the age of the participants to below 25 years Searching peer reviewed academic journals Restricting the language to English.	EBSCO (Academic Search Complete, British Education Index, Child Development and Adolescent Studies, Education Abstracts (H. W. Wilson), Education Research Complete, Educational Administration Abstracts, ERIC, PsycINFO, PsycARTICLES, Teacher Reference Center	1st search: Parent views OR perspective OR opinion OR experience OR beliefs AND Autism OR ASD OR autism spectrum disorder AND Family resilience
	Scopus	2nd search: Family resilience AND Autism OR ASD OR autism spectrum disorder AND Culture or cultural OR ethnicity OR identity or values
	Science direct	3rd search: Family resilience AND Autism OR ASD OR autism spectrum disorder

Table 2.2 Search details for studies on parent views, autism and family resilience.

The six studies identified used predominantly survey methodologies (Greeff & van der Walt, 2010; Bayat, 2007; Kapp & Brown, 2011; Leone, Dorstyn & Ward, 2016), with one using structured tools (Das, Das, Nath, Dutta, Bora & Hazarika, 2017). Three studies used qualitative methodologies, where views were elicited using focus groups, (King, Zwaigenbaum, King, Baxter, Rosenbaum & Bates, 2006) and two used interviews (John & Roblyer, 2017; Heimann, 2002). Of these studies, two explored cultural aspects, family

resilience and raising a child with autism (Das et al., 2017; John & Roblyer, 2017). These will be discussed towards the end of the review.

2.4.1 Themes

The researcher identified themes of 'social support, 'theoretical frameworks' and 'belief systems' across the articles which explored parent views, autism and family resilience. Each theme will be discussed below, before proceeding to consideration of theoretical and conceptual frameworks, research design and analysis.

2.4.1.1 Social support

All the studies were underpinned by a resilience framework with resilience defined as a concept stemming from the field of positive psychology; and although it has not been researched much in the disability field, it has shifted focus from deficit models (Bayat, 2007). The concept of family resilience has been looked at either as two groups of risk and protective factors, or as a flexible process, indicating a family's strength at different points (Bayat, 2007).

A significant protective factor across the findings was the importance of social support, acceptance and having a positive outlook for the child and family (Kapp & Brown, 2011; Greeff & van der Walt, 2010; Bayat, 2007; Leone, et al., 2016). Social support was deemed one of the most important protective factors, as families with a supportive environment experienced more cohesion and commitment to helping each other. However, it is debatable whether support was largely determined by the services around the family, as opposed to support from family members.

2.4.1.2 Theoretical frameworks

Studies drew from a number of theoretical frameworks, including Walsh's (2003) Family Resilience Framework (Leone et al., 2016; Bayat, 2007) and McCubbin and McCubbin's (1996) Resiliency Model of Family Stress, Adjustment and Adaptation (King et al., 2006; Greeff & van der Walt, 2010; Kapp & Brown, 2011). A noticeable difference in reported findings is that studies drawing from McCubbin and McCubbin's (1996) model reported socioeconomic status as playing a large role in the family's adaptation to raising a child with autism, with middle to upper class families described as 'better adapted' (p. 352, Greeff & van der Walt, 2010). With this in mind, the Resilience Model of Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1996) was considered an

effective contextual framework to understand resilience within families (Greeff & van der Walt, 2010).

In comparison to McCubbin and McCubbin (1996), studies underpinned by Walsh's (2003) framework focussed on family strengths across key areas of belief systems and organisational and communication patterns. This is in line with Walsh's (2003) suggestion that family resilience is driven by internal characteristics. As such, external factors such as socioeconomic status and access to services may promote family resilience but is not considered the primary driving force.

It can be argued that there are differences in themes from the application of both frameworks. However, unlike popular assumptions that families struggle to cope with major stressors of raising a child with autism, findings have shown that families can strengthen as a result of adversity.

2.4.1.3 Belief systems

A major theme across findings was the importance of belief systems in mediating the relationship between parental stress and overall adjustment to raising a child with autism (King et al., 2006; Bayat, 2007; Greeff & van der Walt, 2010). Belief systems also encapsulated spiritual and religious beliefs, as well as general parental perceptions of disability (Bayat 2007; Leone et al., 2016). However, there were conflicting findings around the role of religion as some identified religion as having a positive contribution to family adaptation to their child's disability (King et al., 2006; Leone at al., 2016; Bayat. 2007), while others did not mention religion as having a positive contribution to family resilience (Heimann, 2002; Greeff & van der Walt, 2010).

Belief systems also composed of future beliefs and expectations of families. In Heimann's (2002) qualitative study, parents expressed a strong belief in their child and in the future. Positive belief systems meant an optimistic outlook was obtained with a realistic view and acceptance of their child's disability. However, one may argue that parents who participated in this study had already accepted the diagnosis and the implications it might have on the child's future. Therefore, belief systems are variable and could be dependent on the time in which the child was diagnosed and the sense of meaning families assigned to the experience at that moment in time.

To support this hypothesis another shared finding, was how parental world views and values adapted over time (Bayat 2007; King et al., 2006). This was considered a minor theme in Bayat's (2007) study, compared to a significant theme in King et al. (2006)'s

findings. In King et al.'s (2006) study, this included how they thought of life, themselves, the family and their child, and the implications this had for the future.

The change in beliefs reflect the powerful nature of how family resilience can contextually reframe experiences, by viewing them from a different perspective. The qualitative approach in King et al.'s (2006) study allowed for deeper exploration of how views changed over time. This might explain the difference in the theme being categorised as a minor theme within Bayat's (2007) quantitative study.

2.4.2 Research design

Only two qualitative studies were identified which directly elicited parents' views through face-to-face interviews (Heimann, 2002; King et al., 2006).; however, Heimann's (2002) study used structured quantitative and qualitative tools to conduct the parent interviews. Findings from this study revealed that the main contributing factors to family resilience included positive and supportive communications with family, and having continuous psychological support from family members and professionals.

Similar findings were identified in King et al's (2006)'s study, where parents were appreciative of the positive contributions made by support networks around them and society as a whole. Both studies recorded families making positive adaptations over time, which meant they were able to gain a sense of control over their circumstances. To build on this, King et al.'s (2006) study gave some insight into the world views and belief systems of parents, namely how their world views encompassed people's strengths and the value held to happiness, achievement and making positive contributions.

While the quantitative studies ascertained that family resilience was present in families raising a child with autism, results were measurable and not subjective, potentially limiting the breadth of information on feelings, meanings and experiences. It could be argued that the quantitative approaches in the studies have advocated for a descriptive purpose, to examine predictors, correlational relationships or factors impacting family resilience.

For some studies, parents completed at least five questionnaires (Kapp & Brown, 2011; Leone et al., 2016; Greeff & van der Walt, 2010) which might have caused respondent fatigue. The reliance on self-report measures may have also caused social-desirability bias across the quantitative findings, particularly around child rearing questions or social support. Whilst powerful in offering insights in patterns of opinions / beliefs, quantitative approaches do not explore parents' own stories in detail. It has also

been said that operationalising family resilience by quantitative means can be problematic (Bayat, 2007).

2.4.2.1 Data collection

Only one study used an exploratory design to elicit the views of parents through focus groups (King et al., 2006). While rich data was produced, the focus groups also included professionals, which might have made parents feel under pressure or obliged to speak positively about their experiences of raising a child with autism. Personal interviews may have provided more scope for the researcher to understand views, and may have allowed for deeper exploration of individual experiences. However, the study did demonstrate credibility, as data was triangulated and member checking took place. Transparency was also considered as a team of five individuals from different backgrounds analysed the transcripts.

Some studies obtained qualitative data through surveys (Kapp & Brown, 2011; Greeff & van der Walt, 2010). This format, including more structured interviews may have restricted opportunities for engagement with parents, such as allowing space for reflection, further prompting and expansion or clarification of answers. These studies lacked the standards of rigour of more collaborative qualitative studies, such as triangulation and multiple checks during the analysis stage, due to the specific features of data gathering process. Qualitative studies using interviews (Heimann, 2002), on the other hand, cannot be generalised to other populations and are only representative of the participants in the study. Nonetheless, they provide a richer understanding of parents' unique experiences, and the emotional journey they embarked upon.

Studies that used a survey methodology had varying numbers of participants, from nineteen (Kapp & Brown, 2011), to 175 participants (Bayat, 2007). It was felt that sample sizes for most of these studies were considerably small for the quantitative approaches and therefore the reliability and validity of tools should be considered. Additionally, it can be argued that the data was difficult to contextualise, especially as there was little opportunity for respondents to expand upon answers.

2.4.2.2 Participants

Qualitative studies used small sample sizes, such as three focus groups in King et al. (2006) and larger samples sizes, such as thirty-two interviewed in Heimann (2002). Although rich data was sought from King et al's (2006) study, the use of intensive

sampling meant that participants were purposely selected from non-diverse backgrounds. These participants were also considered 'key informants', representing parents who had a wealth of experience of their child's disability and the services available. This could mean their views were more likely to be more informed than those of typical parents and they might have emphasised points, including strengths and adaptability, to a greater degree, than if parents were selected differently.

On the whole, participants were recruited from a range of areas and settings. Some were from more rural than urban areas (Greeff & van der Walt, 2010); others from one support group (Bayat, 2007); one school (Kapp & Brown, 2011); recruited through organisations (King et al., 2006) and across districts (Leone et al., 2016; Heimann, 2002). Again, most of the authors discussed the potential limitation this might have in relation to accessing resources and paying for services.

This leads on to the major limitation discussed in the studies, which is the largely homogenous samples with an over-representation of families from middle to upper class or higher socioeconomic groups, making samples not representative of the wider populations. In Greeff and van der Walt's study (2010) all the participants were considered to have a high socioeconomic status and in Bayat's (2007) study, 63 percent were middle to upper class white families. It is then questionable whether resilience in these studies is due to accessing resources more easily due to the financial status of the family, as opposed to internal characteristics such as individual or family strengths.

2.4.2.3 Country of study

The studies investigated included participants from Israel (Heimann, 2002), South Africa (Kapp & Brown, 2002; Greeff & van der Walt, 2010) and a range of ethnic backgrounds (Bayat, 2007). Although religion was discussed briefly in some studies (King et al., 2006; Bayat, 2007), surprisingly, none of the authors considered the possible impact of religion and culture and how this might be intertwined with components of family resilience. Additionally, the meaning and understanding of autism might be different across countries and culture, for example, it might be more medicalised in some countries than others. This is likely to affect how families respond to the diagnosis and their perceptions on their ability to adapt to raising a child with autism.

Overall, the studies have contributed valuable information on the evidence of resilience in families with autism. The findings suggest that when working with families it is important to capture the whole experience, both positive and negative. As such, it is

evident that families have been able to adapt successfully and be resilient, despite the challenges faced from having a child with autism. Despite methodological limitations, the studies have explored resilience from a holistic perspective, where the child is seen as being as part of the family and not as a separate entity. The studies have also demonstrated that theoretical models on family resilience such as Walsh (2003) and McCubbin and McCubbin (1996) are useful contextual frameworks.

2.5 Family Resilience, Autism and Culture

The databases and search terms for studies that explored parent views, autism and family resilience are presented within Table 2.2. Details of the inclusion and exclusion criteria and screening process can be found in Appendix IV and Appendix V, with the final studies included presented in Appendix VII.

Only two studies explore family resilience, autism (or disability) and culture from the perspectives of parents (Das et al., 2017; John & Roblyer, 2017). As seen by the screening process in Appendix V, these studies were identified as a result of the initial literature search around family resilience and autism. Both studies were conducted in India and adopted contrasting approaches to their research. Authors shared the same rationale for carrying out the study - which was that little was known about family resilience in sociocultural contexts where resources are scarce.

The studies identified that despite the stigmatisation of children with autism in India, families demonstrate they have the necessary coping skills to overcome adversity. John and Roblyer (2017) identified that Indian mothers utilised a combination of fact-based and religious explanations to come to terms with their child's disability. A prominent theme within their findings was that resources the mothers accessed were at personal, family and societal levels. Internal resources such as perseverance and self-perception were more evident at a personal level and were considered coping strategies. The concept of coping strategies was also identified within Das et al.,'s (2017) quantitative study. Parents felt supported by their family and neighbours in the community which is in line with John & Roblyer's (2017) theme of seeking support at a family level.

A sample size of thirty-five was relatively small for Das et al.'s (2017) quantitative study, meaning that generalisation of the findings might not be feasible. John and Roblyer (2017) interviewed forty-seven mothers as part a larger study but these were described as brief by the researchers suggesting there might have been some time constraints. Furthermore, a structured interview was used which suggests there would have been

restricted opportunities to expand answers, provide clarity or engage in a more collaborative process of exploration.

John and Roblyer's (2017) analytic approach was grounded in an interpretivist paradigm with the focus to identify a coherent account of the participants' responses. Notably, as the interviewer spoke Hindi and was considered to have cultural perspective, the familiarity with culture and language meant mothers felt comfortable to share their experiences. However, during analysis, definitions for constructs within the stress and resilience framework were defined by the authors. Sharing these definitions with participants might have strengthened the trustworthiness and triangulation of the data within an interpretative paradigm.

In contrast to the rich information sought, Das et al.'s (2017) administered six survey tools, with the majority of them demonstrating good internal reliability and validity. The author recognised that social desirability bias was likely and that due to the time required to complete questionnaires, parents may have been fatigued. It is also questionable how much parents would understand the constructs in the tools as they comprise of lengthy statements and some technical terminologies.

It is important to note that both studies included participants from middle to upper socioeconomic backgrounds and therefore were not representative of the wider population. As with the aforementioned limitations, families would have a greater advantage in accessing resources. Further research is needed to examine family resilience across different contexts with a more representative sample.

2.6 Literature Review Summary

The research identified includes the views of parents of children with autism from a range of diverse backgrounds. A review of the literature on culture and autism indicates an awareness of, and respect for, culture and the potential impact this has on raising a child with autism. These studies highlight the importance of culturally sensitive research designs, providing an opportunity for parents to share their experiences of raising a child with autism from various cultural perspectives. They also reported on the challenges of raising a child with autism through cultural lens. The small-scale exploratory nature of the studies gave rise to rich data; however, they cannot be generalised beyond the contexts in which they were sought. Most importantly, the cultural aspects highlighted were predominantly negative. Further research on how positive psychology can be applied to identify positive aspects of culture and communities would start addressing this gap.

Despite methodological limitations, the studies on family resilience have shown that strength-based approaches can be well attuned to exploring cultural aspects of families raising a child with autism. These studies indicate there is a need for further exploration of parent views and family resilience in the disability field. This was highlighted by the small sample sizes within quantitative studies on family resilience, meaning findings should not be generalised. The qualitative studies provided preliminary insight into parents' views around family resilience and raising a child with autism. However, while research is developing within the field of family resilience, as yet, there is no exploratory research in the U.K on parent views, family resilience and culture. This would further validate the importance of listening to parents' views using an exploratory research design that elicits what is meaningful to them.

Given the methodological characteristics and findings considered, it is possible that positive psychology approaches could offer a shift in perspective, reframing dominant medical or deficit models of autism across cultures. Additionally, it can promote cultural awareness amongst professionals where parents and professionals alike can consider strengths within the family, instead of focussing on deficits of the child or the label.

With this in mind, it appears there is scope for a small-scale exploratory study to elicit the views of parents from BME families within London on culture and raising a child with autism.

2.7 Research Aim

In presenting a review of the literature, the research aim for this study was to adopt family resilience perspective to exploring the views of BME parents on raising a child with autism. An exploratory research design using semi-structured interviews was used to elicit parents' views.

2.8 Chapter Summary

This chapter provided a comprehensive and systematic review of the relevant research on parent views, autism, culture and family resilience. The chapter covered details of aspects of a systematic literature search process, followed by a critical and systematic analysis of the research findings. Themes within the findings were discussed and critically analysed, along with the research design. Theoretical and conceptual frameworks were considered and to conclude a summary of relevant literature

was provided. The methodological considerations in this chapter provide a basis for the following chapter which will present the Methodology.

Chapter Three: Methodology

3.1 Chapter Overview

Having reviewed the literature and knowledge relevant to the area under study, this chapter presents the methodology used in the current study. It will discuss the theoretical, conceptual and epistemological frameworks, followed by the rationale for a qualitative research design. The chapter will then go on to discuss the participants involved in the study, followed by ethical considerations, the research timeline, pilot study and data collection methods. Finally, the chapter will provide details of the data analysis method used and consider the quality of the research.

3.2 Research Question

The current study adopted a family resilience perspective to exploring the views of BME parents of children with autism. Semi-structured interviews were used to elicit what was meaningful to parents. The semi-structured interview addressed the overarching exploratory question and sub-questions:

From a family resilience perspective, what are the views of BME parents on raising a child with autism?

Sub-questions:

1. What are the views on the role of family and relationships?
2. What are the views on the role of values and beliefs?
3. What are their experiences on their response to the diagnosis?

3.3 Theoretical and Conceptual Frameworks

In order to clarify the relationship between the proposed study and the reviewed literature, this section will present the theoretical and conceptual frameworks that underpinned the design of the study. These frameworks allowed the researcher to link theory to the research and therefore, enabled her to understand, explore and make meaning of family resilience and raising a child with autism. The frameworks provide clarification on what was investigated, and enabled clarity on what the study intended to achieve.

3.3.1 Ecological perspective

In contrast to a highly individualised Western society that focusses on the 'self', an ecological perspective, within a resiliency framework, considers systems around the individual (Walsh, 2016). This framework offered a helpful model that considers contextual aspects within a holistic approach, recognising the whole phenomenon under study as being a part of a complex system (Patton, 2002). To facilitate this understanding, Bronfenbrenner's ecological model (Bronfenbrenner, 1994) as illustrated in Figure 3.1, provides a theoretical framework to this research for understanding family, culture and disability.

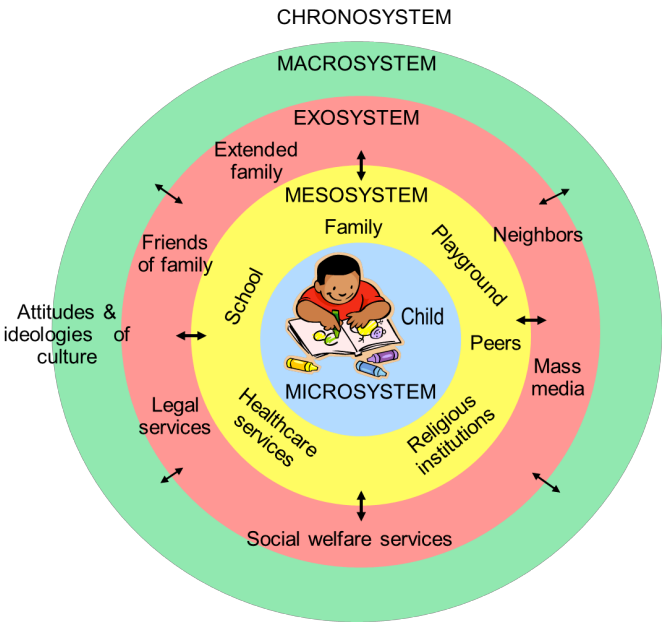

Figure 3.1 Bronfenbrenner's (1994) Ecological Model

Briefly described, the model illustrates layers or systems that can take a broad perspective on viewing family resilience and multiple levels. As such, sources of resilience are understood as being dynamic, emerging from interactions between individuals, their families, communities and larger systems (Walsh, 2012). The proximal processes, focussing on direct interactions (e.g. with family members or friends), take place within the microsystem. Following this, the mesosystem constitutes relationships between microsystems (e.g. family relationships or parent-professional relationships). At a more distal level, the exosystem comprises resources available for the family to access (e.g.

schools meeting the needs of their child). Extending further out is the macrosystem, which encapsulates culture with all its beliefs, values and assumptions about the world.

With these layers in mind, it can be argued that beliefs about autism exist at a cultural (macro level) as well as individual (micro) level; therefore, the ecological model provided a useful framework for exploring culture and disability. It also reveals complex interconnected systems where influences at one level permeates to another (Ravindran & Myers, 2012).

3.3.2 Family resilience

As mentioned above, a key conceptual contribution is made by the concept of resilience, which falls within the realm of positive psychology (Simon, Murphy & Smith, 2005). Resilience informs strength-based approaches in EP practice (Wilding & Griffey, 2015) and is a complex evolving construct, associated with the recognition of risk and protective factors (McCubbin & McCubbin, 2005). It can also be defined as the "ability to withstand and rebound from serious life challenges" (Walsh, 2016, p. 4). Extending beyond the contextual view of individual resilience, family resilience focusses on shared beliefs and positive narratives that capture a sense of cohesion, collaboration, competence and confidence (Walsh, 1996). A systemic viewpoint defines family resilience as an interactional process driven by an evolving ecological context that strengthens a family unit over time.

Family resilience has significant relevance to the rapidly changing and diverse nature of families. As reviewed in the literature, studies examining processes such as acculturation (Berry, 1997) have indicated that immigrant families are becoming more resilient (Walsh, 2016; Buckingham & Brodsky, 2015; Mohamed & Thomas, 2017). As well as family resilience being well attuned to exploring cultural diversity (Fernandez, Schwartz, Chun & Dickson, 2014), a family resilience framework can also be useful for understanding key processes in families who have children with developmental disabilities (Walsh, 1996). As such, Table 3.1 refers to key processes within Walsh's (2012) Family Resilience Framework that the researcher used as a conceptual map:

Key Processes
Belief systems • Making meaning of adversity: A relational view of resilience where stress/adversity if normalised and contextualised • Positive outlook: Having hope, optimism, courage and perseverance • Transcendence and spirituality: Larger values or purpose, faith, religion, learning and growth from adverse experiences
Organisational patterns • Flexibility: Openness to change and adapting to the situation, parenting mutual respect • Connectedness: Mutual support, collaboration, commitment, respecting individual needs, differences and repairing any grievances • Social and economic resources: Social and community networks, balancing work, financial security and large systems (e.g. schools or services)
Communication and problem solving • Clear, consistent messages: clarifying information and seeking the truth • Open emotional expression: Sharing painful feelings, respite and empathic responses • Collaborative problem solving: Resourcefulness, sharing decisions, focussing on goals and taking a proactive stance.

Table 3.1 Key processes in family resilience (Walsh, 2012).

3.4 Epistemological and Ontological Considerations

As a practitioner-researcher designing this research, one had an ethical and social duty to be fully aware of the ontological and epistemological bases when carrying out the research (Moore, 2005). By considering research paradigms, researchers are invited to position themselves in a way where thinking, practices and research design are congruent with theoretical concepts (Dickerson, 2010). The concept of a 'paradigm' refers to a commitment to worldviews or systems of beliefs; an all-encompassing way of thinking about, and experiencing the world (Kuhn, 1996). To determine the nature of inquiry, clarity is sought by making connections across the three fundamental concepts of ontological, epistemological and methodological assumptions (Guba & Lincoln, 1994). Each paradigm is formed of ontological and epistemological positions which represent distinct belief systems on the nature of reality and how knowledge about the world is sought. In order to guide this process of inquiry, researchers should go beyond recognising their general paradigm and seek clarity based on connections that should be made between the assumptions underlying the chosen paradigm (Cresswell, 2009).

According to Guba and Lincoln (1994), a positivist epistemology assumes that a singular reality exists; therefore, the researcher remains independent from the participants with the aim to avoid threats to validity. Defined as realism, where knowledge is studied in an objective manner, a quantitative methodology is adopted with the aim to verify a hypothesis. This study does not examine knowledge in this way, but in contrast, adopts a relativist ontological position, which rejects the notion that we can ascertain the 'true' nature of reality (Braun & Clarke, 2013). Instead, the nature of reality is pluralistic, where knowledge is discovered**,** not created (Scwandt, 1994). This position informed a social constructionist epistemological paradigm which assumes there are multiple realities, socially constructed through experiences across time and contexts (Ponterotto, 2005). From a constructionist position, there is shared meaning that is socially constructed and context dependent (Patton, 2002). Individual meanings are unique and discovered by acknowledging subjectivity, and the interrelation between researcher and participants.

Constructionism views resilience as an outcome of negotiations between individuals and their environment, which can be expressed differently by individuals, families and communities (Ungar, 2005). From a constructivist position, the expression of resilience can change as culture and context continually shape constructions of the world, which in turn, has implications on experiences and interactions with others (Crotty, 1998). Indeed, by adopting this position, the current study has changed in its analysis approach,

as initially the researcher intended a deductive data analysis method, whereas the data collected guided the research towards an inductive method, which preserved the richness of the participants' accounts. This will be explored in a relevant section below.

3.5 Research Design

With a constructionist epistemology underpinning this research, to ensure a strong research design, Patton's (2002) strategic framework (Appendix VIII), incorporating fundamental qualitative and epistemological assumptions, was used to inform the current study's process of inquiry. The goal of this research was exploratory, to provide insights into the experiences and perceptions of parents, with the aim of eliciting meaningful information that informs EP practice. The aim was to look for themes and ideas rather than to confirm a hypothesis.

Qualitative research is unique as it is interested in the meaning of participants' experiences and views (Braun & Clarke, 2013). A qualitative methodology allows for a deeper understanding of these views, utilising language as a vehicle for the researcher to make sense of participants' inner world (Morgan, 2007). As well as providing a voice to participants, using language can lead to *thick* descriptions - one of the most important concepts qualitative research (Ponterotto, 2006). By recognising that subjectivity exists, thick descriptions refer to the importance of context, emotions and social relationships that may connect people within and across these contexts (Geertz, 1973). Fit for the purpose of this study, thick descriptions should lead to thick interpretations (Denzin,1989), providing readers with a clearer sense of the participants' feelings, thoughts and perspectives.

As well as the concrete distribution of research findings, the qualitative methodology of the current study holds value to the impact of multicultural research (Ponterotto, 2010). By demonstrating a strong interest in parents' views, the actual act of understanding their worldview promoted empowerment. It enhanced communication and positive partnerships with the most important people in a child's life, therefore having an impact on improving outcomes for CYP.

3.5.1 Role of the researcher

Qualitative paradigms value participants' language and agency when co-constructing different versions of reality. During this co-construction, the researcher and participants become emotively connected, engaging in a relational process that is

collaborative and reflective (Larner, 2004). The researcher accepted their role as a *subjective researcher* which assumed their presence and involvement elicited data representing the complex nature of human experiences and interactions (Frost, 2016).

Although the researcher does not have a child with autism, the researcher is also from an ethnic minority background, which facilitated a culturally sensitive approach. Aspects of shared knowledge and understandings are implied, providing opportunities for collaboration, reciprocity and voice (Tillmann-Healy, 2003).

3.5.2 Reflexivity

The researcher also adopted an explicitly self-aware position throughout the research, where exploration led to reflexivity (Drake & Heath, 2011). By including the 'self' throughout the process (Etherington, 2007), reflexivity recognises that personal insights and engagement are an important part of understanding the phenomenon (Patton, 2002). As the researcher actively influenced the construction, collection and interpretation of data (Finlay, 2003), reflexivity aided the progressive synergy between the theoretical and conceptual frameworks, and the relationship with participants and the research design. The awareness of researcher positionality also promoted the understanding and response to any potential power imbalances that arose during the research process (Frost, 2016). It was recognised that the researcher's own values and ideas were brought to the research process.

3.6 Research Context

The researcher, who was in her second and third year of the Professional Doctorate in Educational and Child Psychology, was in a privileged position to be actively engaged in establishing a synergy between practice and research. The research was undertaken as a doctoral thesis from the University of East London (UEL) and carried out the researcher's then placement, at an Educational Psychology Service (EPS). In team meetings and training days, EPS recognised the need to consider issues around culture and diversity in EP practice. As the research was carried out in an inner London borough, 83 percent of families are from a BME background, which is much higher than other parts of England (ONS, 2011). Communities living in and around the Local Authority come from a range of ethnicities, religious background and socio-economic status.

In addition to recruiting parents from EPS, participants from a local organisation

were also recruited. The organisation was running a project that supports BME parents of children with autism. The local organisation is a non-profit organisation funded by the Big Lottery Fund and works across seven London boroughs. As well as promoting community empowerment and raising cultural awareness, it aims to support, encourage, train and increase levels of confidence among BME parents raising a child with autism. The researcher liaised with the EP running the project who shared an interest in the purpose and nature of the current research. At the end of the research, it was agreed that the findings of the research will be disseminated to all stakeholders involved in the research. The researcher will be presenting findings at the local organisation, inviting all parents who were included in the study. The organisation has also requested for the summarised research to be posted on their website.

The current study advocated for a knowledge driven model (Weiss, 1986) whereby a qualitative design meant knowledge was generated and co-constructed in all aspects of the research process. The research process was dependent on the collaboration with professionals, local organisations and most importantly the co-construction of data with parents. Additionally, knowledge was developed on consultation skills, cultural competence and using strength-based approaches to EP practice. In adding value to the research, collaboration strengthened the research design and applicability (Fox, Martin & Green, 2007). Additionally, the researcher also developed and utilised skills in consultation, which is a widely utilised model of service delivery in EP practice (Watkins, 2000).

3.7 Participants

3.7.1 Purposive sampling

Participants included in this research were parents from a BME background, of children with autism. Parents were recruited using purposeful sampling, which is based on the researcher's practical knowledge of the research area, the literature and the context of the study itself (Marshall, 1996). The focus of this method was to select participants who are information-rich and can provide significant insight into the phenomenon being researched (Patton, 2002). It was intended that rich qualitative data was to be produced, with the purpose to generate insight into the topic of interest (Braun & Clarke, 2013), not to generalise the findings beyond the specific context of the research. This sampling

method involved selecting participants according to an inclusion and exclusion criteria (Appendix IX), in order to recruit participants who were credible for the study.

As qualitative data yields thick descriptions which capture parents' views, the sample consisted of ten parents, all of whom had a good understanding of English. It was felt that this number of participants was manageable for the researcher to undertake given the time-frame and resources available for the study. Additionally, it is argued that an appropriate sample size for a qualitative study is one that adequately answers the research question (Marshall, 1996). The rationale for a small sample is in the potential to provide valuable in-depth information which carefully considers the importance of context (Patton, 2002).

3.7.2 Participant characteristics

The sample comprised of parents from a range of ethnic minority backgrounds. Table 3.2 illustrates the participants' characteristics. Three out of ten parents were recruited through other EPs who had referred parents who they thought might be interested in taking part in the research. The remaining seven signed up to take part after the researcher presented information about the study at a parent coffee morning held at SMA. Parents were from at least four different inner London boroughs and all had a CYP diagnosed with autism with ages ranging from 5 to 20 years old. Nine parents had a son with autism but one parent also had twin daughters with autism. Although only one father took part in the study, some fathers signed up to take part in the study at the parent coffee morning, but became unable to attend the interview due to other commitments.

Participant	Parent	Ethnic Background	Religion (if known)	Marital Status (if known)	Child(ren) with autism (and siblings without autism)
1. KA	Mother	Black British – African and Chinese heritage	Christian (non-practising)	Married	10-year-old boy (and step sibling)
2. GA	Mother	Jamaican	-	Married	20-year-old boy
3. AI	Father	Ghanaian	Christian	With partner	7-year-old boy (and sister)
4. JO	Mother	Brazilian	Catholic	Married	5-year-old boy, (and twin sister)
5. SH	Mother	Black British	-	Single parent	17-year-old boy
6. SI	Mother	Black British - Jamaican	-	-	16-year-old boy
7. ED	Mother	Cameroon	Christian	Separated	19-year-old twin girls and 16-year - old boy (and younger sister)
8. LE	Mother	Black British – Jamaican	Christian	With partner	5-year-old boy
9. IK	Mother	Ghanaian	Islam	Separated	10-year-old boy (and sister)
10. AZ	Mother	British South Asian	Islam	-	5-year-old boy and 17-year-old boy (and sister)

Table 3.2 Participant characteristics.

3.7.3 Recruitment

Participants were recruited using a staged approach to ensure a suitable number of parents were recruited. The two methods for recruiting parents are detailed below:

- **Parents recruited through the Local Authority (LA) where the researcher worked:** The researcher asked other EPs in the service if they had any parents in mind who would be interested in taking part in the study. The inclusion and exclusion (Appendix IX) criteria was shared via email. The researcher's placement supervisors, who were also EPs, referred three parents to take part in the study. The parents were then asked if they were interested in taking part and if consent was given for their contact details to be passed onto the researcher. The EP then either contacted the parents directly if they had worked with them recently, or passed on the information through the SENDCo at the child's school. In both instances the Information Sheet (Appendix X) was shared with the parents. Once parents expressed an interest, their contact details were passed onto the researcher and they were contacted directly to make further arrangements with the researcher.
- **Participants recruited through the local organisation:** The researcher approached a local organisation , who were running a project, to enquire whether organisation was interested in referring parents for the study. The EP leading the project expressed an interest via email (Appendix XI) and agreed for the researcher to recruit parents who attended workshops at the local organisation. The researcher then met with the EP and founder of the local organisation and the EP running the project, to discuss what the research entailed. Upon agreeing that the researcher could recruit parents through the organisation, the researcher was invited to present the research at a parent coffee morning. Parents across seven London boroughs were informed about the research through a poster (Appendix XII) inviting them to a coffee morning. At the coffee morning, the researcher then presented an outline and purpose of the research and distributed Information Sheets (Appendix X). At the end of the presentation, the researcher stayed to have lunch with the parents and those interested, provided their contact details on a sign-up sheet. This also gave the researcher an opportunity to engage with parents and meet them on a more informal level. Through the sign-up sheet, parents gave consent to be contacted via emails and/or telephone. Following this, the researcher contacted

parents a week or so after the coffee morning and made arrangements for the interviews.

3.8 Ethical Considerations

Ethical approval was obtained by University of East London's (UEL) Ethics Committee (Appendix XIII), along with approval from the EPS where the research was conducted (Appendix XIV). Consent was obtained to work with parents from the local organisation via email (Appendix XI) and further arrangements were made through face to face meetings.

Local Authority policies and procedures were also considered and required permission were granted by the Principle EPs for the research to be conducted. Ethical principles from the BPS Code of Ethics and Conduct (BPS, 2018), BPS Code of Human Research (BPS, 2014), UEL Code of Practice for Research Ethics (UEL, 2015), and HCPC Code of Conduct, Performance and Ethics (HCPC, 2016) informed the planning of this research. The following ethical considerations were also given:

3.8.1 Informed consent

Issues of informed consent and details around conduct and debriefing were outlined in the Information Sheet (Appendix X), Consent Form (Appendix XV) and Debrief Letter (Appendix XVI). Parents were invited to contact the researcher at any time for further questions. In the case of any issues of distress, parents were reminded at several points throughout the research process that they can withdraw at any time, without any explanation, disadvantage or consequence (BPS, 2018). However, they were informed that after starting the data analysis process, their data would not be able to withdrawn from the research. The parents were also informed of the scope, purpose and benefits of the research.

Participants were also asked to consent to the interviews to be audio taped (BPS, 2018) and informed that recorded interviews would be written up as a transcript, typed up word for word with all names anonymised, and kept by the interviewer for the duration of the project.

3.8.2 Confidentiality

In accordance with the Data Protection Act (2018) and General Data Protection

Regulation (GDPR) (European Commission, 2018), participants were made aware that all data would be anonymised and kept in a safe and secure place. Data stored electronically was password protected and all confidential data was stored only until it was analysed and the research had been passed by the university. In the research report, parents were given a replacement name and any mention of schools, staff names or family members were anonymised. The interview transcripts were shared with the researcher's supervisor at UEL and anonymised transcripts were also shared with peers at university. The recordings, transcripts and personal details (Consent Forms) were stored securely on a password protected computer that was locked away, along with other confidential paper copies, and only the researcher had sole access to them. The information used in the research write up and any quotations selected were anonymised. At the end of the research project, a summary of the findings will be shared with local organisation, parents who took part, as well as professionals in the Local Authority.

3.8.3 Debriefing

Throughout the research process, thought was given to potential questions or areas that may create possible discomfort. Participants were also debriefed and informed that a summary of the findings would be shared with them at the end of the study. They were also provided with further information on the research process and useful websites, as stated in the Information Sheet (Appendix X) and Debrief Letter (Appendix XVI).

3.9 Timeframe

As the research took place alongside daily EP practice, the researcher recognised that carrying out research in addition to other commitments can be demanding (Robson, 2002). To manage these expectations a research timeline was presented in a Gantt Chart, alongside a summarised research timeline (Appendix XVII) to allow clear tracking against the research timeline. The researcher considered the time required to seek ethical approval and recruit participants through the relevant methods presented. The interviews took place between February and April 2018.

3.10 Pilot Study

A pilot study was carried out with a parent who attended the organisation's project coffee morning with the purpose to refine questions for the Semi Structured Interview (SSI) (Appendix XVIII). Given that the purpose of qualitative research is to yield

information-rich data, refining the SSI schedule can strengthen the process of interactive data collection (Braun & Clarke, 2013). Before the pilot study, the SSI schedule was checked with the researcher's supervisor at the university, who is an EP and researcher, and approved by UEL's Ethics Committee. The researcher invited the parent to comment on the questions, allowing any suitable adjustments to be made. The purpose was also to check whether the questions were comprehensible, whether some questions were more easy or difficult to understand than others and to check if any needed re-structuring.

The parent's feedback was that it was an enjoyable experience to be asked about the journey she had been on raising a child with autism. Minor adjustments were made, for example, asking about their child's weaknesses and how they overcame them. The remainder of the questionnaire remained unchanged and the researcher made field notes regarding prompting questions and the length of the interview.

3.11 Data Collection

3.11.1 Semi-structured interviews

Data was collected using a SSI schedule devised by the researcher (Appendix XVIII). SSI's are widely used, they are flexible and applicable for studies that focus on meanings or experiences for individuals (Robson, 2002). The current research employed this approach as it allowed parents to talk openly while giving an opportunity for the researcher to clarify information and ask for answers to be expanded if necessary. Research discussed in the literature review utilised this method of data collection in studies with researcher's commenting on the rich data generated (Theara & Abbott, 2015; Habib et al., 2017; Munroe at al., 2016).

The SSI addressed the aims of the study by using open-ended, strength-based questions that explored aspects of culture and family resilience. Appropriate for an exploratory design, the SSI schedule was devised using Walsh's Family Resilience Framework (Walsh, 2012), covering domains of culture and family resilience, following the stages recommended by Rubin and Rubin (1995). Examples of SSI's from the research reviewed in this area (e.g. Habib et al., 2017; Munroe et al., 2016; Theara & Abbott, 2015) were also referred to, to ensure questions were fit for purpose.

To facilitate an open discussion, the researcher maintained empathic neutrality by being sensitive and responsive while also remaining fully present (Patton, 2002). The researcher was careful in ensuring that questions were not misleading in any way. The SSI schedule was also checked by the researcher's university tutor as well as UEL's Ethics

Committee to ensure the questions were objective and non-judgemental. In constructing the questionnaire, it was important that questions were worded in a simple way, so that they could be easily understood my parents.

The structure and content of the interview meant it offered a flexible way to explore the views of parents using a strength-based approach. The face-to-face aspect of interviews meant the researcher could modify their responses to a particular line of enquiry and explore responses in a way that quantitative or self-report measures could not provide (Robson, 2002). Also, the lack of personal interviews was deemed a limitation by the reviewed literature investigating family resilience (e.g. Bayat, 2007). With the majority of studies on family resilience using a survey methodology, interviews meant that the participants in this research were not limited by their ability to write in the English language, which was a second language for many of the parents.

The open-ended questions gave the opportunity to evoke responses that were meaningful and salient to the participants. In contrast to structured interviews where questions have fixed wording, SSI permits for richer data and allows for interesting ideas to be explored further through questioning, something that structured interviews would not provide (Smith, 1995). Probes and prompts (Robson, 2002) were used during the interviews, allowing certain ideas to be explored or clarified. However, these were used with caution to ensure the SSI schedule was still maintained.

The interview structure of the current SSI consisted of a small number of open-ended questions. However, the researcher could scaffold questions throughout the interviews without changing the established agenda. This meant that the questions were adapted according to the demands of the individual and the particular context (Taylor & Ussher, 2001). A caveat to successfully using SSIs is that it is necessary to establish a balance between ensuring the data obtained is relevant to the research question, whilst also offering room to the participant to explore what is relevant to them. Despite this, SSIs mean there is a shift towards conducting research *with* the parents rather than *on* the parents. It was stated at the start of the interview that there were no right or wrong answers and that the purpose was to elicit their views, opinions and experiences.

As well as empowering parents, rapport was aided by using a conversational manner in the interviews. It also gave opportunities for the interviewer to utilise skills in consultation to ensure the process was collaborative and views were elicited in a meaningful way. Sufficient time was given between interviews to ensure the researcher could reflect, refine and synthesise the unique experience with each parent. During this

process, trustworthiness was ensured as parents communicated responses and feelings through their voice as well as their behaviour.

3.11.2 Procedure

Once parents provided consent to take part in the study through the recruitment methods, data collection was carried out in private rooms to maintain confidentiality. Due to practical, ethical and safety reasons, all interviews took place at a public location where the parent felt comfortable. This was either the school their child/children attend, EPS offices, a public library or at the office of the local organisation. Interviews were scheduled at a time convenient for the parent, with the researcher making necessary research or placement adjustments. In all locations, the researcher ensured parents felt comfortable by making minor adjustments such as sitting at a 90-degree angle to the participants and offering tea or coffee before starting the interview. For interviews at EP Offices, the researcher checked that the location was easy for the parent to get to and the rooms were reserved for public use so were accessible. Interviews lasted between 45 and 60 minutes and timings were agreed by the researcher and the parent.

From the outset, parents were reminded about the Information Sheet (Appendix X) which they were previously provided with, either via the EP who had referred them, the SENDCo at their child's school, or the researcher at the organisation's parent coffee morning. Parents signed the consent form at the start of the interview and the interviewer checked that they understood the purpose and format of the interview. It was important that parents were given opportunities to go over any questions they may have based on information provided; in one instance, the parent said she was dyslexic, so the researcher went through the Information Sheet with the parent to ensure understanding. It was explained that the interviews would be audio-recorded but that in the transcripts, all names would remain anonymous.

Before the interview, parents were informed that notes would be taken throughout the interview to help with transcribing and data analysis, but that all names were anonymised. Parents were also asked what term they preferred to use to refer to autism (Autism, Autistic Spectrum Disorder (ASD) or Autistic Spectrum Condition (ASC)) and this term was used throughout the interview. The researcher explained what to expect from the interview, such as length of time (around 45 minutes) and that they could take a break if they wished to do so. Parents were also reminded that there were no right or wrong answers and that the researcher was interested in their views, opinions and experiences.

An explanation of informed consent took place and parents were notified that if they felt uncomfortable at any point during the interview, they had the right to withdraw at any time. At the end of each interview, parents were also given an opportunity to ask questions and to be debriefed.

In order to facilitate the transcription process, field notes were made on the SSI schedule during interviews. These were made visible to participants to promote transparency and reduce feelings of judgement. A research diary was also used as a means of developing a thoughtful and richer research journey from a reflexive position, samples of reflective diary extracts can be found in (Appendix XIX) The diary contained concrete descriptions of the research process as well as any emotional aspects that might have affected the research (Gilbert, 2001).

3.12 Data Analysis

In acknowledging the researcher's theoretical position, Thematic Analysis (TA) is an appropriate method for addressing an exploratory research question as it aims to give voice to the participants (Braun & Clarke, 2013). The approach is considered to be context dependent and acknowledges the meaning individuals make of their experiences and how the social or cultural context can affect these meanings. It is considered a flexible qualitative method for identifying, analysing and reporting patterns in the data (Braun & Clarke, 2006).

An inductive approach was taken to data analysis where data coding and analysis adopted a bottom-up approach, driven by what is seen in the data (Braun & Clark, 2006). Codes and themes are derived from the content of the data, to the extent that what was mapped by the researcher during analysis, closely mirrored the content of the data. It is important to note that it is impossible for the analysis to be purely inductive, as the subjectivity of the research design meant that the researcher would have brought something to the analysis in addition to the theoretical concepts presented.

According to Boyatzis (1998), TA is a method that can be used for identifying, analysing and quantifying qualitative data. It allows immersion in the data to take place in order to make sense of parents' views and identify shared meanings in the data. Thematic analysis can be used as a method for identifying relationships between themes, as well as systematically organising the data into thematic maps. An advantage is that as well as being flexible, it has a broad application and has been previously been used by several researchers who have explored the views of parents (Habib et al., 2017; Fox et al., 2017;

King et al., 2005; Bayat, 2007). By using the same data analysis method, comparisons may be possible between the findings of this research and other research in this area.

A potential disadvantage of TA is that interpretation is limited if it is not used within an existing theoretical framework (Boyatzis, 1998). This is relevant to what Boyatzis (1998) refers to as analysis at semantic or latent levels, which is similar to Braun and Clark's (2006) inductive and deductive analysis. At a semantic level, themes are identified from the surface meaning of the data (inductive). In contrast, analysis at a latent level involves data being interpreted before being organised into themes. If a latent level is used, researchers would have to have a clear understanding of the ideas and assumptions that have influenced the semantic content. Rationale for analysis at a latent level would have to be consistent and clarified throughout the research process as analysis would be going beyond what has been directly said. As the current research adopts a social constructionist position, the importance and meaning of language lends itself to thematic analysis at a semantic level.

Data analysis follows six phases outlined by Braun and Clark (2006) as presented in Table 3.3.

Phase	Description of the process
Phase 1. Familiarising with the data	Transcribing the data, reading and re-reading the data, noting down initial ideas
Phase 2. Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code
Phase 3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme
Phase 4. Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic map of the analysis
Phase 5. Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme
Phase 6. Producing the report	The final opportunity for analysis. Section of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature producing a scholarly report of the analysis

Table 3.3. Six phases of Thematic Analysis

Photographs in Appendix XX document the thematic analysis process which was done using hard-copy data where codes, potential subordinate themes and themes were clearly marked. The researcher transcribed the interviews themselves and found this process a significant part of immersing themselves in the data. The researcher found doing it by hand useful to visually conceptualise the themes and move them around. To generate initiate codes, the researcher analysed transcripts and identified and collated codes using post-it notes. These were then organised into themes and master themes on larger A3

papers and these were named and described. The use of post-it notes facilitated the process of moving themes around. It is recognised that checking the codes and themes with the participants could have improved accuracy (Elliot & Timulak, 2005), but due to time constraints this was not possible. The researcher did, however, check the meaning of what was said during the interviews. The thematic maps and analysis process was also checked with an experienced researcher and university supervisor.

3.13 Quality of the Research

When considering the quality of qualitative research, issues of confirmability, credibility, trustworthiness, transferability and dependability and are considered key criterion (Tuli, 2010; Tracy, 2010). Alongside this, consideration is given to reflexive validity which underpins a constructive paradigm. With Patton's (2002) strategic framework in mind, the following constructs provided a platform for researcher to learn, practice and reflect on strengthening the qualitative research process (Tracy, 2010).

3.13.1 Confirmability

Confirmability refers to the assumption that each researcher will bring a unique perspective to the study (Tuli, 2010). In order for the research to be considered sincere (Tracy, 2010), the researcher was honest and transparent about the researcher's potential biases, goals and how this might have impacted the methodology. Subjectivity intertwined with being reflexive, meant that the researcher engaged in a process of triangulating information through on-going discussions with supervisors, reflection and field notes.

Transparency was also practiced by being honest about decisions made in the research process. Checking and re-checking of data took place, with regular supervision sought, in addition to keeping an audit trail for data analysis. Rigorous data analysis took place and transparency was given to the process of sorting, choosing and organising the data.

3.13.2 Credibility

Credibility refers to the trustworthiness and plausibility of the research findings (Tracy, 2010). It holds regard to whether readers feel trustworthy enough to act on or make decisions in line with the research rationale, design and findings. Enhancing credibility was achieved through thick descriptions and triangulation in the research process. The descriptions presented detail, context, emotion and the maps of social

relationships that joined one person to another (researcher and participants or participants and those they chose to talk about) (Ponterotto, 2006). This was evident in the data analysis process that built a clear picture of the individuals in the context of their culture and family. In providing context and meaning to the findings, the researcher was aware that credibility was achieved as accurately as possible, capturing the views, thoughts and emotions felt by the parents in the study.

Triangulation assumes that if two or more sources of data, theoretical frameworks or researchers converge to similar conclusions, then the conclusions are more credible (Denzin, 1989). This was strengthened during data analysis were transcripts and codes were shared with the researcher's university supervisor. The researcher could have included "members checking" in the analysis process whereby findings (or final themes) are shared with participants, providing opportunities for question and feedback and collaborative analysis (Tracy, 2010). Some studies included in the reviewed literature used this approach (e.g. Jagatheesan et al., 2010), which strengthened triangulation and trustworthiness of the data. However, due to time constraints the researcher was unable to engage in this process.

Attention was given to the data being as 'true' as possible by referring to audio recordings, using supervision and reflecting on potential tacit knowledge, which refers to the unarticulated understandings or hidden assumptions guiding actions or speech (Altheide & Johnson, 1994), to ensure both implicit and explicit issues were recognised. The researcher's own reflexivity through the use of supervision, field notes and a research diary was also vital to the development of trustworthiness. The researcher chose to transcribe the interviews herself, which increased familiarity with the data. During data analysis, trustworthiness was ensured by checking and re-checking themes. Transcripts were also shared with another researcher and EP to ensure that codes and themes reflected the responses in an inductive manner.

3.13.3 Transferability

Transferability refers to the degree to which the findings can be generalised or transferred to other contexts (Tracy, 2010). In this research, the purpose was not to generalise findings but to engage in a research process that produced social and culturally contextual knowledge. As such, the findings did not intend to be generalised or used to

predict future practice. Instead, the intention was to provide to direct insight into the views of parents, engaging in a process that promoted empathy, insight and perspective. The researcher remained mindful of finding a balance between depicting the participants' views and subjectivity.

3.13.4 Dependability

To enable readers to have a thorough understanding of the research methodology, the researcher has provided sufficient detail for the research to be repeated. In addition to rich descriptions of data collection procedures, rigorous analysis was also marked by transparency in the process of sorting, choosing and organising the data (Tracy, 2010). However, in the instance of replication, the importance of context and subjectivity should be recognised as being integral to the uniqueness of the data.

3.13.5 Relational ethics

Relational ethics involved the researcher maintaining an ethical self-consciousness where the researcher was mindful of their actions, character and the responses this might have on participants (Tracy, 2010). In doing so, reflexive validity involved the researcher recognising the impact they might have had on the research, which was facilitated by referring to reflexive questions throughout the process (Appendix XXI). With reflexivity being a core principle of quality qualitative research, it also helped to create the transparency and dialogue that is needed to form ethical research relationships with participants. The researcher, also a trainee EP, recognised that reflexivity permeated every aspect of the research process, challenging the researcher to be fully aware of the reflexive use of the 'self' throughout (Etherington, 2007).

It was recognised that reflexivity could have led to introspection that meant the researcher's position was unduly privileged, blocking out the participant's voice (Finlay, 2002). The researcher was therefore required to maintain a balanced level of self-awareness throughout data collection and analysis. As the researcher was a practitioner-researcher on placement, the researcher was receiving high quality supervision with two EPs, in addition to the university tutor who was an experienced researcher and EP. Supervision was used as a space for reflexive analysis, as well as a safe space to reflect on the values of mutual respect and connectedness between the researcher and the researched.

In considering catalytic validity, the underpinning theoretical, conceptual and epistemological framework facilitated the process of data collection that was empowering for parents. The strength-based approach to the interviews meant they were at times uplifting and promoted a participant focussed process that energised parents. Some parents also commented on feeling proud that they were taking part in the study and felt inspired to provide support to other parents in the community.

3.13.6 Personal insight

In considering the importance of resonance, which is the researcher's ability to meaningfully reverberate the research experience (Tracy, 2010), it was important to reflect on the social and cultural contexts of the research. In doing so, the researcher's personal insight involved reflecting on their role as a practitioner-researcher, their personal and professional background and the potential impact this might have had on the research process. The researchers background in psychology would have also affected theoretical data interpretations (Mosselson, 2010).

The researcher is also from an ethnic minority background and has come from a teaching background in inner London schools. The researcher has worked with CYP with autism, taught in a mainstream primary school and a secondary special school for young people with social, emotional and communication difficulties. Additionally, the researcher has worked closely with parents, specialist outreach teachers, speech and language therapists and other professionals to support children with a range of special educational needs. In particular, the researcher has maintained an interest in empowering ethnic minority families and strengthening communities. Although they may not have shared the participants' life experiences of raising a child with autism, culturally, there may have been shared cultural meanings between the researcher and participants.

It was felt this contributed to an insider's perspective which enriched the understanding of the study and provided a better understanding of ethnic minority experiences of parents of children with autism. Tillman-Healy (2003) indicates that this perspective has the potential to validate and interpret cultural information appropriately and facilitate the cultural knowledge of the researched. With the researcher also being from an ethnic minority background, the power imbalance may have been reduced between researcher and the participants. This was an important consideration in the studies reviewed in the previous chapter on parent views and culture. Most of the researchers were from an ethnic minority background or shared the same ethnicity as the participants

(Fox et al., 2017; Theara & Abbott., 2015; Jagatheesan et al., 2010; Habib et al., 2017) and these researchers' reflected on how this enriched the findings and trustworthiness of data.

From the onset of planning this research, as well as reflecting on the researcher's own practice, this study includes parameters that intend to go beyond a tokenistic glance at culture. Rather, the research hopes to encourage other EPs and other professionals to reframe narratives around culture and autism by promoting more positive outlook and approaches to practice. The goal would be to facilitate working with parents towards shared understandings that support their child to thrive and succeed.

3.14 Chapter Summary

This chapter has outlined the epistemology, ontology and conceptual framework within which this research is placed. Methodological considerations were also given in relation to the reviewed literature in this area. Following this, the research design was presented alongside participants' characteristics and ethical considerations. Data collection methods used, together with the method for data analysis, were also discussed. The chapter concludes with reflections on the quality of the research in relation to confirmability, credibility, transferability and dependability. Consideration was also given to reflexive validity and the researcher's personal insight. The following chapter will present the research findings.

Chapter Four: Findings

4.1 Chapter Overview

This chapter presents the findings of the qualitative data obtained from interviews with the parents. A summary of themes from the analysis of the data will be presented, followed by thematic maps which illustrate the master themes, themes and subordinate themes generated from the data. The chapter will then explore the themes, using quotes from interview transcripts to illustrate the description and interpretation of the specific theme being discussed. To conclude each section, attention will be given to interrelated concepts drawn from the data and how this interlinked with the researcher's reflections of the data analysis process. The chapter will end with an overall summary of the findings and chapter summary.

4.2 Summary of Themes

Ten themes were identified in the data across three master themes which answer the main research question and sub-questions:

From a family resilience perspective, what are the views of BME parents on raising a child with autism?

Sub-questions:

1. What are the views on the role of family and relationships?
2. What are the views on the role of values and beliefs?
3. What are their experiences on their response to the diagnosis?

Table 4.1 represents a summary and description of the themes identified under each master theme.

<table>
<tr><td colspan="4">Family and relationships
This theme encapsulates the importance of family and relationships and the roles that they play in the lives of the families.</td></tr>
<tr><td>Family as a unit</td><td>Relationships</td><td>Communication</td><td>Community</td></tr>
<tr><td colspan="4">Values and beliefs
This theme represents the important values and beliefs that underlie the parents' views and experiences of raising a child with autism.</td></tr>
<tr><td>Child as an individual</td><td colspan="2">Values and beliefs</td><td>Positive outlook</td></tr>
<tr><td colspan="4">Response to diagnosis
This theme reflects aspects of how the parents responded to the diagnosis and resilience factors that contributed to how the parents and their family managed the experience.</td></tr>
<tr><td>Managing reactions to diagnosis</td><td colspan="2">Coping with the diagnosis</td><td>Resilience</td></tr>
</table>

Table 4.1 Themes and subordinate themes identified from thematic analysis of the data.

In line with principles of thematic analysis, each theme was developed in their own right, but also in relation to the research questions and in relation to the other themes (Braun & Clarke, 2013). During the process of analysis, the researcher was mindful of the purpose of qualitative research which was to capture the complexities of socially constructed realities, centring on the lived experiences of the parents who took part in the research.

4.3 Thematic Maps

The findings were represented in three thematic maps presented in Figure 4.1, Figure 4.2 and Figure 4.3 which illustrate the following master themes: 'family and relationships', 'values and beliefs' and 'response to diagnosis'. The themes were derived from codes, as illustrated in Appendix XXII, collated from the data which enabled the

researcher to explore concepts and topics that lead to patterns (themes) across the data. A transcript example, with analysis of codes and subordinate themes, can be found in Appendix XXIII.

The thematic maps provided a way to visually explore the connections between aspects of the data. The choice for the organisation of the maps illustrate how the themes occur at three main levels. The use of individual circles as themes signifies the uniqueness of each theme which was developed in their own right, as well as in relation to the research questions and in relation to other themes. Each circle builds on the previous layer and can be seen as a building block or facet of the wider picture. The master theme at the 'core' was seen as centralised concepts identified in the data. In the second layer, themes were represented by smaller circles that capture components of the master themes. The final layer is represented by the smallest outer circles, representing subordinate themes which explore more detailed meanings evoked in the data.

Visually conceptualising the data in this manner provided a rich representation of the data and also allowed for the researcher to identify relationships between themes. Although the themes were constructed within their own right, the researcher identified that some subordinate themes were strongly interlinked and these are represented by arrows. The lines and arrows between some subordinate themes and themes represent tentative relationships which will be reflected on towards the end of the chapter.

Master theme

Theme

Subordinate theme

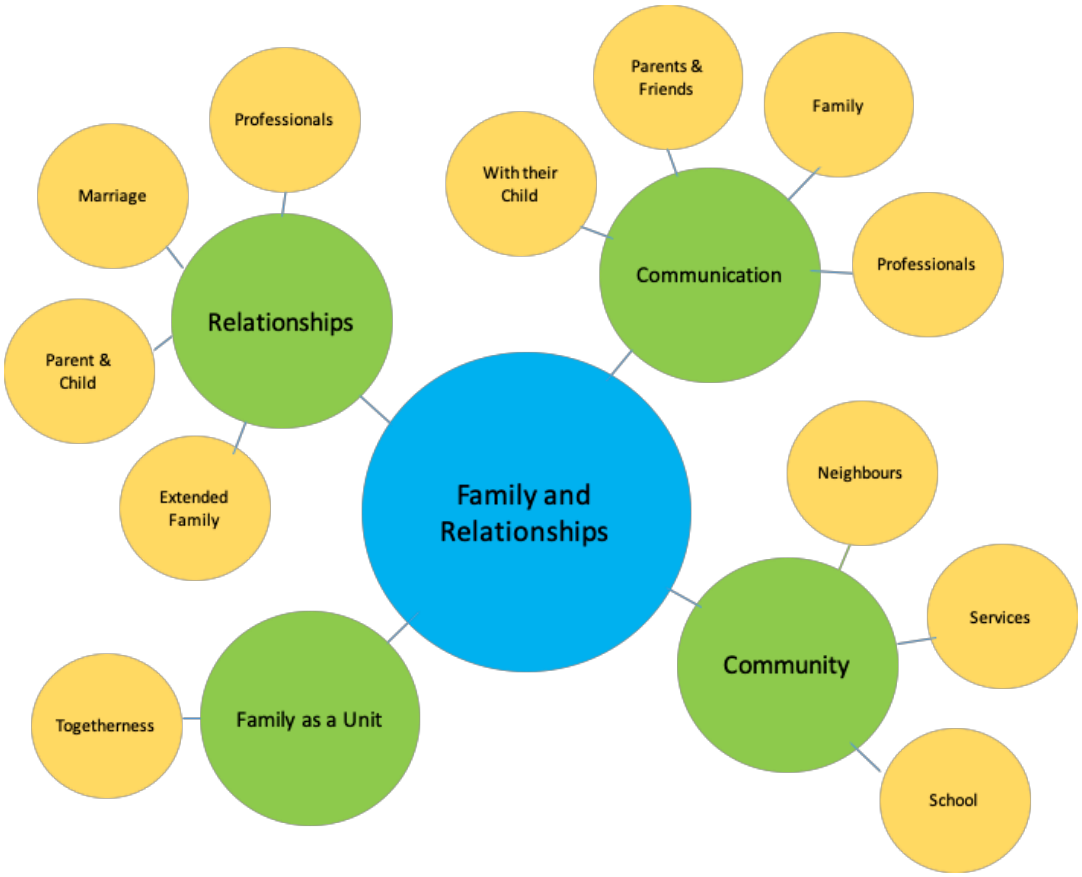

Figure 4.1 Thematic map for ‘family and relationships’.

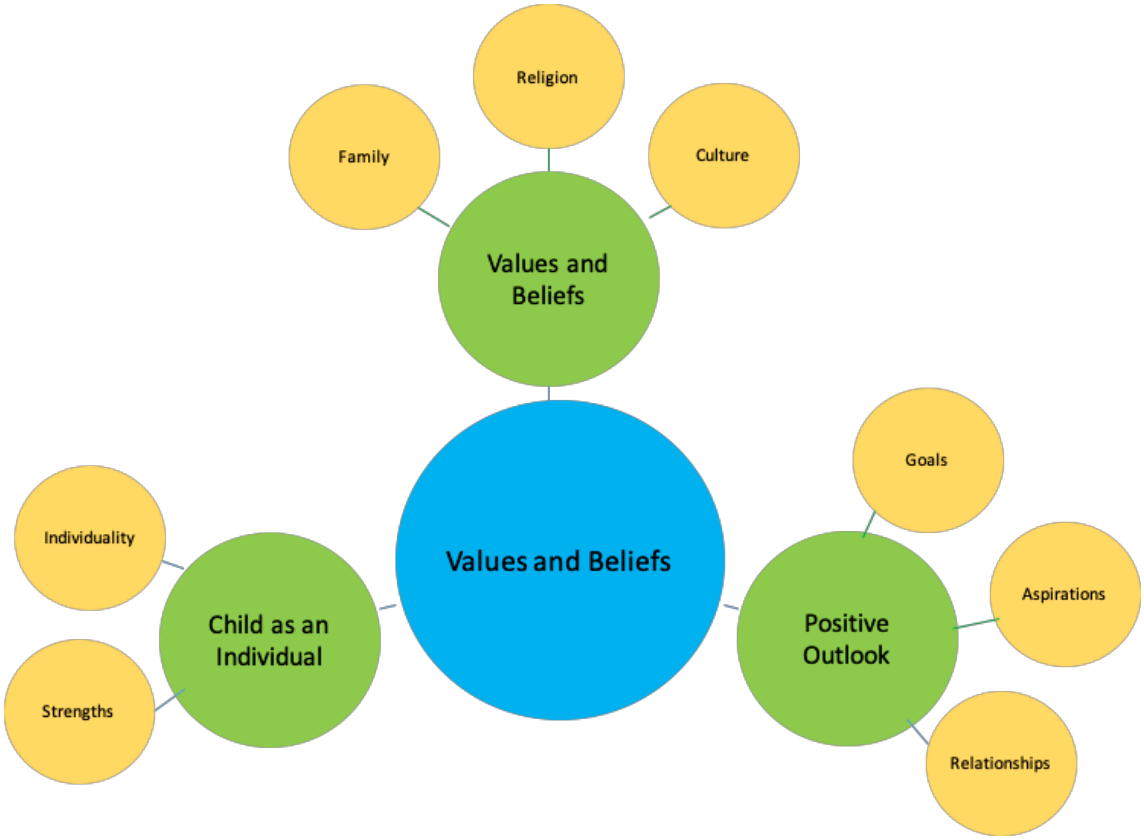

Figure 4.2 Thematic map for ‘values and beliefs’.

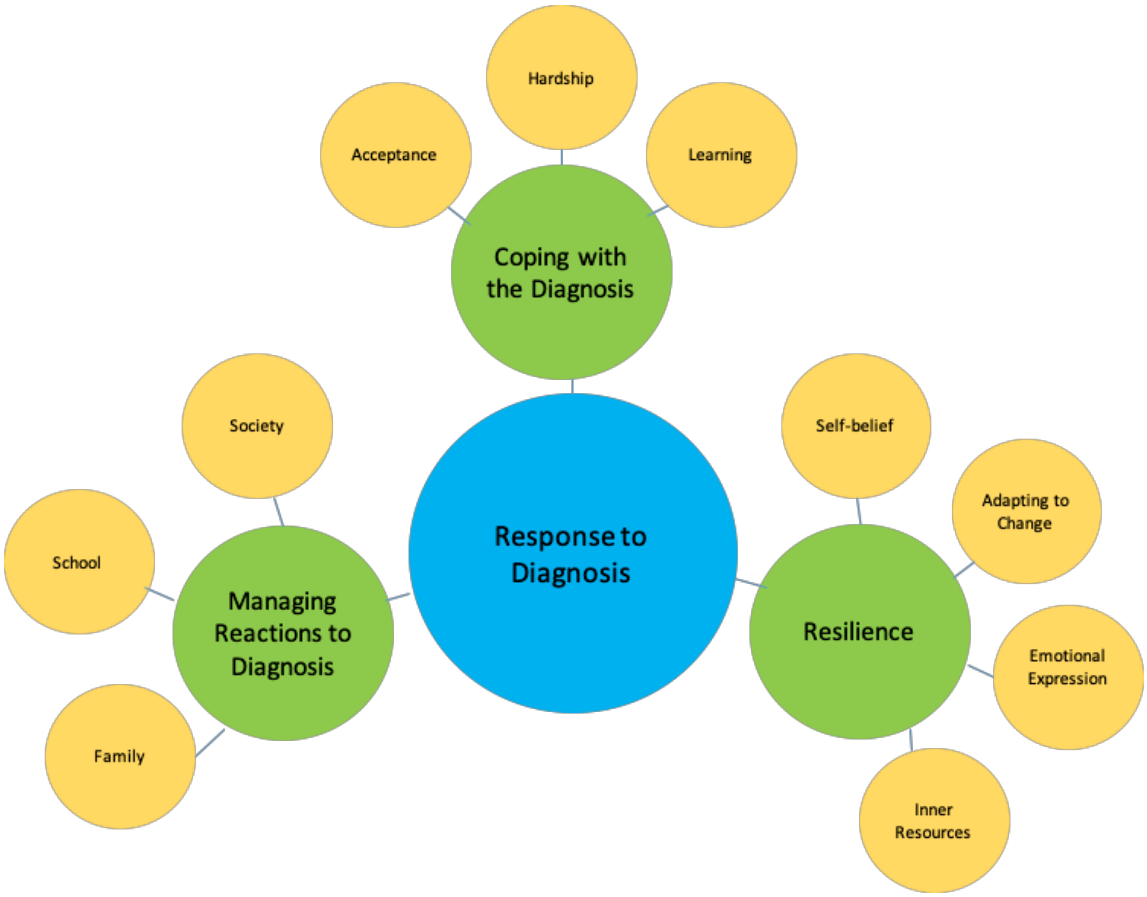

Figure 4.3. Thematic map for 'response to diagnosis'.

4.4 Analysis of Themes

Each theme under the master themes will be discussed in turn and the subordinate themes will be explored. A summary is provided after each master theme discussing the components as a whole and any interrelationships between themes and subordinate themes.

4.4.1 Master theme: Family and relationships

This master theme comprised of themes 'family as a unit', 'relationships', 'communication' and 'community'. It depicts the role of groups of people who were important to families and provides a context for the importance of family level and community level resources.

4.4.1.1 Theme: Family as a unit

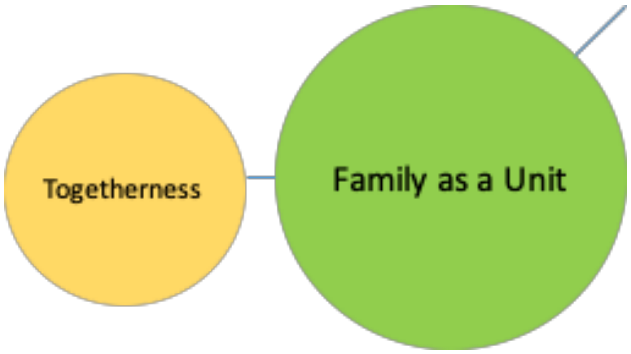

Figure 4.4. 'Family as a unit' theme with subordinate theme.

4.4.1.1.1 Subordinate theme: Togetherness

This theme was significant across all the parents, who described their family as being a close unit. When parents reflected on the importance of family, they referred to feeling a sense of togetherness and cohesiveness felt between family members. When asked about what helped their family thrive and be happy one parent expressed that:

> Well... the first word I associate with family is 'together', so that's what I believe, being together is the difference because if we are not in the same kind of space it is not really a family you know. (T: 2, L: 318-320)

As well as living and sharing the same environment, it was important to parents to feel connected and have a strong bond with their family. Some parents spoke about siblings and the love and protection they had towards each other. In some families, parents described how a special bond existed between older siblings and the child with autism. One parent shared a song she would sing when her children fought at home with lyrics conveying the importance of family:

> We sing the Family Song to make us happy (sings), "families are great, families are great, no matter what happens, families are great"" so all of us will be singing that and be together, hug and kiss each other. (T: 2, L: 318-321)

Love and care towards family members contributed to families feeling close. The sense of family was also defined by having physical time together as well as having source of emotional support. All the parents perceived their families as being closer and united as a result of having a child with autism.

4.4.1.2 Theme: Relationships

This theme consisted of relationships with groups of people who were important to parents and consisted of four sub-themes, 'extended family', 'parent and child', 'marriage' and 'professionals'.

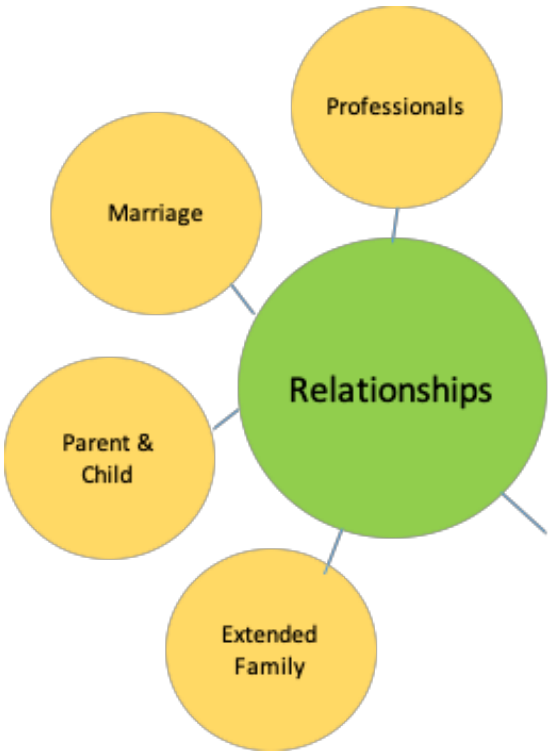

Figure 4.5. Relationships theme and subordinate themes.

4.4.1.2.1 Subordinate Theme: Extended Family

The role of extended and immediate family was mentioned across all parents. One parent described how appreciated and rewarded it felt to be praised for their parenting skills, expressing that, "Mum always said to me she thinks I'm a better mum than her… she does think I am a fantastic Mum" (T: 8, L: 143, 146). Despite parents taking on most of the responsibility for looking after their child, it was evident that having a positive and supportive relationship with family members was important. One parent spoke about the influence and impact of her own grandparents describing them as, "just loving people who helped me a lot in his early years of growing up" (T: 1, L: 185, 186). Extended family also provided some parents with rest bite by taking their child out on the weekends.

As well as providing help with child care, it was important to some parents that family members treated their child as their own, despite having autism:

> My own family has been supportive, actually they are and that is the other thing - my family are very supportive, they just embrace these children so they take them over to go on holiday with them…I think with that help was very helpful my brother and sister and I'm the big sister and they were treating them like their own children. (T:7, L: 93, 94, 102-106)

All the parents expressed how a supportive family made them feel encouraged to be better parents as well as seek emotive support, rest bite or just to feel understood. Being held in mind by family members also seemed to be important. For one parent this included receiving texts from her Mum to see how she was doing, which made her feel uplifted (T: 8, L: 324). It appeared that it was important for parents to know that their family network was empathetic and supportive.

4.4.1.2.2 Subordinate theme: Parent and child

The relationship between the parent and the child was identified as a significant theme in the analysis as all the parents reflected on how much they loved and valued the relationship they had with their child. Some parents mentioned the sense of closeness they felt which allowed them to take the perspective of their child and therefore share a unique relationship with them. One mother spoke about how a special relationship she shared with her son was strengthened by understanding how he viewed the world around him:

> As a parent, I really do get it because he is in his own world, his understanding is different from me and the way he sees things is different from the way I do and so if I don't understand him who else will? (T: 2, L: 157-160)

In some instances, the relationship with their child improved after receiving the diagnosis due to understanding their child in a different way. Parents spoke about the importance of understanding their child and relating to the child at their level to see their perspectives on situations. This led some parents to speak about the sense of closeness they felt with their child. For example, despite having siblings, one parent commented that, "he is most close to me, 10 times an hour he will come and say he loves me" (T: 10, L: 224). It also seemed important to parents that the relationship was reciprocal, based on mutual trust and respect. The sense of commitment to one another was demonstrated through helping parents with daily chores or merely bringing humour and happiness into their lives. One parents with three children with autism shared how her children lift her spirits and give her a sense of purpose:

> My relationship with them is very strong as I've been with them from day 1…we depend on each other. When they are around like holiday time, some parents find it stressful but for me, when I have all of them I am ok! We complement each other. (T: 7, L: 123-133)

This sense of coherence was felt by all of the parents who spoke positively about how they felt closer to their child with autism, compared to their other siblings:

> Oh we are lovely together, very lovely together. I think I have a soft spot with him… he understands me a lot and has a strong feeling for me too, he doesn't want to see me sad. (T: 9, L: 164-168)

To exemplify these feelings, another parent spoke about how their child is "very territorial and protective" (T: 6, L: 44, 51) over them. The concept of protection led this parent to reflect on how much love they had for their child, despite challenging times she faced around managing his behaviour.

4.4.1.2.3 Subordinate Theme: Marriage

Nearly all the parents spoke about how raising a child with autism affected their marital relationships. For parents who were married, it was important that differing views around autism were addressed and spoken about. When views did differ, especially around diagnosis, some parents spoke about how it was important to listen to and understand their partner. In one instance a parent expressed:

> I was stressed thinking 'what can we do, what are we going to do?' For me I just wanted to have some space to think really before I could really talk to him (husband) about certain things because when I do he might think something different - I might not explain myself properly. (T: 8, L: 357-362)

More often, parents reflected on differences in child rearing practices and perceptions of autism. However, they reflected on how they learned to negotiate with their partner, understanding each other's perspectives and work through differences together.

Some parents also spoke about the marital breakdown as a result of having a child with autism. One parent explained that this was often to do with their partner lacking an understanding of autism, experiencing difficulty in accepting the diagnosis.

4.4.1.2.4 Subordinate Theme: Professionals

Most of the parents spoke about the significant role professionals had in supporting the child and the family. Some parents spoke about particular professionals who appeared to have made extra efforts to listen to their stories and support their child's needs.

One mother expressed immense gratitude towards a doctor who acknowledged her efforts even just by saying, "you're doing a good job" (T: 3, L: 366). Relationships with certain professionals appeared to be built on trust and feeling listened to. One mother spoke about a GP who had a significant impact:

> Once person that was amazing to us was one GP…I had a time that was bad, very bad she said to me, one day I went to take the kids they said, "Mum they don't have anything, you need to see a doctor, go and see a doctor and ask for pills for depression" and I was like "mm". So I went to book an appointment with that doctor and said, "I need this" and she said "no I'm not giving you pills, you're gonna come here every week and talk to me. You're gonna book an appointment and we're gonna talk" and that helped me a lot. (T: 3, L: 424-433)

The response of this GP highlighted how important it was for parents to be respected and listened to. As much as providing information about autism was helpful, it was deemed just as important for parents to have a safe person and space to reflect. It also highlighted the quality of relationships with professionals and the need for their own well-being to be valued as well as their child's.

Parents also spoke positively about their relationship with teachers and how sharing information enabled them to have an open and honest relationship. One mother commented on their child's teacher being, "one of the friendliest person I've ever met", expressing that "I can't even blame him for not showing effort, because he is so friendly to everybody" (T: 10, L: 384-387). It appears that parents valued the extra efforts of professionals and this contributed to a trusting, constructive and meaningful relationship.

4.4.1.3 Theme: Communication

The 'communication' theme consisted of four subordinate themes exploring the parents' experiences of communication 'with their child', 'parents and friends', 'family' and 'professionals.

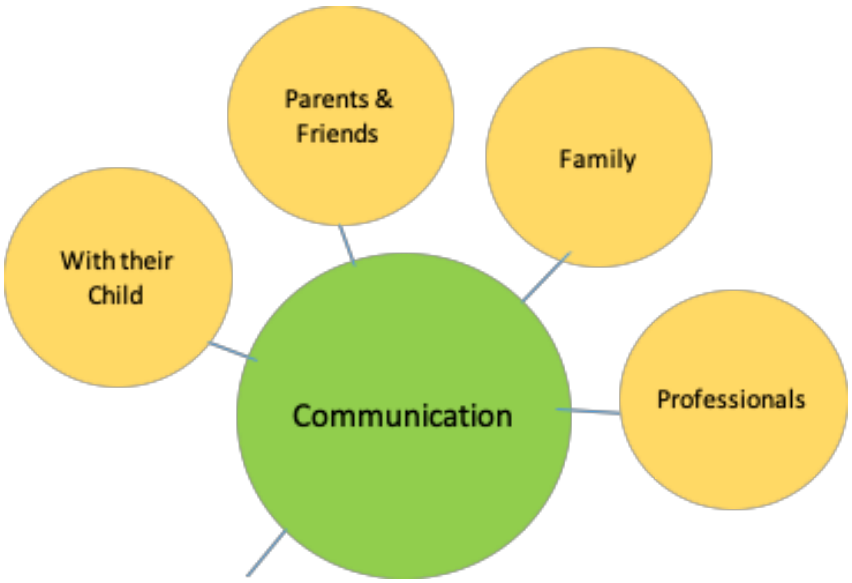

Figure 4.6. 'Communication' theme and subordinate themes.

4.4.1.3.1 Subordinate theme: With their child

All the parents expressed how understanding their child depended on how well they communicated. Sometimes this meant coming down to their child's level of understanding such as one parent who said, "I keep on talking to J consistently, if you see me and J walking by the roadside, you might think I'm 7 (years old)" (T: 2, L: 166-167).

Parents used examples of how they adapted ways of communicating with their child. This often involved being patient, using trial and error and observing what their child responds to. A common example was making rules clear at home and having open conversations to explain things to them:

> I try to let him know what we do now, then and after so he has an idea…I'm constantly just doing that and hopefully he will pick up something and having that conversation, even when the words can't get out. Before I would say the word for him but now I just like "ok... I'm listening" (T: 8, L 166-169)

The process of communicating with their child enabled parents to understand their perspectives and therefore help them to communicate their needs to the outside world.

4.4.1.3.2 Subordinate theme: Parents and friends

All parents reflected on their experiences on communication with other parents and friends around their child's diagnosis. Communicating with other parents played a significant role prior to, during and after diagnosis. One parent expressed how she wished she had known another parent going through a similar experience at the time her child was diagnosed. Another spoke about feeling reassured after speaking to other parents and also helping other parents:

> It makes me feel better to know I'm not the only one and I feel more comfortable around them now they know who my son is… I've always been person who is listening, hearing, advising anyway anyone. (T: 8, L: 328-339)

Speaking to other parents and friends provided opportunities to share stories, ask for help and listen to each other. This included meeting in person at school events or over the phone: "I've got friends who have children with autism or ADHD and we're on contact on the phone everyday talking about different issues you know supporting each other" (T: 5, L: 290-292). It seemed as meaningful to provide support to other parents as well as to feel supported. One parent spoke about the importance of talking, expressing the importance of communication, in particular "what's going on and not bottling it up and not leaving it to fester you know just dealing with it straight away" (T: 5, L 331-332). Parents sought comfort from hearing others going through similar experiences which helped them to generate new ways of thinking, clarify issues and share proud moments about their child.

4.4.1.3.3 Subordinate theme: Family

Communication with family was deemed important by parents who spoke about their experiences of being open and honest with regards to parenting a child with autism. This included explaining things to their family as well as feeling supported and comfortable about asking for help. In some instances, parents and family members had to work towards a shared understanding of issues:

> It will depend on me, the communication, how I will explain things to them and to understand that he is not the only one with this autism, they have to understand that it is not something to do with spiritual thoughts nothing like that, but it could be genetic and anything could have it. (T: 2, L: 187-190)

The regularity of communication was also important for families with grandparents who lived abroad. This also gave opportunities to share achievements and provide updates on their child's progress:

> We speak a lot, we do speak to them…everything that J does, I call them and tell them, I call Brazil and I say, "J has done that" and I tell my sister "oh J has done...!". It's like he's a kind of hero. (T: 3, L: 508-510)

Sharing stories about their child made parents feel elated and have a sense of pride. It also enabled them to remember the positive moments amongst stressful or more challenging times.

4.4.1.3.4 Subordinate theme: Professionals

Parents felt empowered and were proactive in seeking support, maintaining communication and establishing constructive relationships with professionals. Some parents spoke about certain professionals who had made an impact by being honest in ways to support their child. It was also important that communication was maintained over time, strengthening the trust and relationship built between parents and professionals. One parent appreciated the openness of one consultant who adopted a person-centered approach to practice:

> I took him to a consultant…I used to go every year for 10 years. He used tell me, you know being academic is not important…he was very supportive…focussing on social capabilities of the child…so he has helped me a lot. (T: 7, L: 239-244)

For this parent, it appeared that respecting her son's individual needs was important. Communication with services was essential to parents in order to seek support or clarify information. One parent spoke positively about the way professionals communicated with their child:

> All the docs were really good and funnily enough, it was the only time A was well-behaved, so it must be a good thing going on in there as before he would lash out! (T: 8, L: 86-88)

4.4.1.4. Theme: Community

The 'community' theme consisted of three subordinate themes which were 'neighbours', 'services' and 'school.

Figure 4.7. 'Community' theme and subordinate themes.

4.4.1.4.1 Subordinate theme: Neighbours

When asked about what community meant to parents, some referred to neighbours who lived in close proximity. A safe neighbourhood was associated with helping others, such as looking after their child after school. The sense of community cohesion was also defined by how inclusive neighbourhoods were:

> All the kids are lovely and there are a few disabled children…but everyone's inclusive…and everyone just talks to everyone so he felt like safe around there. (T: 1, L: 209-2012)

4.4.1.4.2 Subordinate theme: Services

Other parents commented on services within their community which they found helpful. All the parents reported that services such as parent support groups, charities and local organisations were accessible. Several parents shared how much they valued services in the community such as health visitors, the GP and speech and language professionals. Accessing and sharing information with these services enabled them to meet other families and mobilise community networks. One parent spoke about the contributions of an EP she encountered:

> I did not know much, but L (EP) helped me a lot. I found a lot of favours for her, she was an EP and at the time she got involved around the time when I was doing the statement and establish it so she was coming round more than she needed to. (T: 7, L: 177-179)

4.4.1.4.3 Subordinate theme: School

Most parents spoke positively about their school and efforts made within school to bring parents and the school community together. One parent felt that the school was the heart of the community:

> For me community is the school… we enjoy the school activities and they do sometimes perform functions, previously we used to organise the summer fare, we used to do quite a lot of things in the school with PTA. (T: 9, L: 281-285)

For this parent, school was a medium for meeting other parents and a source of learning through courses and parent mornings. Regular communication with teachers and the SENDco was also important in establishing a sense of belonging within the school community.

4.4.1.5 Summary for master theme: Family and relationships

This master theme illustrated the importance of family, communication and relationships. The subordinate themes illustrate the necessary factors for families to feel connected with each other as well as with services and their community. The themes 'relationships' and 'communication' were important as separate as well as connected entities. Many parents reflected on the important meaning of relationships they had with groups of people. However, the manner and quality of these relationships were determined by the role of communication which enabled families to become united.

The master theme as a whole, illustrates how parents viewed meaningful relationships they had developed. The themes support previous findings on the significance of social support which provides a sense of cohesion and commitment to individuals helping each other, whether this was within families or in communities. As a result, this led to shared understandings and stronger relationships developed within their own family as well as professionals and the community.

4.4.2 Master Theme: Values and Beliefs

This master theme comprised of themes 'child as an individual', 'values and beliefs, and 'positive outlook'. The themes illustrate values and beliefs on the parents'

overall outlook as well as on raising a child with autism within different systems around the child and the family.

4.4.2.1 Theme: Child as an individual

This theme is presented in Figure 4.8 and consisted of the subordinate themes 'strengths' and 'individuality'.

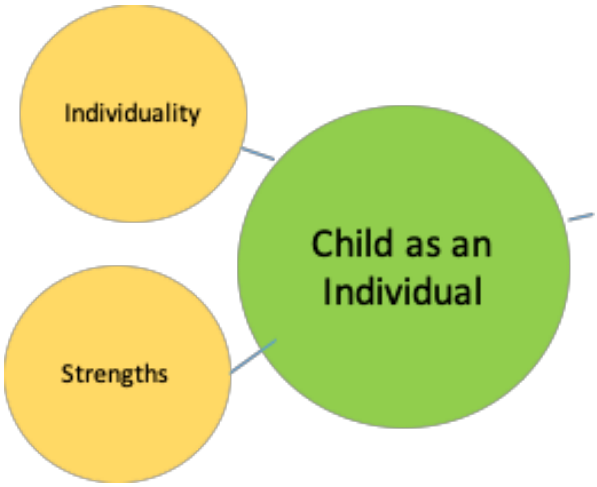

Figure 4.8. 'Child as an individual' theme and subordinate themes.

4.4.2.1.1 Subordinate theme: Strengths

All parents spoke proudly about their child's strengths and achievements. This included being talented in school work or pursuing their own hobbies and interests at home. One parent described how their child is smarter than he might appear:

> With Y, he has down points but he is smarter than other children, I have to say I have been noticing a lot of other stuff…he is so smart on understanding, he understands more than other children sometimes. (T: 10, L: 6-10)

Another parent of a young person who was in college expressed how proud she was of his academic achievements. One example described was a son's talents in operating computers and setting up businesses online. This parent also reported how school staff comment on "how brilliant he is as a person" (T: 5, L 38). Other parents spoke about their child's creative and entrepreneurial skills. Such comments led to the parent to

reflect on improvements their child had made and how their strengths shaped them to be the person they are.

All the parents expressed pride when they spoke about their child's achievements such as when their child helped another person or received awards at school. They spoke warmly about humorous moments shared with their child and how their unique personalities shined through in different ways.

4.4.2.1.2 Subordinate theme: Individuality

This subordinate theme reflects the children's diverse range of skills, strengths and personalities they harnessed. Being their own person contributed to each child's individuality. For example, one parent spoke about their son who likes football but takes initiative to choose a position he is comfortable with: "he likes to be by himself so he will be a goal keeper, so he is by himself but he is still participating, so he's kind of planned that by himself" (T: 1, L: 34-37). This suggests that some children had a sense of awareness of their own likes and dislikes.

All the parents supported their child's interests and shared examples of how parenting their child meant adapting to their needs by trying to understand their world. One parent explained her son as being, "a bit different, the way he sees, the way his brain works, it's different" (T: 3, L172-173). When parents spoke about their child being different, this was embraced and often separate from the autism label. Instead, it was deemed important that their child was valued and seen as an individual with a wide range of skills, interests and talents.

4.4.2.2 Theme: Values and beliefs

This theme was significant in the findings as it encompassed a diverse, strong and broad array of views and experiences underpinned by values and beliefs at different levels around the family. The theme is presented in Figure 4.9 and consisted of the subordinate themes of 'family', 'religion' and 'culture'.

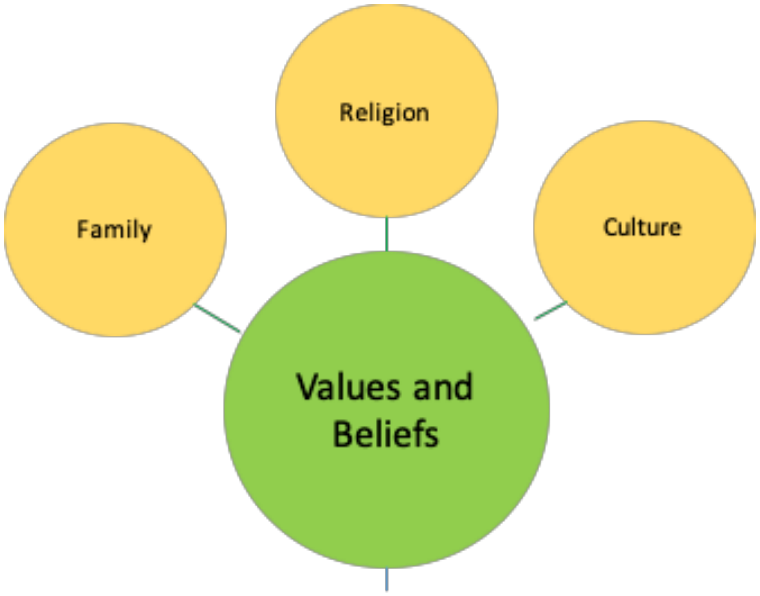

Figure 4.9. 'Values and beliefs' theme and subordinate themes.

4.4.2.2.1 Subordinate theme: Family

Parents shared their views on the role and expectations of immediate and extended family. These were embedded by values that were meaningful to parents and influenced decisions they made about their outlook to parenting. Some parents spoke openly about the values they enforced around gender roles and traditions with one parent expressing:

> I lay emphasis on and even though they are boys I try let them do things because of in this part of the world, there is not job for a woman or no job for a man, everyone is doing the same thing. (T: 9, L: 36-38)

In a similar manner, other parents expressed how they actively wanted to raise their child differently as opposed to how their own parents did. Sometimes this meant having difficult conversations with their child's grandparents and challenging family expectations of raising a child with autism. One mother was adamant that, "it has to be in a good environment for A, and they (grandmother) will have to listen to what I want before I hand him over" (T: 8 L: 202-203). Another parent spoke about the importance of promoting the work ethics passed down by her father:

> You know he (grandfather) felt that was really really important…that we went to work and earned a living and was not on benefits or anything like that, that we did our absolute best and I guess I am the same for J I want him to do 100% the best. (T: 5, L: 76-78)

All the parents were able to draw on family values they had chosen to pursue and reject those that they felt were too traditional and were not appropriate for their child. When advice given by other members of the family conflicted with their own, most parents tolerated these differences and tried to repair conflicts in a constructive manner.

4.4.2.2.2 Subordinate theme: Religion

This subordinate theme emerged from the data for parents who spoke about religion as being significant part of their lives. For these families, religion enabled parents to maintain a positive attitude towards life and do everything to support and help their child. Whilst parents varied in the religion they identified with, religious beliefs gave some parents a sense of hope during challenging times with one parent sharing: "I was kind of depressed already but then I found God and began to believe that all is not lost and believe there is hope" (T: 7, L: 45-47). Religion promoted strength within families and brought meaning and comfort to their lives. One mother spoke about her families' belief in God and how this brought her family closer:

> It keeps us as a family close like it's something that we do as a family, not because J needs, no its because we are a family and I think for us, at the end of the day, you realise having him is a gift. (T: 3, L: 145-147)

Religious beliefs and values that permeated into daily life provided some families with how they viewed the world with a parent sharing: "It is for us to change our way of viewing people, viewing life, view to everything because…nothing is bad" (T: 3, 156-157). As well as enabling families to value acceptance, religion provided families with a sense of optimism, hope and support. Going to church was deemed peaceful and reassuring:

> It is very encouraging and amazing because sometimes you break down as a parent but going to church, listening to the word of God, it gives you hope and tells you that there is hope that no condition is permanent…There is assurance from God, there is hope that something can change. (T: 2, L: 300-302)

Religion eliminated blame during adverse times and enabled parents to embrace, appreciate and feel proud of their child. Evident from statements from parents who had a spiritual belief system, faith and religion were an important source of comfort and strength.

As well as religion being a coping mechanism, parents also spoke about how spiritual gains strengthened their family and provided parents with a sense of appreciation for their child and purpose of existence. For example, one parent expressed:

> Honestly I am proud of Y and I never regret that and I believe in God and God gave me an autistic child and never had the thought 'why me?'. I am proud that he picked me - to have one of them is amazing believe me. (T:10, L: 77-80)

When religious teachings were integrated into daily life, parents reflected on the influence this had in raising their child and helped them to learn values such as kindness and appreciation:

> It has a great influence in our lives…doing good to other people and then believing in god. So if you believe in God, you understand that all the belief is 'do not kill, do not hurt, do not spoil somebody's things or do not be jealous' a whole lot of those things. If you look at it, it is the general understanding of life as well, I lay emphasis on that and we try. (T: 9, L: 48-53)

As a result, they showed greater compassion for their child and embraced their existence. As well as teaching and learning values, religious practices also brought some parents closer to their child and strengthened their family as a unit: “He sees his mum praying 5 times and he says, “Mum is it prayer time, shall I come and join you?”” (T: 9, L: 60-61).

4.4.2.2.3 Subordinate theme: Culture

Some parents spoke about how autism was viewed in their culture and responses varied across individuals and cultures. Parents were from a range of cultural backgrounds with some cultures viewing autism as a curse, due to spiritual influences or involving witchcraft. However, while parents recognised that these views were held, they also expressed how this was due to a lack of awareness in other countries. Families did not necessarily associate with one culture. For example, one parent shared how she liked to take things from different cultures:

> I try and teach him other things…like Buddhism because I like some of the culture as well…so I take a little bit of different cultures, anything that is really good and helping for the soul. (T: 1, L: 354-359)

Some parents commented on how they avoided talking about their child having autism as the label was unknown within their culture. Others spoke about their child with

pride and took it upon themselves to explain what it meant to others in their family or community:

> You know that from my part of the world, there is very little awareness of that…people shy away from it and people see it like a downfall to you. For myself, it took a long time to even tell my own sisters that my son has autism. (T: 9, L: 61-64)

Other parents took it upon themselves to raise awareness within their country of origin. This included liaising with the community doctor or becoming involved in running support groups that raised awareness of autism.

One mother spoke about the importance of raising awareness within ethnic minority communities as information is not easily accessible to them. Another parent spoke about how she experienced stigma and isolation from her community when her child was first diagnosed, but then found acceptance through her church community. As well as raising awareness within communities, some parents spoke openly about how they intended to tell her own parents about her son's autism and what it meant:

> I will explain things to them and to understand that he is not the only one with this autism, they have to understand that it is not something to do with spiritual thoughts nothing like that… I will let them know…Sit them down and let them know this is what is happening and it's not new. (T: 2, L: 186-193)

4.4.2.3 Theme: Positive outlook

This theme is presented in Figure 4.10 and consisted of the subordinate themes 'goals, 'aspirations' and 'relationships. Parents expressed the importance of hope with respect to future goals and there being plenty of opportunities for their children's future.

Figure 4.10. 'Positive outlook' theme and subordinate themes.

4.4.2.3.1 Subordinate theme: Goals

All parents referred to goals that believed their child could achieve in the future. A sense of success was defined by getting good grades in school as well as achieving their best and fulfilling their potential:

> I want him to do 100% the best he can you know at this moment when he needs money for his business maybe do a part time job to try and supplement for it or something like that. (T: 5, L: 76-80)

Seeing their child growing into a happy individual was one of the most important factors with one parent expressing:

> I can see that he is happy and that makes us happy. I am being selfish just talking about him, but V and J are happy, what else do we need? (T: 3, L: 613-615)

4.4.2.3.2 Subordinate theme: Aspirations

All the parents spoke about the importance of their child developing independence and becoming a contributing member of society. A father's aspirations for his son were that "he can go out and use up his skills, because he has skills and to get paid, have his own family and children. That's what I wish for him" (T: 2, 324-326). Another parent spoke about her best hopes as well as her son's aspirations:

> My hope is that he will do really well at the end of this three year course he is doing. He will come out with good grades. He doesn't wanna work for anybody else, my hope is that he will achieve that he'll have regular income coming in. (T: 5, L: 337-344)

Regardless of the age of their child, all parents expressed aspirations they had for their child to fulfil their potential and being the best that they can be. One mother spoke about her best hopes for the future of working alongside her children to help others in the community:

> For me I see, my dream, I see a centre where they are helping parents, children, not only with autism but any sort of challenges they might have. I may even see my children working in that centre and then me doing the accounting. (T: 7, L 292-293)

Some parents spoke about their own aspirations of returning to higher education and doing more courses to continue the desire to learn. For these parents, it was important to acknowledge that it was never too late to learn and take on new challenges.

4.4.2.3.3 Subordinate theme: Relationships

When asked about their best hopes for the future, some parents expressed hopes for their child to get married and have a family:

> My hope is that he does achieve his goals in terms of that and also that he may achieve a nice family life but that's not always possible. (T: 5, L: 343-344)

For this parent, having a family was considered a bonus to achieving his goals. Maintaining close relationships as a family was deemed as important as their children raising their own family.

4.4.2.4 Summary of master theme: Values and beliefs

This master theme illustrated the role and influence of values and beliefs on raising a child with autism. The 'child as an individual' theme was a separate entity as parents appeared to view and value their child regardless of their family or cultural beliefs. Subordinate themes of 'family', 'religion' and 'culture' can be seen as being interlinked as one cannot assume bi-directional influences between these entities. The subordinate themes reflect the equal contribution these influences had on raising a child with autism. However, some parents clearly accepted and rejected certain values and beliefs based on whether they made positive contributions to their child's needs and strengths.

All parents adopted a positive outlook which depicted the interrelated subordinate themes of 'goals', 'aspirations' and 'relationships'. The parents' experiences led them to examine how their values and beliefs enabled them to redefine the importance of adopting new perspectives. As such, parents reflected on their child's strengths and positive contributions they have made which enabled them to be successful in life. The importance of having a positive and adaptive belief system meant that parents expressed a strong belief in their child and their child's future.

4.4.3 Master Theme: Response to Diagnosis

This was a strong master theme that encapsulated the positive, challenging and heartfelt experiences parents shared in relation to raising a child with autism. The themes represent components of resilience as concept across multiple levels of the individual, family, school and society.

4.4.3.1 Theme: Managing reactions to diagnosis

This theme is presented in Figure 4.11 and consisted of the subordinate themes representing groups of people and their reactions to the diagnosis: 'family, 'school and 'society.

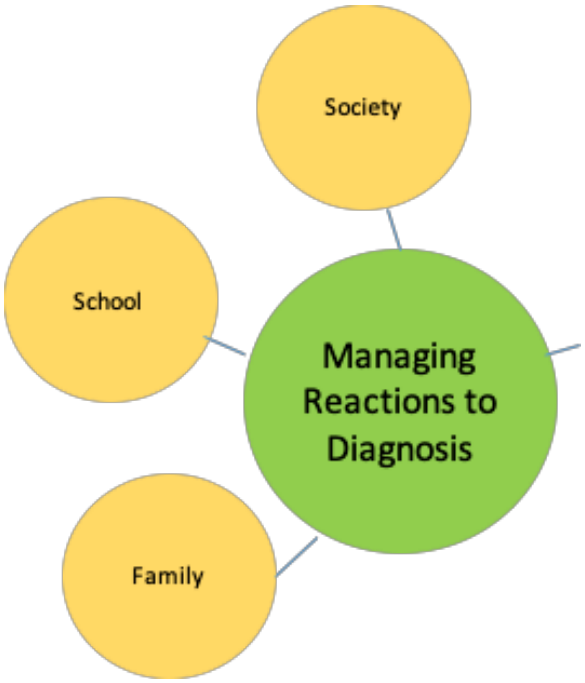

Figure 4.11. 'Managing reactions to diagnosis' and subordinate themes.

4.4.3.1.1Subordinate theme: Family

As previous themes have revealed, the families had a unique set of beliefs that influenced how their family responded to the diagnosis. For some parents it was important to communicate with their family and help them to overcome the denial. Several parents disclosed their experiences of dealing with relatives and grandparents who lacked an awareness of autism. One mother spoke about how her family refused to believe her son had autism sharing that:

> When I told them that he was autistic, they didn't believe and they said 'no no no they want to label everybody um I dunno what you're talking about' and I was saying 'look you don't live with him, I live with him so I see him on a day to day basis. (T: 5, L: 89-9)

It was important to this mother to share information with her family, reassure them and maintain open discussions about their concerns and perception of autism. This also involved receiving support from services to bring the family together towards a shared understanding: “They recommend that we did like a family thing where all the family came and discussed what autism was and that I should give them all leaflets…but I found it difficult to arrange because I just felt sad that they weren't embracing what the diagnosis” (T: 5, L: 102-109). Another parent expressed how they addressed misconceptions of autism directly with family members:

> I know there was a time where my Mum did say the wrong word like, “oh A is sick” and I said, “my son is not sick”, and I think she felt really bad because she was frustrated at the time because she was really upset for him, because she loves him so much, but she knew she said the wrong thing. (T:8, L: 188-199)

This parent felt it was important to articulate that she did not want negativity around her son and as a result, encouraged her mother to research autism.

Cultural factors also influenced the response of family members to a child’s diagnosis of autism. For example, a few of the parents spoke about how family members looked for a physical deficit in their child. Refuting this, they shared examples of how they tried to explain things to them in that it was more to do with communication and social interactions. Reflecting on this moment, one parent expressed:

> I remember I was telling them that he had a problem, "what was the problem?”, "well he doesn’t talk properly like his peers,". I didn’t tell them much because they won't understand. So we went to visit in 2016

> and as soon as I get there "but there is nothing wrong with him, what problem has he got? He doesn't have any problem?" (laughs) they did not know. (T: 9, L: 177-181)

4.4.3.1.2 Subordinate theme: School

Parents expressed gratitude towards school professionals and their response to supporting their child's needs. However, parents reported that schools struggled to cope with their child's behaviour. Often this was due to the child not being able to tell a teacher why they were upset and as an example from one parent:

> Last time they called me from school to come and get him because he was crying…and he said, "Mummy they are teaching and I don't understand the teaching and so if I do it and I get it wrong I am going to be in trouble" (T: 2, L: 38-42)

This parent felt that her son's behaviour was often misunderstood by teachers as he found it difficult to communicate his needs in class. However, they were able to empathise with the expectation of teachers, stretched resources in school and pressures within school system to support a class with a wide range of needs.

In contrast, other parents also spoke positively about the cooperation and support they received through school with one mother expressing: "Now when I need referrals I come through school. They are doing a lot, SENDCo is being an angel, she's doing a lot for us" (T: 3, L: 525-526). Many of the parents, especially of children in primary school, praised and embraced educational opportunities that were offered to them. In particular, parents valued the regular communication with teachers and the efforts made to meet their child's educational needs on a daily basis.

4.4.3.1.3 Subordinate theme: Society

While all of the parents had come to terms with their own response to the diagnosis, a few parents commented on society's mentality to 'label' children. This was in relation to expectations of others such as friends and family and the connotations attached to the autism label. One mother received the response of: "Ohh it's just a label of don't listen to them bla bla bla'' (T: 6, L: 242), and another parent received a similar response from their family members about professionals, with their family expressing " they want to label everybody" (T: 5, L: 89). Both parents authorised their position about what autism meant for their child and explained the importance of seeing the bigger picture beyond the label.

4.4.3.2 Theme: Coping with diagnosis

This theme explores aspects of coping with the diagnosis and is presented in Figure 4.12 and consisted of the subordinate themes of ‘acceptance’, ‘hardship’ and ‘learning’.

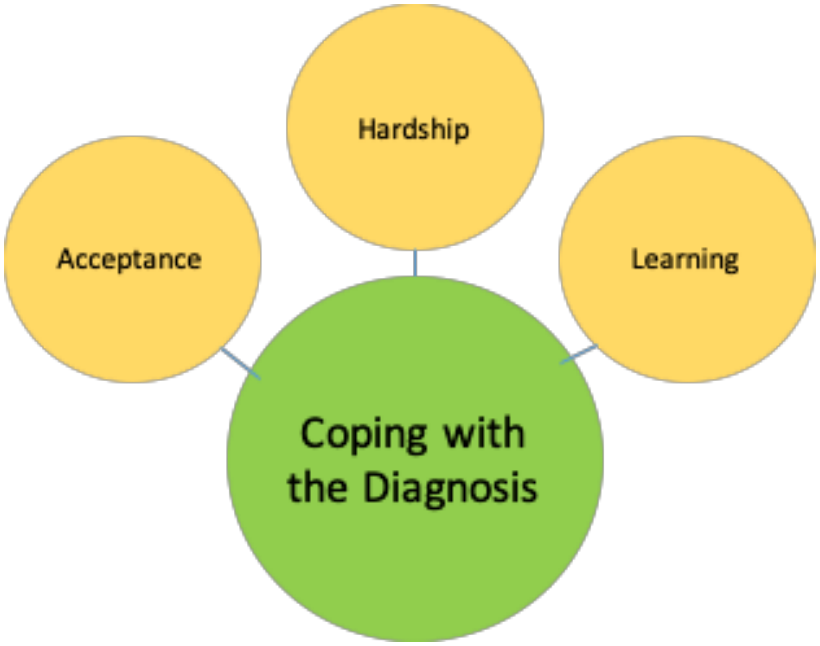

Figure 4.12. ‘Coping with the diagnosis’ theme and subordinate themes.

4.4.3.2.1 Subordinate theme: Acceptance

All parents were able to reflect on and spoke openly about the process of accepting their child’s diagnosis. One might assume that they had all accepted the full meaning of the diagnosis and the implication this had on families. With this in mind, most parents provided a vivid picture of how they felt when they heard of the diagnosis. Some parents expressed the difficulties in accepting the diagnosis, raising questions round their own hopes and vision of their child and themselves as parents:

> At the beginning it was really really tough, I won't say it was "oh he’s autistic that’s fine". But I didn’t want to see, I didn’t want to accept that. (T: 3, L: 160-163)

On the other hand, receiving the diagnosis reassured some parents that their instincts were right. One parent reported:

> I mean more like relieved over sad, I was relieved I got the answer…I was prepared as a mother; it was like I diagnosed already because I know my son. (T: 10, L: 119-123)

Similarly, for another parent, receiving the diagnosis was a sense of relief from the guilt of treating her child the same as her other children. Upon hearing the diagnosis, this parent shared her initial reaction:

> I cried that day, like uncontrollably, I was like "how?! why J!". Oh god that day, it was so emotional, I get home and I called him and I said "J I'm really sorry for shouting at you for those times when you were naughty and I know now there is a reason for that. (T: 2, L: 132-134)

Accepting the diagnosis empowered some families to come to terms with their own values and beliefs and the implications this had on raising their child. One parent had realisations that coming to terms with the diagnosis was the only way of moving forward:

> They have autism, they don't know it, the problem is not with them the problem is with me. The problem is with the outside who do not know how to deal with them but he is very happy…So I had to come to that realisation about myself that there is no point being depressed, because the child is not sick. (T: 7, L: 61-65)

For all the parents, acceptance involved taking on the highs and lows, seeking clarity and understanding their own and others' perception of the diagnosis.

4.4.3.2.2 Subordinate theme: Hardship

As well as recognising the strengths gained from experiences of raising a child with autism, parents experienced considerable hardship. This was often described as an emotional journey that carried feelings of depression, guilt or confusion. Nevertheless, parents drew on how such hardships enabled them to grow stronger as parents and as a family.

One parent spoke honestly about earlier memories of when her child was diagnosed: "I think...it's been very hard, very hard especially for the first six years of his life" (T: 1, L: 330-334). However, admitting to the hardships was how the parents worked through stress and overcame challenges.

For one parent, it was particularly stressful when she was seeking the truth about her child's needs and this gave rise to mental health difficulties: "It is giving me depression because I am stressing myself. I am researching things over and over and I know there is something wrong but I am not getting the help" (T: 10, L: 107-108).

Some parents spoke about how they received psychological help such as counselling or talking to a professional. Other parents spoke openly about mental health and experiencing depression after marital breakdowns. It was important to them to recognise the implications these factors had on raising their children as one mother expressed:

> Me personally, I believe that if you are ok your head, then the child is ok. If I am depressed, then there is no hope for my children. But if I am not depressed and ok and I believe I can go out and leave the twins, but if I am down there is nothing. (T: 7, L: 258-259)

4.4.3.2.3 Subordinate theme: Learning

In the process of accepting their child's diagnosis, all parents demonstrated a desire to learn more about autism. Some parents developed their own strategies for gathering information whether this was by looking for resources and services available in their community. Other parents used the internet to sign up for courses and access information that was readily available such as the Local Offer. Most parents drew on a combination of sources to increase their knowledge and understanding of autism:

> After he got the diagnosis, I started learning and reading and oh my god non-stop and I think for me, most of the books say kind of the same things but you always learn something different, at least I do. (T: 3, L 270-272)

One mother highlighted that she wanted to learn as much as she could to support her child, while also promoting his independence. Another parent began researching before her child was diagnosed as she noticed his behaviours were different from his peers. Her desire to look for answers and seek clarity led a to a referral being made to the paediatric team and outcomes that confirmed her initial beliefs.

4.4.3.3 Theme: Resilience

This theme is presented in Figure 4.13 and consisted of the subordinate themes of 'self-belief', 'adapting to change', 'emotional expression' and 'inner resources'. They explore different components of resilience demonstrated by the families throughout their journey of raising a child with autism.

Figure 4.13. 'Resilience' theme with subordinate themes.

4.4.3.3.1 Subordinate theme: Self-belief

All of the parents in the study referred to their sense of self-belief around knowing their child had additional needs and believing that they could be successful in raising a child with autism. Before receiving their child's diagnosis, one mother shared:

> My instincts were right about my child. I was determined and nobody was going to stop me from getting to the bottom of what was wrong so in the end… but you know they're entitled to their beliefs…but you know I was 100 % sure. (T: 5, L: 139-140; 145-146)

Some parents reflected on how their self-belief and independence enabled them to overcome hardships. One mother tried to reach out to her family and take concrete steps towards getting her child's diagnosis. However, she encountered some conflict and reported:

> I think the complication in my case was because I was bipolar people were disbelieving me as thinking it was down to the bipolar you were kind of you were confused. (T: 5, L: 126-127)

Despite her mental health difficulty, she was able to manage the conflicting views of family members. This process was an important part of externalising her beliefs and reinforced her instincts as a mother.

4.4.3.3.2 Subordinate theme: Adapting to change

Adapting to change was a process experienced by all parents in relation to coming to terms with their child's diagnosis and recognising the positive contributions made by their child. Some parents made adaptations at home and others adapted their parenting style such as one parent who said, "I see, I watch, and see what's going on and then I tailor it from there rather than instruct him and tell him what to do" (T: 5, L: 65-67).

After gathering information on how to support their child educationally, another parent made changes in her approach to supporting his learning:

> After he was diagnosed I worked closer with him on like colours and numbers, otherwise I wouldn't just treated him like a normal child, and to bring him to the normal category of children, I need to give him extra time and teach him in a different way' (T: 10, L: 119-123)

Reflecting on what had changed, another parent said:

> A lot has changed, for example the way I speak to him, how I explain things and…his thoughts... I know whatever he is doing he is not doing it on purpose. It is nothing to do with him being naughty. (T: 2, L: 209-212)

For other parents, part of adapting was making positive contributions to the community or by supporting other parents. One mother gave the example of running a parent group in the local church:

> I am trying to help the mothers, whether administrative or not. I mean it is early days, but I've come to the point where like I've said, I am ready to give out what I have to other people. I have come to point where I am not stressed anymore. (T: 7, L: 155-159)

4.4.3.3.3 Subordinate theme: Emotional expression

Several of the parents spoke openly about the extreme emotions they experienced and the significance this had to their response to managing challenging times. Talking about their experiences of raising a child with autism elicited strong emotions in some of

the interviews as one parent expressed, “I am very emotional person as you can see (laughs) it is the way to take from my shoulders” (T: 3, L: 409-411). Another parent spoke about being open about emotional expression disclosing that, “I'm somebody that when I get emotional or when I am worried there is no way I can hide it, you will see it all over” (T: 2, L: 145-146).

As well as recognising when they felt a certain way, another parent spoke about strategies she used to calm herself down when she felt herself becoming angry:

> I do sometimes build up anger and tell myself to calm down, because it’s really painful seeing him. Apart from that yeah. At the moment it has been like an emotional journey, I just feel a bit isolated. (T: 8, L: 104-107)

The expression of feelings was shared by most parents and was an important part of coping with challenges as well as embracing successes and bouncing back. One mother shared how she dealt with painful feelings but was able to start a fresh on a new day:

> I mean don't get me wrong, it has not been easy, it is not that it is very rosy every day. I mean there are evenings where you sit and cry or get upset because it’s a struggle you understanding…But you cry, you go to bed, you wake up and its another day! (T: 7, L: 311-313)

4.4.3.3.4 Subordinate theme: Inner resources

As well as reflecting on challenges and positive aspects of raising a child with autism, parents also spoke about a greater understanding they had of themselves. They learned about inner resources such as patience, acceptance, tolerance and perseverance. A strength across all families was resilience explained by one parent as: “In a week you can have one bad day or two sometimes, but you have to pick yourself up and try again” (T: 7, L: 321-322). For this parent, it was important to have an awareness that things can get better.

Parent also made comments about how the highs and lows had helped them to appreciate small things in daily life, in particular special moments with their children or achievements. Becoming more compassionate, kind and courageous were cited as strengths that complimented the challenges they had faced in raising a child with autism. There was also a strong sense of appreciation for their child and the experiences they encountered with one parent expressing, “you know I always tell them you’ve got to appreciate what you’ve got, what you have you know, life is not easy but you need to appreciate it” (T: 3, L: 653-655).

Parents gave examples of how grateful they were of their child and the strengths they had gained as a result of raising their child:

> Everyone has their own challenge but I am grateful - I have developed a grateful heart, that's my strength, I just developed it and learned to love people no matter what, it is not easy it is painful sometimes. (T: 7, L: 316-318)

Inner resources such as perseverance were considered personal attributes as well as coping strategies necessary to overcome adverse experiences. However, parents also shared how they felt supported by their family and friends who helped them come to terms with their child's autism. While parents spoke about their own inner resources, they also shared their child's strengths and courage that enabled them to overcome their own challenges.

4.4.3.4 Summary of master theme: Response to diagnosis

This master theme illustrated the how parents overcame adversity they experienced from raising a child with autism. The three themes of 'managing reactions to diagnosis', 'coping with diagnosis' and 'resilience' are strongly interrelated as they illustrate how the parents made positive meanings from challenges encountered. All parents articulated how acceptance, hardship and learning were affirmative strengths gained as a result of raising a child with autism.

Underpinning parents' experiences were components of the theme 'resilience' which were categorised as 'self-belief', 'adapting to change', 'emotional expression' and 'inner resources. These were considered interrelated as they depict how the process of resilience changed over time and had a unique influence across families and cultures.

4.5 Summary of Findings

Analysis of the findings was provided alongside direct quotes from the interview transcripts that yielded rich data. Embedded within these experiences were a diverse range of values and beliefs that contributed to the resilience demonstrated by all the families. Across all parents in the study, positive adaptations were made leading them to adopt a positive outlook for their child's future.

The main findings indicate overwhelming support for the positive aspects of raising a child with autism that are embedded with values and beliefs across individual, family and cultural contexts. The qualities of resilience demonstrated by families enabled

them to function and remain optimistic in challenging situations. Parents spoke about the emotions evoked from both positive and negative experiences which contributed to the strong and positive relationships they developed with their child. Positive belief systems meant that all parents maintained an optimistic outlook and a realistic view of their child's disability.

Lastly, the findings illustrate the sense of empowerment and control parents felt in shaping their experiences of raising a child with autism. Not surprisingly, there were commonalities among families in the process of responding to their child's diagnosis. These included resources that enabled them to overcome change and challenges, as well as reflections on perseverance and self-belief that enabled positive adaptations to take place.

4.6 Chapter Summary

In this chapter, the findings from the thematic analysis were presented in three master themes with associated themes and subordinate themes. The analysis illustrated the life changing experiences of BME families on raising a child with autism. All master themes were discussed in their own right outlining the parents' views and experiences based on the main research question and sub-questions. Interrelationships between themes were also explored. The following chapter will be the Discussion which will discuss implications of these findings and the researcher's reflections on the research process.

Chapter Five: Discussion

5.1 Chapter Overview

This chapter considers the research findings in relation to the aims of this study. It examines the link between the research question and main themes presented in Chapter Four, alongside the existing literature that has previously been discussed. The chapter also presents limitations and strengths of the current study. Finally, the role and position of the researcher and reflexivity are considered.

5.2 Review of the Research Aim and Key Findings

5.2.1 Research aim

The current study aimed to adopt a family resilience perspective to exploring the views of BME parents of children with autism. Semi-structured interviews were used to elicit what was meaningful to parents. The semi-structured interview addressed the overarching exploratory question and sub-questions:

From a family resilience perspective, what are the views of BME parents on raising a child with autism?

Sub-questions:

1. What are the views on the role of family and relationships?
2. What are the views on the role of values and beliefs?
3. What are their experiences on their response to the diagnosis?

5.2.2 Summary of main findings

Despite a diverse set of beliefs and backgrounds across parents in the study, a number of common themes emerged that indicated the nature of family resilience. The themes arising from the qualitative analysis indicate that despite the challenges experienced from raising a child with autism, families were able to gain a sense of control and make positive adaptations to their lives. Reasons for these adaptations included families valuing the importance of relationships between family members and their community.

To a large degree, the findings echo the literature, that has reported families vary in their pathways in resilience and this is dependent on their values and beliefs, resources,

obstacles and sense of purpose. Parents' experiences also illustrated the importance of hope, positive outlook and a supportive environment. Together, these themes show the importance of values and beliefs in the coping and positive adaptations of families over time. This is supported by the literature in that parents have a unique set of beliefs with a world view that encompassed their own, their child and their families' strengths and capabilities. In the following sections, the findings are discussed within the context of the identified literature.

5.3 Addressing Research Question One: The Role of Family and Relationships

5.3.1 Family connectedness

As reported in previous studies, parents felt that a sense of togetherness was important, especially when defining their family as a unit. Parents described how doing things together as a family contributed to the feeling of closeness, as well as providing emotional support. Bronfenbrenner's (1994) ecological model provides an explanation for this holistic view of family relationships. The microsystem encompassed the direct interactions between parents, their child, school staff and other family members. Parents reflected on the importance of these primary relationships within their own right, as well as the communicative factors that determined the meanings of these relationships.

Similar to King et al.'s (2006) study, relationships with siblings were also important, with some parents discussing how they observed the sibling love towards the child with autism and the special bond formed between siblings. The act of working together to support each other led to more understanding and stronger relationships between family members (Bayat, 2007). As Greef and van der Walt (2010) also identified, family time together is important in order to facilitate family adaptation. When parents described their support from their immediate and extended family members, coping and hardships were accompanied by stronger and more positive bonds in the family. This sense of closeness reflected how parents related to the needs of others (e.g. expectations of grandparents), their acceptance and ability to recognise their child's, as well as their own, personal needs.

Some of the parents spoke about conflicting viewpoints they had from family members around the meaning of the diagnosis. These conflicting messages were similar to findings in Fox et al's (2017) study, whereby some family members were left confused by differing viewpoints of family and professionals. Similar to Bayat's (2007) study, parents were able to utilise the resources they had in order to be flexible and open with other

family members. This was deemed necessary in order for family members to understand the situation and take up the role or responsibilities to support parents. Cohen, Slonim, Finzi & Leichtentritt (2002) commented that family connectedness and flexibility were important when parents shifted roles between providing support to being supported.

The findings addressing this research question illustrates how viewing the family as a unit steers away from within-child factors (Walsh, 1996). Referring to Walsh's (2012) framework, parents reflected on repaired grievances with other family members and how this process led to shared understandings, promoting cohesion and collaboration between families.

5.3.2 Community cohesion

At a more distal level within Bronfenbrenner's (1994) framework, the findings highlight the role and meaning of community to parents, which lies in the exosystem. When parents were asked what community meant to them, they referred to the neighbours, services and schools, all of which were underpinned by relationships established within each system. These findings were consistent with research that reports parents develop resilience by accessing resources at individual, family and community levels, as depicted in Bronfenbrenner's (1994) model (John & Roblyer, 2017).

Supporting this, a systematic review by Llias, Cornish, Kunmar, Sang-Ah Park & Golden (2018) also identified that social support from family members and the community were found to be a coping mechanism that alleviated stress. One parent in this study spoke about the importance of forming positive connections with members of the community to foster a sense of belonging. However, unlike findings in Fox et al.'s (2017) study, all the parents in the current study spoke positively about communicating and accessing services in the community. This is likely to be due to the participant inclusion and exclusion criteria (Appendix IX) for the present study, as all parents spoke English confidently, meaning there was no language barrier when accessing support.

It was interesting to note that only one parent mentioned school in relation to the meaning of community. This sheds light on the importance of home and school partnerships and how this can foster community cohesion. In previous research, parents have voiced that clear communication between schools and parents is an important enabler for community engagement (Lawrence, 2014). This was also echoed in Habib et al.'s (2017) study where mothers shared positive experiences of working with their child's schools.

Another noteworthy finding was the reference to professionals who had a significant impact on parents' experiences. This included professionals signposting and providing information to parents, but also the emotional and therapeutic support given. These findings shed light on the family-centered approach adopted by professionals when working with families.

5.4 Addressing Research Question Two: The Role of Values and Beliefs

5.4.1 Culture

Findings that address this research question illustrate the role of culture in the macrosystem of Bronfenbrenner's (1994) ecological model. According to Walsh (2012), cultural belief systems encompass larger values and influence growth and learning from challenging experiences. Supporting findings from Theara and Abbot's (2015) qualitative study with South Asian parents, the significance of ethnic minority experience of raising a child with autism has also been highlighted in this research.

In a conceptual paper by Ravindran and Myers (2012), it was reported that cultural beliefs influence families' perception, experience and response to a diagnosis of autism. Therefore, the current study has gained more of an understanding of disability across a range of cultural contexts. The findings confirm theories that have highlighted how culture can inform the social construction of autism and how experiences can vary across cultural groups. This suggests that beliefs exist at both a cultural or meta level as well as within the minds of individuals. Relating to the importance of social support, this can also be explained as being a factor typical of collectivist cultures (Llias et al. (2018)

In the present study, all parents were open to sharing differing cultural beliefs about autism such as the diagnosis being viewed as a curse or due to spiritual influences. However, a noteworthy finding was that some parents held separate beliefs to their own culture. They recognised the need to adopt a different position or perspective on autism for it to be meaningful and supportive for their child and family. These findings conflicted with Munroe et al's (2016) study where mothers reported feelings of shame and isolation due to conflict with their cultural identities. An explanation for this could be that parents in the present study developed an understanding and respect for similarities and difference between the mainstream culture (Western culture) and their own, which can be seen as a source of strength for families and society (Walsh (2016).

Some parents in this research spoke about sharing aspects of more than one culture. Berry's (1997) strategies of acculturation – integration, assimilation, separation

and marginalisation - provide a valuable understanding to some parents' experiences in the research. Acculturation can be described as a process of change when individuals have different cultures and come to experience changes in the cultural patterns from their original culture and newly adopted culture. Parents in the study depicted integration, which is when an individual (or family) retains a strong ethnic identify while also identifying with the new society or mainstream culture. As such, parents in the study displayed successful acculturation by thriving to maintain a positive sense of identity on an individual and family level. The findings provide insight into how families perceive their own cultural beliefs around autism when compared to how it is defined and constructed in the U.K.

Most of the parents in the study have family members in another country and spoke about differences between their culture and the mainstream culture in the U.K. Supporting research with immigrant families, the current findings illustrate that families were more resilient in navigating and adapting to challenges when they maintained family ties and cultural norms with both worlds. With these families being referred to as being bicultural (Falicov, 2007), this supports the notion that families who have adapted to a new culture are more 'culturally aware', allowing them to understand their own disposition within the new culture and context (Winterowd, Adams, Miville, & Mintz, 2009). Parents in this study appeared empowered to express whether they agreed or disagreed with their own cultural views on disability. Therefore, from a perspective of acculturation, parents were able to make positive adjustments to their way of life to best support raising their child with autism.

Some parents also shared how they chose *not* to associate with one particular culture. As such, they might have passed integrated cultural values onto their children who would have experienced of being a 'Third Culture Kid'. These are children who have spent most of their developmental years being raised in a culture different from their parents (Pollock & Van Reken, 1999). Having an impact on the individual and family system, this has been linked to a stronger sense of cultural balance and view of the world (Peterson & Plamondon, 2009). Additionally, families who have positively assimilated multicultural experiences were also likely to have higher levels of intercultural sensitivity. (Lyttle, Barker & Cornwell, 2011).

As most of the parents who took part were mothers, some commented on the cultural expectations of gender roles within the family. However, it is important to note

that when children were the main responsibilities of their mothers, this has been found to cause maternal stress (Sabih & Sajid, 2008).

5.4.2 Religion

This theme identified in the current study confirms previous findings where spiritual beliefs, hope and acceptance have been found to be important protective factors for families with children with additional needs (Munroe et al., 2016; Fox et al, 2017; Poston & Turnbull, 2004). In echoing findings from Habib et al's (2017) study in the U.K, the current study also identified that religious beliefs were considered to be important protective factor for parents. However, spiritual belief systems have been found to offer parents meaning and comfort (Munroe et al., 2016), which Walsh (2016) refers to as being distinct from religious belief systems.

The distinction lies in religion being defined as an organised faith system with a set of traditions, practices and a belief in a higher ordinate power. For example, some parents in the study spoke about the how religious practices were carried out at home or in a place of worship. This might have also included making their child aware of religious teachings and integrating these into daily family lives. It was also a way to enforce positive values in their children. Spirituality, on the other hand, is defined by Walsh (2016) as an overarching construct that permeates into values and beliefs in daily life and relationships.

For parents in the study for whom religion and spirituality were pertinent in their daily lives, values and beliefs were internalised and provided a sense of coherence, meaning and connection with their child, family and others. Similar to Jagatheesan et al's (2010) study, some parents expressed how they felt blessed to have a child with autism. This meant they were encouraged to maintain a positive attitude and ensure as a parent, they did everything they could to support their child. As a result, parents were encouraged to raise their children with pride and knowledge of their community roots and ethnic heritage.

The study's findings on the role of religion and spirituality indicates that they could be mediating factors to accepting the diagnosis.

5.4.3 Growth

The theme 'values and beliefs' encapsulated the importance of personal growth that recognised that although parents shared stressful experiences, the process of

overcoming them led to new perspectives, coping skills and growth. Defined as post-traumatic growth from the field of positive psychology, research has found evidence that new and positive viewpoints form due to the psychological adjustments made to stressful situations (Park & Fenster, 2004). Numerous studies have revealed the post-traumatic growth of parents of children with autism (e.g. Tedeschi & Calhoun, 2004; Zhang, Yan, Du & Liu, 2013. This supports findings in the present study which demonstrated how resilient families were able to make positive meaning out of adversity. Zhang et al. (2013) identified that personal strength and seeing new possibilities were particularly evident in mothers raising a child with autism.

One might argue that personal growth and the desire to learn is a coping strategy. However, all the parents in the current study explicitly reflected on how they as parents, as well as their family, were able to grow despite challenging experiences. Rather than referring to coping, they reflected on the importance of acceptance, inclusion and recognising the important things in life. Similar findings from qualitative research on resilience and families living with autism found that parents were able to redefine what was important to them and adopt new ways of seeing the world (King et al., 2006). There is an abundance of research that supports the notion that on an individual level, personal growth enables individuals to manage and thrive in stressful situations (Anderson, 1997).

In line with Fox et al's (2017) study, upon accepting their child's diagnosis, personal growth also meant the parents thrived to learn more about autism, seeking ways to gather information and learn as much as they can. These findings relate to Rotter's (1975) concept of internal locus of control as parents actively sought information and knowledge and therefore took initiative and responsibility. According to Breunlin (1988), this can be explained by self-understanding being accelerated during times of instability or having a lack of equilibrium. The challenges provided opportunities for them to learn by viewing situations in a different way. In addition, research has identified that parental resources to overcoming stress of raising a child with autism included having a sense of coherence, seeking social support and locus of control (Siman-Tov & Kaniel, 2011).

Aspects of personal growth also included parents who spoke about fulfilling their own potential as well as their child's. For example, some parents spoke about their own aspirations of returning to higher education and doing more courses to continue the desire to learn. For these parents, it was important to acknowledge that it was never too late to

learn and take on new challenges.

Personal growth also included building on interpersonal relationships by promoting a sense of optimism (Cohen et al., 2002). This was illustrated by some parents in the present study who had positive aspirations for their child and used humour to share stories about their child.

5.4.4 Optimistic outlook

A universal theme across findings of the current study and previous studies is that parents do what they can to help their children to achieve wellness and success (Yu, 2013). There is an abundance of literature that has identified that optimism, social support and coping strategies are contributing factors to post-traumatic growth (Prati & Pietrantoni, 2009). All parents in the study commented on a positive future and the importance of seeing their child grow into happy individuals. This is in line with findings from Heiman's (2002) study where all parents expressed a strong belief in their child and their child's future. Parents in both studies envisaged an optimistic outlook with a realistic and holistic view and acceptance of the situation.

According to Blacher's (1984) theory, this might be because parents who had participated in the present study had accepted the meaning of, and implications of, their child's disability, and therefore adapted themselves to it. Consistent with findings from other studies on family resilience and raising a child with autism (e.g. Bayat, 2007; Heiman, 2002), positive meaning was sought from their child's autism as well as the lessons learnt along the way.

5.5 Addressing Research Question Three: Experiences on their Response to the Diagnosis

5.5.1 Challenging stigma

As all the parents had children who had been diagnosed with autism, it could be assumed that they had come to terms with the diagnosis. In sharing their perceptions of autism, a few parents commented on society's mentality to 'label' children. Findings from this theme corroborated, and added to, findings from previous research where parents have referred to stigma attached to the label. Lilley's (2013) exploration of experiences of mothers of children with autism found that some feared the stigma attached to the label.

Similarly, Connolly and Gersch's (2016) exploratory study identified that parent's experiences were overshadowed by the implications of having an autism label.

In some instances, stigma has reinforced families to hide their child and delay seeking help, as identified in Fox et al's (2017) study. However, these findings were contrary to the present study as instead of delaying seeking help, the parents sought clarity and shared experiences of challenging the stigma of autism with family members. They had conversations to encourage family members to move forward in their thinking towards a shared understating of what autism meant for their child. As a result, these parents felt empowered and demonstrated self-belief, perseverance and determination. This was in contrast to Munroe at al (2016) where the majority of parents in the study felt isolated as a result of negative attitudes towards autism from others (family, friends or the community).

5.5.2 Acceptance

Acceptance was a significant theme within findings, and supported other studies on how parents coped when their child was diagnosed with autism. However, this theme was in contrast to Fox et al.'s (2017) study where parents delayed seeking help due to not being able to accept the diagnosis. In contrast, all the parents in this study sought help and asked questions to clarify their understanding and implications of the diagnosis. This might relate to parents in the study having supportive environments which meant they felt empowered to seek support from family and professionals.

The psychological impact of accepting the diagnosis has been found to shape parent's perception of their child's diagnosis. Lawrence (2014) identified that when children received a diagnosis, this also shaped the relationship between parents and professionals. As such, parents' experiences in the present study highlighted that the process of acceptance meant keeping an open mind and being flexible in responding to needs of their own, their child and their family. Eventually, this led to family systems becoming more cohesive as it meant parents, professionals and families alike were able to reach a shared understanding of what autism meant for the individual child.

5.5.3 Emotional expression

In the same way that acceptance of the diagnosis was a factor of resilience, many of the parents described their experiences of raising a child with autism as an emotional journey. In dealing with adversity, the positive effectives of emotional expression are well documented, as resilience has been found to be determined by the ability for individuals to express and tolerate a range of emotions (Walsh, 2016). This supports the present findings

where parents shared experiencing negative feelings such as sadness, fear and frustrations, to positive feelings of joy, gratitude and courageousness.

Similar to Heiman's (2002) study, parents reflecting on a range of emotions meant they could develop coping skills that contributed to their family thriving as a unit. Expressiveness also meant that parents were able to interchange between emotional roles such as being 'supported' to being the 'supporter' to family or friends. Such expressiveness might have enabled parents to regulate their own emotional reactions towards others and therefore reinforcing family values of trust and security.

As well as recognising the strengths gained from experiences of raising a child with autism, this theme highlighted how experiencing hardship enabled families to grow stronger. Hardships included issues around marital breakdowns and mental health difficulties and consistent with Heiman's (2002) study, parents shared feelings of depression, frustration and confusion. Nevertheless, sharing painful feelings is a form of self-disclosure (Walsh, 2016) which could have been empowering for parents. According to Walsh's (1996) framework, this communicational characteristic has been found to promote clarity with family members through open, emotional sharing. These components contributed to the quality of family cohesion and have been found essential for family climate and adaptation (Olson, 1993).

Emotional expression in findings also included positive feelings of gratitude, which agree with findings from the small scale exploratory study by Timmons, Ekas & Johnson (2017). A thematic analysis of gratitude letters from mothers of children with autism similarly identified mothers feeling grateful for what they have, and appreciating the positive attributes of their child and other individuals.

5.6 Review of Overall Findings

5.6.1 Summary of findings

When examining at the overall findings to the research questions addressed, the study provides overwhelming support for how families respond to raising a child with autism with strength and resilience. This fits with the application of a positive psychology approach where value is held to subjective experiences that envisage a future of hope, optimism and a present of happiness (Seligman & Csikszentmihalyi, 2005).

The aforementioned themes were explained with reference to Bronfenbrenner's (1994) model, which provided a useful framework for conceptualising the findings in the current study. Using this model, the study is in line with literature, evidencing that

resources were accessed at individual (personal resources and positive attributes), family (social support) and community levels (professionals and services within the community) (John & Roblyer, 2017). At the distal level in the macro system, the study illustrated how cultural and religious belief systems also had a significant role on individual values and beliefs.

As such, these resources serve as being protective factors that permeated through the systems around the child including their families and external support systems (exosystem) (Garmezy, 1991). The protective factors presented in the study represented attributes of people, environments, situations and events that related to positive adaptations made by families (Gutman, Brown, Akerman & Obolenskaya, 2010). Using these resources meant that parents were able to respond proactively to challenges, as well as to add meaning to their experience of raising a child with autism.

Holding onto these findings, the research is in keeping with the concept that family resilience is not innate or definite, but a developmental process (Walsh, 2012). The researcher concludes that overall findings demonstrate how family resilience encapsulates dimensions of growth, development and the ability to bounce back and improve (Valentine & Feinauer, 1994). With this understanding in mind, it can be concluded that resilience is not a singular, but rather a developmental pathway taken by the family (Hawley & DeHaan, 1996).

5.6.2 Epistemological and ontological considerations

In considering the epistemological and ontological position of this research, the researcher would argue that as well as the study eliciting components of family resilience, a social constructivist approach meant that parents were able to share what they valued and what was meaningful to them. Value was held to the nature of reality being pluralistic, where it was believed that each person has different beliefs and values, and that knowledge was discovered**,** not created (Scwandt, 1994). The researcher recognised that individual meanings were unique and discovered by acknowledging subjectivity, and the interrelation between researcher and participants having an impact on the research process.

The research was aligned with a relativist ontological position, which rejects the notion that truth is ascertained and that there is 'true' nature of reality (Braun & Clarke, 2013). Instead, it was assumed that multiple realities existed and were socially constructed through experiences across time and contexts (Ponterotto, 2005).

5.7 Strengths of the Research

Adopting a social constructionist approach enabled a qualitative research design that led to rich insights into the parents' views and experiences of raising a child with autism. Holding a constructionist view of resilience gave rise to experiences that reflected negotiations between individuals (parents and their child) and their environment, as expressed differently by individuals, families and communities (Ungar, 2005). Bronfenbrenner's (1994) model provided a lens to view how resilience was expressed across cultures and contexts by having implications on experiences and interactions with others (Crotty, 1998).

The research design meant parents felt comfortable and empowered to express their views, which were apparent from the diverse range of views and experiences underpinned by personal, family, cultural, religious values and beliefs. Some parents expressed how enlightening it felt to reflect on how their child and family had strengthened as a result of having a child with autism.

To ensure a more meaningful participation of the parents, the researcher found it was helpful to meet some parents prior to the interviews at a coffee morning. Having presented the aims and purpose of the research, it should be noted that eight of the ten participants volunteered to participate as they valued the nature and principles underpinning the research. This self-selection indicated that they shared and valued the nature of the research. As the research was a small-scale exploratory study, this also provided insight into the views and experiences of some BME families living in South East London.

A particular strength of the research was that as the researcher was from an ethnic minority background, this enriched the study by ensuring a culturally sensitive research approach. Tillman (2002) indicated that this 'insider perspective' can potentially facilitate cultural understandings of the researcher and participants.

As the researcher worked with an EP running the project at the local organisation for BME families with a child that has autism, this also provided a medium to present the research and in doing so, empowered families and raised awareness of strengths within families by raising a child with autism.

5.8 Limitations of the Research

Limitations of this study include some methodological issues with the sample being small and representative of families who lived in the South-East London boroughs.

Therefore, this could be affected by availability of Local Authority services and provision in the area. For this reason, findings were insightful, but the generalisability of the findings is limited.

Most of the parents had a son with autism and were mothers, with only one father taking part. Although the researcher did have some fathers who volunteered to take part at the parent coffee morning, they were not contactable thereafter. This may reflect work patterns or a reluctance to discuss their child. However, this might warrant further attention as it is possible that gender could be a factor that shaped the experiences shared.

It is also important to note that the findings could have been strengthened by member checking during the analysis stages. However, due to time constraints in collecting and analysing the data, this was not possible. Had time not been an issue, data could have been triangulated by sharing transcripts with parents, providing additional insight into the views and experienced shared by families (Jagatheesan et al., 2010).

As most of the participants were self-selected and the majority accessed the local organisation that support ethnicity minority families with autism, these families already had access to support within the community. It is possible that this would have influenced findings, as the parents were already at the stage of accepting their child's autism and as a result, were resourceful. The research also required parents to have a good level of English in order to express their views in the manner they were obtained. Although semi-structured interviews allowed for misunderstandings to be made apparent, some parents may not have felt confident to ask clarifying questions or for terminologies to be repeated.

From a theoretical perspective, as Walsh's (2012) framework of family resilience was referred to in the study, the findings identified were specified within this theory. It should be noted that alongside other frameworks of family resilience such as McCubbin and McCubbin's (1996) model, there was likely to be other strength factors that were not reported in this study. In relation to cultural dimensions, it is also important to note that a lot of the experiences and views shared were not necessarily culture specific and are likely to be experienced by all parents of children with autism.

A final point for consideration is that the study only focussed on parental views and experiences from one perspective. This raises the question of transparency and strengthening the credibility of the research as to whether the views would be consistent with the child's (depending on age) and other family members.

5.9 The Researcher and Reflexivity

As reflections are based on the researcher's view on their position within the research, this section is written in first person and draws on the researcher's reflections on the research process in its entirety.

Keeping in mind a social constructionist position, I was aware that this invited me to look outward towards the realm of interactions, discourse and the development of shared meanings (Finlay, 2002). In particular, it was important that I was mindful of the dynamics between myself and participants, which I recognised shaped the findings and research process. Adopting a reflexive stance was necessary to examine the impact myself and the participants had on each other and the research. The challenge was that reflexivity was applied at different levels – at a less conspicuous level, it meant recognising my own biases and blind spots and therefore explicitly locating my position in the research process. At a more active level, I had to engage in an explicitly self-aware position throughout the research process.

5.9.1 Personal insight and impact

In the pre-research stage, I reflected on my personal insight into the area under investigation. In considering the importance of resonance, I felt it was important to reflect on the social and cultural contexts of the research. In doing so, I found myself reflecting on my role as practitioner-researcher, being continually aware of my personal and professional background, and the impact this had on the research process. This meant reflecting on what kind of EP I wanted to be, the principles I valued, and the position I hoped to be taking as I embarked on my journey to becoming a qualified EP. It led me to revisit my core values and beliefs around the importance of community, a sense of belonging and to be flexible and adaptable.

Prior to carrying out the research, I recognised the importance of examining motivations, assumptions and my own interests as to how this would skew the research. The research enabled me to carry out research and practice in line with my interests around promoting the voice of parents, as well as recognising the impact of culture and family resilience. I explicitly related this to my previous teaching experience in a mainstream and special school in London and was aware that this could have blinded my position and approach, thus preventing me from being fully open to the aspects of the research process. However, I found my experience was instrumental in helping me

understand the perspectives of BME parents and the important role differing belief systems can have on raising a child with autism.

In revisiting the notion of having an insider perspective (Tillmann-Healy, 2003) and being from an ethnic minority background, I felt this facilitated a culturally sensitive approach. To a certain degree, aspects of shared knowledge and understandings were implied, which provided opportunities for collaboration with parents. I felt that this also enriched the findings and the trustworthiness of the data. I also observed that this reduced the power imbalance when asking about the role of culture and religion. This is an important consideration in research that explores cultural aspects, as previous researchers have been from an ethnic minority background or shared the same ethnicity as the participants (e.g. Fox et al., 2017; Theara & Abbott., 2015; Jagatheesan et al., 2010; Habib et al., 2017).

5.9.2 Blind spots

Throughout all stages of the analysis, I remained mindful of what was important to the parents and what they would say or think in relating to sorting codes and themes. Holding in mind their voice helped me to keep in sight the purpose and nature of the research and underpinning paradigms. This was particularly important for considering my blind spots in relation to noticing aspects I wanted to see, as opposed to what the data was showing. I was constantly reminding myself that although the research advocated for a strength-based approach, sharing the painful experiences and emotions were just as pertinent to the process.

In returning to a position of neutrality, one example of this was when I was devising the semi-structured questionnaire. I realised that I should not have *assumed* that all parents encountered positive experiences, therefore, I adjusted questions to make them appear less leading. I later realised the importance of this, as one parent suggested that asking about difficulties as well as strengths meant they could reflect on how they overcame these difficulties.

From an inductive analysis vantage point, I considered the importance of language on a surface level. This meant having a clear understanding on the theoretical and conceptual frameworks that might have influenced the content of themes. When I felt I was becoming drawn into organising subordinate themes into certain categories, I reminded myself of the reflective and thoughtful contributions made by parents. This became a process of trial and error as I held in mind whether they would agree with the

theme; what shaped their perspectives and what was the dominant voice coming through - my own, parents or the preconceived psychological knowledge.

5.9.3 Relationships and interactions

During the data collection process, I reflected on the quality of interactions between myself and the parents by revisiting principles of consultation. I also recognised that being too reflexive could block out the participant's voice (Finlay, 2002) and therefore it was important to externalise my thoughts as well as keep personal reflections. Through supervision, I was able to keep a balanced level of self-awareness throughout data collection and analysis. I used supervision as a space to reflect vigorously on the data collection process. Additionally, I had supervision with my university tutor who supported me when reflecting on the process from a researcher's perspective. This helped me to become more aware of how I positioned myself during interactions and helped me to become more transparent in my decisions and thought process.

A particular aspect of the research process that I enjoyed and valued the most was when I was interviewing parents, as this was the most collaborative part of the research process. It reminded me of the important values in my practice, such as mutual respect and connectedness. I also remained extremely appreciative of the time and effort parents made to meet with me amongst their busy schedules.

Not dissimilar to a therapeutic process, I found carrying out qualitative research both painful and challenging, but also emotionally satisfying for myself and the participants. However, reflecting on my experience of listening and asking questions, I had to be aware of my role as a researcher rather than an EP. Maintaining an equilibrium and managing the competing demands of these dual roles meant sometimes I found myself adopting a supportive role when parents were feeling upset or emotional. During these moments, I had to make an ethical decision to ensure these emotions were recognised and that I responded in a supportive and contained manner. I also held in mind the importance of the relationship I had with participants, which meant I had to be very sensitive to any power imbalances. As an EP, I value the non-expert position and at times, I felt being seen as a 'researcher' was perceived as being more powerful than an EP.

To ensure I was able to rebalance my role as a practitioner-researcher, I engaged in a process of reflection-*in*-action, that Schön (1983) argues is a vital attribute to being an effective practitioner. I also held in mind the principles of attunement, which defines

interactions as reciprocal and sensitive to the other person's feelings, as well communicating this sensitivity to the person (Erskine, 2015).

5.9.4 Being a practitioner-researcher

Reflecting on my role as a practitioner-researcher has led me to consider the gap between Evidence Based Practice (EBP) and Practice Based Evidence (PBE) (Fox, 2003). It is argued that this gap can be bridged by promoting a progressive synergy between theoretical and conceptual frameworks, the relationship with participants, and the research design (Lunt & Majors, 2000). In doing so, carrying out this research enabled me to have a critical awareness of distinguishing between theory related knowledge and practice related knowledge that might support or challenge my practice.

5.10 Chapter Summary

The chapter reviewed the research findings in Chapter Four in relation to the research questions. It also summarised the main findings of this study and linked them with previous research, theoretical and conceptual understandings and epistemology. The chapter presented the limitations and strengths of the study and concluded with reflections on the researcher's role, position and reflexivity in the research process. The following chapter will conclude the thesis by exploring the implications for future research and EP practice. It will also discuss how this research has made a distinctive contribution to the research literature and will conclude with some final reflections.

Chapter Six: Conclusion

6.1 Chapter Overview

The previous chapter discussed the main findings of the research in relation to research questions and the existing literature. This final chapter outlines the distinct contribution of the findings, suggestions for future research and implications for EP practice. To conclude, final reflections will be made in relation to the research aims and the role of the researcher.

6.2 Implications for Future Research

The study's findings have demonstrated that despite challenges faced by parents raising a child with autism, families show evidence of resilience. Parents reported having a positive outlook and remained hopeful for a successful future for their child. Families developed resilience when they pursued solutions to their challenges, looking beyond hardships and focussing on making the best of the resources available to them.

Given only one father took part in the study, future research might want to explore experiences and perceptions of fathers of children with autism. There is little research within this field, but paternal involvement is considered to be an important strength of resilient families (John & Roblyer, 2017). Additionally, this has become a reoccurring gap within exploratory research on families raising a child with autism.

While Walsh's (2012) framework provided a useful conceptual framework for the study, future research might want to refer to other resiliency frameworks to further highlight other components of family resilience. To add to this, Bayat's (2007) points out that family strengths and family resilience could be explored as separate constructs, for example, to consider whether strengths were formed as a result of raising a child with autism. However, this goes beyond the realm and purpose of the current study.

As the current findings highlight the role of cultural and spiritual values and beliefs, a longitudinal study might provide richer insight to family and community environments and how these contribute to the resilience of families. A longitudinal design can capture a richer picture of the lived experiences of families raising a child with autism. Additionally, it might provide insight into resilience as a *process,* that might change at different points in time as families adjust to challenges they encounter (Bayat, 2007).

As the present study included a majority of parents who attended training and support from the local organisation, future research might want to build on this by adopting a community-based, participatory approach, underpinned by principles of community engagement and empowerment (Minkler & Wallerstein, 2010). With additional time and resources, the co-production of this type of study would mean participants could become actively engaged in the research. This would strengthen findings by member checking, to ensure views and experiences were more accurately reflected in the findings.

6.3 Implications for EP Practice

The current study has implications for EP practice on several levels. This includes adopting strength-based perspectives, reflecting principles of positive psychology and systemic thinking to provide new points of view when working with diverse families and helping them to thrive. It has implications for EP practice in terms of developing cultural competence (Williams et al., 2015), as well as to working within families' belief systems to promote openness and empowerment (Lawrence, 2014).

The findings from the current study, alongside relevant existing literature, can be summarised in a conceptual framework, underpinned by Bronfenbrenner's (1994) model and family resilience, as illustrated in Figure 5.1.

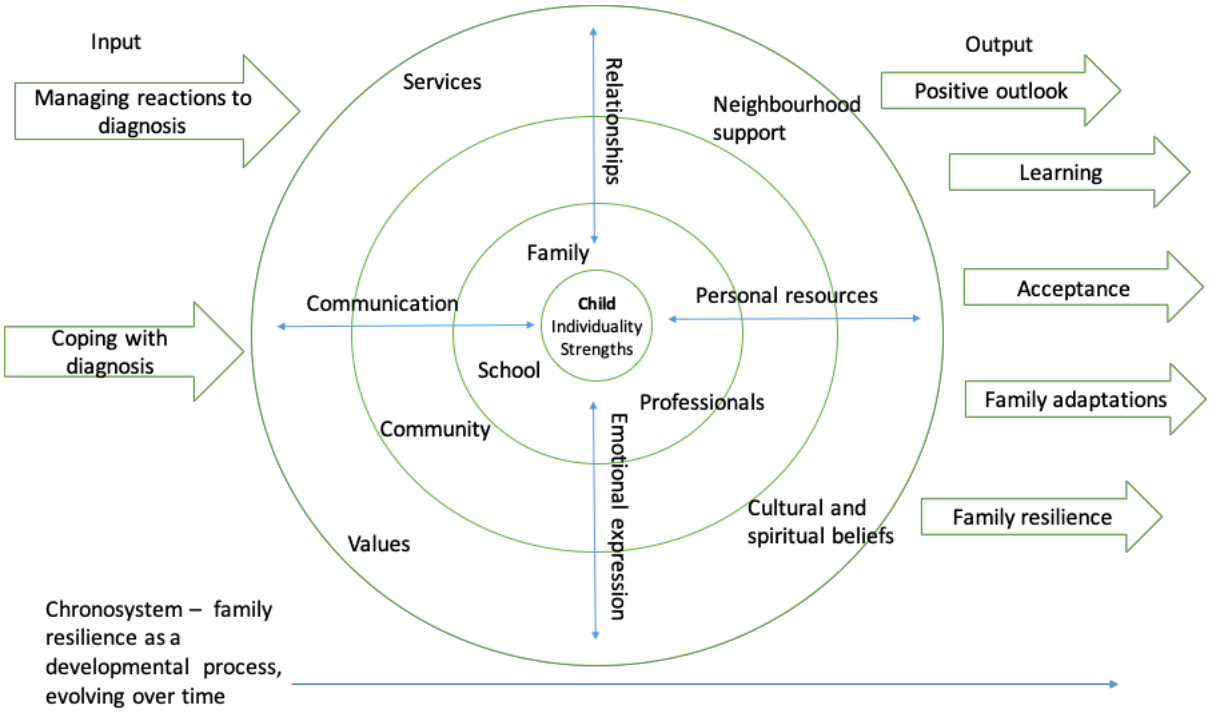

Figure 5.1. Conceptual framework for family resilience.

This overview can form the basis of a strength-based, holistic framework for EP practice, representing systems around the child and components of family resilience that permeate through all systems around the child (as represented by arrows through the layers). It can provide a framework for recognising components and interactions between systems. As well as systems, it considers input or output mechanisms that might change over time and also recognises how challenges can lead to positive outcomes for the child and family as a whole. As all families are unique, the framework can vary in its components. The implications for practice are discussed below.

6.3.1 Strength-based approaches

The findings have significant implications for promoting strength-based approaches when working with ethnic minority families of children with autism. If strength-based practice continues to be utilised, it will provide greater awareness, and a holistic understanding of family perspectives of raising a child with autism (Walsh, 2016). The study also highlights the importance of ascertaining values and beliefs of BME families. In doing so, professionals can then reconsider their practice by recognising the importance of how family values, resources and strengths can determine future goals.

The study has also highlighted the significance of promoting openness when

working with diverse family belief systems. The research process has also shown the value in encouraging, enabling and empowering parents to share their views and perspectives. The data collection process also has implications for a non-expert position during consultation in EP practice.

6.3.2 Working with families

The research highlighted the important role professionals have when working with families. Previous research has noted that families' belief systems should be acknowledged and influential in decision making (Lawrence, 2014). Parents shared the value they held to open communication with services, which reinforces the need for transparency. In turn, this will promote equality in parents and professional's relationships and ensure that adaptations are made to suit families' belief systems.

The premise for the study reinforces principles from the Code of Practice (DfE, 2015), which highlights the importance of listening to the views of parents. Linking this to findings from the current study, understanding values, perspectives and hopes of parents, both with respect to the family as a unit and to attitudes towards autism, is fundamental to working effectively with families. This emphasises the value of family and person-centered planning by being adaptable to individual family characteristics, beliefs and cultures.

The cultural and religious aspects of the findings should remind EPs of the BPS Code of Ethics and Conduct (2009), which states that EPs have the responsibility to protect vulnerable CYP, and consider the implications that culture has on decision making. Professionals should be aware of how assumptions may lead to discrimination in the under-presentation and over- representation of communities.

6.3.3 Cultural competence

From the onset of planning this research, the researcher intended to go beyond a tokenistic glance at culture. Findings have revealed the complex dynamics culture and religion can have on response to an autism diagnosis. With this in mind, culturally sensitive and constructive conversations with families from diverse backgrounds should be held in order to co-construct shared understandings of their child's needs and future.

A significant implication from these findings is that it can lead professionals to address cultural assumptions and competencies in practice. Professionals should have an awareness of how their background may differ from those of the families they are working

with (e.g. culture, values, race), and adapt their attitudes and practice to respond to the diverse needs of families. The findings have shown there could be a role of culture and religion in the perception of an autism diagnosis. When reflecting on next steps, there is a need for evidence that diversity and cultural competence is embedded in EP practice (Williams et al., 2015). Therefore, this requires professionals to make sense of these culturally specific views of autism and other special needs.

6.3.4 Community cohesion

Practically and theoretically, EPs are well placed to recognise the complexities of differing belief systems whether this is between professionals or with families. As the researcher worked with a local organisation who helped to recruit parents for the study, this sheds light on the importance of working in partnership with wider communities to strengthen community cohesion. With this in mind, the main implications indicate the importance of listening to the lived experiences of BME families, building on psychological approaches and evidence-based practice to ensure they are in tune with all communities.

Parents in the current study shared the appreciation they have for the resources available in the community, with some speaking about significant professionals they have worked with. This links in with home-school partnerships, as previous research (Theara & Abbott, 2015) has also placed emphasis on having a positive outlook towards their child's education. Therefore, this highlights the significant role of school in being a key way to engage parents.

The current research provides evidence that EPs are well placed to implement interventions that work with systems around the child to strengthen school, family and community partnerships. One example is Multi-Systemic Family Groups, which is a strength based intervention working with CYP, their family and school. Qualitative research has found that this intervention is culturally sensitive in that the respect for difference has helped promote engagement with ethnic minority communities (Fox, Bibi, Millar & Holland, 2017).

6.4 Distinctive Contribution

From a theoretical standpoint, the research has added a distinctive contribution to the field of culture and autism by adopting a family resilience perspective. In adding to a limited number of small-scale exploratory studies, to date, this research is the first such

study in the U.K. to explore the views of BME parents of children with autism from a family resilience perspective. The qualitative paradigm adopted has shed light onto parents' world views and values, and their hopes for the future. The research process itself achieved practical significance by empowering participants and it reflects a distinctive contribution by capturing the *whole* experience of families raising a child with autism.

On a different level, by using strength-based approaches, the study has enhanced the knowledge of how families operationalise their experiences of raising a child with autism. The findings of this research are unique as they have shown how positive psychology approaches can be helpful in reframing within-child and deficits models of disability. Parents in the study appreciated being listened to and felt empowered to reflect on their own and their family's resilience; the strengths of their child, and a positive outlook as to how their unique strengths can be developed. Ultimately, the research has shown that it is pivotal that professionals adopt a culturally sensitive and strength-based approach to working with families from diverse backgrounds.

6.5 Final reflections

The research and the research process has shed light on how families can become resilient when they pursue solutions to their challenges, looking beyond hardships and focussing on making the best of the resources available to them. One of the main reflections the researcher has, is that the research provides a rationale for professionals to reframe their thought processes and approaches when working with families raising a child with autism.

Considering the difficulties of raising a child with autism, all parents in the study were able to use their inner resources and strengths to overcome challenges, not only for themselves but to strengthen their family as a unit. Shifting thinking to a strength-based approach can give service providers a new avenue for assessment and intervention, which will further promote the growth of individuals and families.

The researcher felt that the research process promoted the value of resilience in children and families, and most importantly has highlighted the quality of the relationships. This is a necessary starting point for other professionals to adopt a strong desire to promote positive partnerships with parents in supporting their child to thrive and succeed.

A final consideration is the significant contribution EPs can make by using person and family-centred approaches to break cycles of dominant, problem focussed narratives

around CYP. Having appreciated the honesty and valuable contributions made by the parents in the study, the researcher has been inspired to continue a journey in professional learning. They hope to continue to develop practice in line with the values and beliefs underpinning the premise for this study. Through collaborative EP practice, EPs and services can continue to promote positive outcomes for CYP by aspiring to work with parents to strengthen school, family and community partnerships.

6.6 Chapter Summary

This final chapter presented how the findings can inform implications for EP practice, the distinct contribution of the findings and suggestions for future research. To conclude, final reflections were made in relation to the research process as a whole and the role of the researcher.

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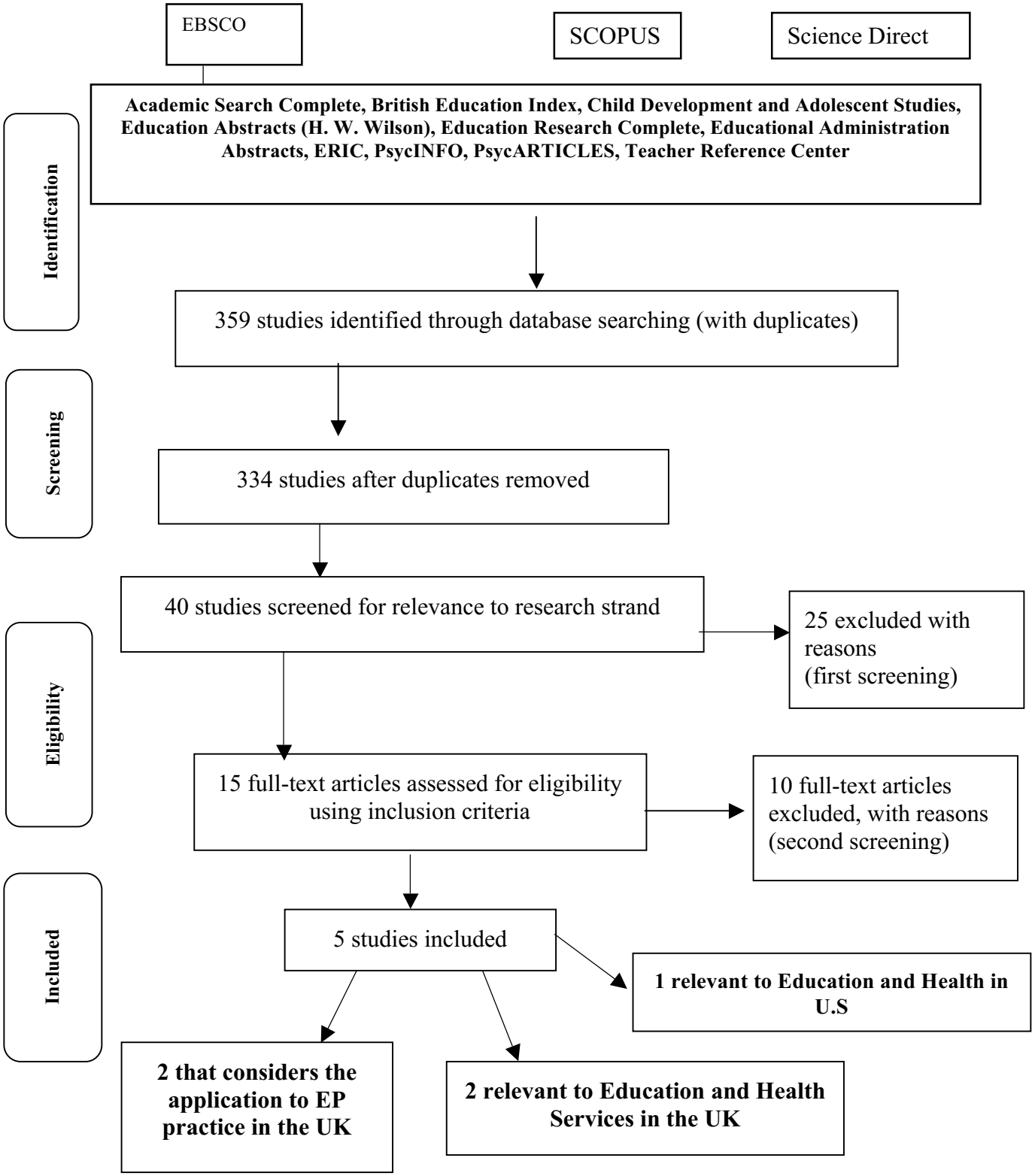
Appendix I – Inclusion and Exclusion Criteria for the Literature Review Strand: Parent Views, Autism and Culture

Criteria	Inclusion	Exclusion	Rationale
Participants	Participants are from a Black and Ethnic Minority background.	Participants are not from Black and Ethnic minority background. Participants' ethnicity is not disclosed.	The focus is on Black and ethnic minority families.
Purpose of study	The study explores information (experiences, attitudes, understandings or perceptions) gathered from parents and relating to cultural aspects and raising children with autism.	The study explores information gathered from parents (experiences, attitudes, understandings or perceptions) related to a different focus e.g. intervention, assessment, treatment, diagnosis or services, parenting styles. The study does not focus on parents.	This review focusses on views around culture and raising a child with autism.
Cultural aspects	The study explores cultural aspects that relate to differing perceptions, values, beliefs or religions.	The study explores other aspects related to culture e.g. language (bilinguism).	This review refers to culture as being socially constructed, comprising of different perceptions, values, beliefs or religions.
Exploratory focus	The study is not evaluative	The study does not use exploratory research methods.	The current review focusses on parent views related to raising a child with autism and does not aim to evaluate services/interventions.

Research design	The study uses a qualitative methodology.	The study does not use a qualitative methodology.	The current study uses a qualitative methodology.
Applicability	The study relates to the professional context of which EPs work in.	The study does not relate to EP related contexts (e.g. health focussed)	The current study considers application to the professional context of Educational Psychology.

Appendix II - Literature Search Screening process using the PRISMA flow diagram for the Strand: Parent Views, Autism and Culture



Appendix III - Final Studies Included from the Systematic Search on Parent Views, Autism and Culture

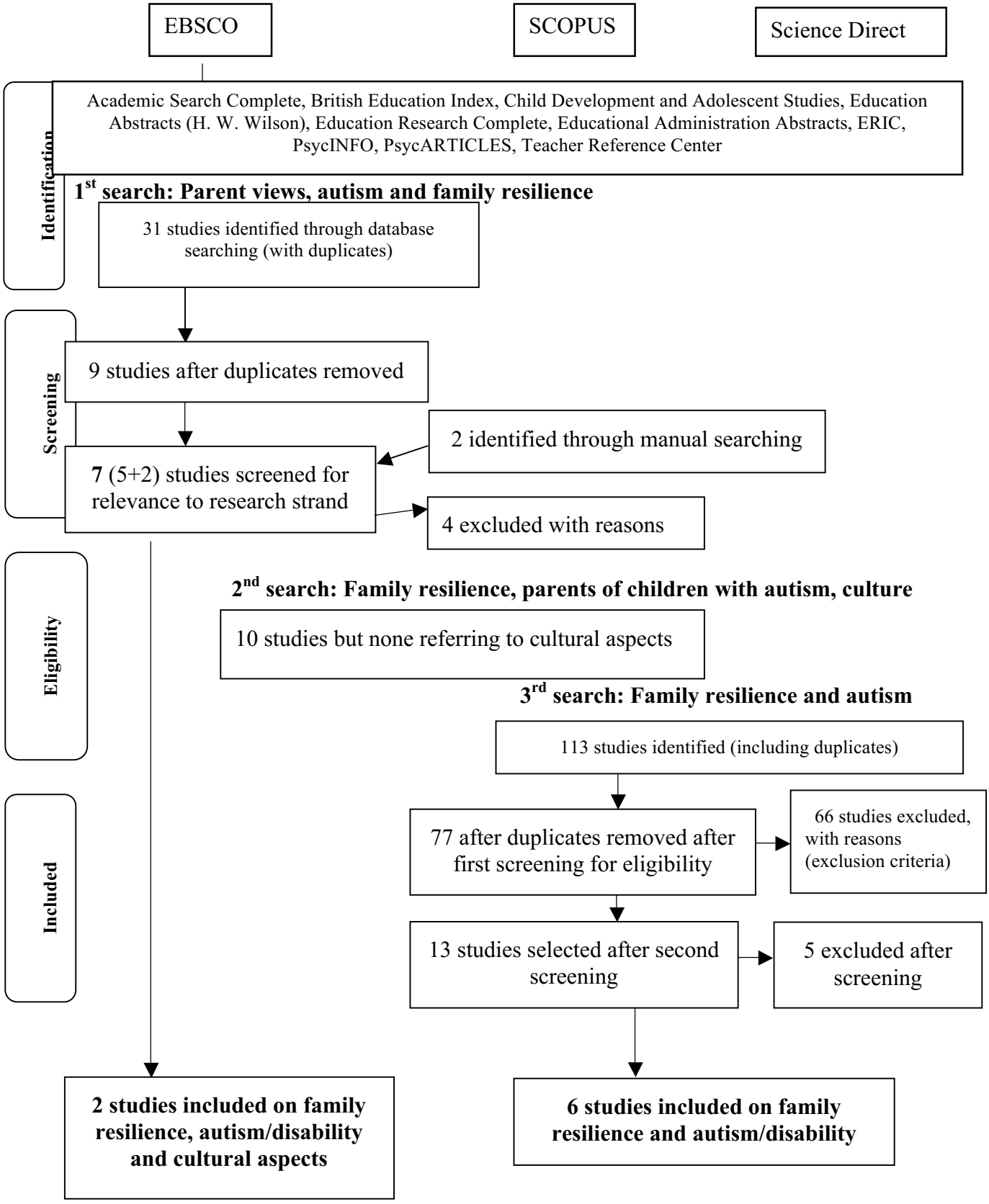
Strand: Parent views, autism and culture				
Study	Participants	Research design and epistemology (if stated)	Analysis	Findings
Theara & Abbott. (2015). Understanding the experiences of South Asian parents who have a child with autism (U.K)	9 South Asian parents	In depth interviews Social constructivist lens and grounded theory approach	Grounded Theory Model (Corbin & Strauss, 2008)	Parents' construction of autism privileged 'medical model perspectives' and this was largely underpinned by cultural values and beliefs.
Habib, Prendeville, Abdussabur & Kinsella. (2017). Pakistani mothers' experiences of parenting a child with autism spectrum disorder in Ireland. (U.K)	7 Pakistani mothers	Semi-structured interviews Constructivist-interpretive	Thematic analysis	Cultural factors impact Muslim immigrant mothers in the Western world and how they perceive autism. Positive experiences and challenges were found.
Munroe, Kathryn, Hammond & Cole. (2016). The experiences of African immigrant mothers living in the U.K with a child diagnosed with an autism spectrum disorder: An interpretative phenomelogical analysis.	6 African immigrant mothers of a son diagnosed with autism	Qualitative methodology - interviews	Interpretive Phenomenological Analysis	Mothers experienced stigma, blame and social isolation. However, religious faith was identified to be a protective factor

(U.K)				
Fox, Aabe, Turner, Redwoord & Rai. (2017). "It was like walking without knowing where I was going": A qualitative study of autism in a UK Somali migrant community. (U.K)	15 Somali parents of children with a diagnosis of autism	In-depth interviews Community-based participatory research approach	Inductive thematic analysis	Cultural attitudes towards mental illness, disability and lack of understanding of autism made it difficult for Somali families to accept and understand their child's diagnosis.
Jagatheesan, Miller & Fowler. (2010). Autism from a religious perspective: A study of parental beliefs in South Asian Muslim immigrant families. (U.S)	3 South Asian Muslim families who have children with autism	Interviews and observations Longitudinal and ethnographic approach through	Analysis was on-going and multilevel (transcripts informed inductive categories)	Families understood the task of raising a child with autism in religious term at home and in the community. Parents also disputed professional's understandings of autism.

Appendix IV – Inclusion and Exclusion Criteria for the Literature Review Strand: Parent Views, Autism and Family Resilience

Criteria	Inclusion	Exclusion	Rationale
Participants	Participants include parents of children with autism or disabilities.	Participants do not include parents of children with autism or other disabilities.	The current review focusses on parent's views.
Focus of study	The study considers aspects of family resilience (or resilience) and raising child with autism.	The study does not consider aspects of family resilience (or resilience) and raising a child (or children) with autism.	This review focusses on aspects of family resilience and parents of children with autism.
Exploratory focus	The study referred to aspects of family resilience and raising a child with autism.	The study did not refer to family resilience and raising a child with autism.	Focus of current review is on family resilience and autism.
2nd search includes the above and this criteria: Cultural aspects	The study considers cultural aspects (including differing perceptions, values, beliefs or religions).	Study explores other aspects related to culture e.g. language (bilinguism).	This review refers to culture as being socially constructed, comprising of different perceptions, values, beliefs or religions.

Appendix V - Literature Search Screening process using the PRISMA flow diagram for the Strand: Parent Views, Autism and Family Resilience



Appendix VI - Final Studies Included from the Systematic Search on Family Resilience and Autism

Strand: Family resilience and autism				
Study	Participants	Research design and epistemology (if stated)	Analysis	Findings
Studies on family resilience and autism/disabilities				
King, Zaigenbaum, Baxter, Rosenbaum & Bates. (2005). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. (Canada)	15 parents of children with autism or Downs syndrome and 4 service providers living in Ontario	Qualitative methodology – focus groups, followed by in-depth interviews	Thematic analysis	Themes indicated that parents were able to gain a sense of coherence and control through changes in worldviews, values and priorities that involve different ways of thinking about their child. Positive adaptations occurred over time with experiences indicating the importance of hope and possibilities that lie ahead.
Heimann. (2002). Parents of children with disabilities: Resilience, coping and future expectations. (Israel)	32 parents of children with disabilities living in Israel	Qualitative methodology - interviews	Qualitative data analysis – a comparative method of analysis to code and categorise the data	Parents expressed a strong belief in their child and their future. Majority had optimistic outlooks and a realistic view and acceptance of the disability.
Bayat. (2007). Evidence of resilience in families of children with	175 parents and caregivers of children with autism	Qualitative - Survey methodology of open ended questions	Qualitative analysis – coding and categorising the data	Findings suggest identification of specific resilience processes such

autism. (U.S)				as making positive meaning of disability, mobilising resources, becoming closer as family and greater appreciation of life in general.
Kapp & Brown. (2011). Resilience in families adapting to autism spectrum disorder. (South Africa)	19 mothers of children with autism from South Africa	Open ended question survey and quantitative measures: The Family Attachment and Changeability Index 8 (McCubbin et al); The Family Hardiness Index (McCubbin, McCubbin, & Thompson, 1986); Family Crisis-oriented Personal Evaluation Scales (McCubbin, Larson & Olson, 1982); The Family Hardiness Index (McCubbin, McCubbin, & Thompson, 1986); The Family Problem-solving Communication; The Relative and Friend Support Index; The Family Time and Routines Index (McCubbin, McCubbin & Thompson, 1986); The Social Support Index (McCubbin, Patterson & Glynn, 1982)	Quantitative analysis using Pearson's r. Qualitative analysis using Tesch's (1990) eight-step model of thematic content analysis	Social support, relationships, family time and togetherness and routines are the most important resilience promoting factors.
Greeff & van der Walt. (2010).	34 parents of children with autism	One open ended question and quantitative	Pearson Correlations and multiple	Resilience factors included higher

Resilience in families with an autistic child. (South Africa)	(South Africa)	measures: Family Attachment and Changeability Index (McCubbin, Thompson & Elver, 1996); The Family Hardiness Index (McCubbin, McCubbin, & Thompson, 1986); The Social Support Index (McCubbin, Patterson &Glynn, 1982); The Relative and Friend Support Index; The Family Crisis Oriented Personal Evaluation Scales; The Family Time and Routine Index; The Family Problem Solving and Communication Scale.	regression analysis Inductive reasoning	socioeconomic status, social support, communication and family environment.
Leone, Dorstyn & Ward. (2016). Definings resilience in families living with neurodevelopmental disorder: A preliminary examination of Walsh's framework. (Australia)	155 mothers of children with neurodevelopmental disorders	Quantitative methodology: Family Resilience Assessment Scale (FRAS; Sixbey 2005); Developmental Behavioural Checklist-Short Form (DBC-P24; Taffe et al. 2007); Positive Contributions Scale, Kansas Inventory of Parental Perceptions (Behr et al. 1992); Modified Child Rearing Practises Report (Rickel & Biasatti 1982);	Independent t sample t tests and Cohen's *d*, effective size estimate and multiple linear regression	Facilitators of resilience included positive belief systems, parental style and nurturing characteristics.

		Depression Anxiety Stress Scales (Lovibond & Lovibond 2005);		

Appendix VII - Final Studies Included from the Systematic Search on Family Resilience, Autism and Culture

Strand: Family resilience, autism and culture				
Studies on family resilience, autism and cultural aspects				
John & Roblyer (2017). Mother's parenting a child with intellectual disability in urban India: An application of stress and resilience framework. (India)	47 Indian mothers of young children with intellectual disabilities	Qualitative methodology - interview based on Reaction to Diagnosis Interview (Marvin & Pianta, 1996). Interpretivist paradigm	Content analysis	Mother's used fact-based and religious explanations to make sense of their child's disability. Despite parental stressors (including child-related factors, financial and family level-challenges), parents reported persona, family and societal resources that helped them cope with stressors.
Das, Das, Nath, Dutta, Bora & Hazarika. (2017). Impact of stress, coping, spcial support, and resilience of families having children with autism: A North-East India-based study. (India)	35 North Indian parents of children with autism	Quantitative methodology – Parental Stress Scale, Social Support Appraisals Scale, Coping Self-Efficacy Scale and Family Resilience Assessment Scale	Descriptive statistics	Despite an array of stress factors, families had coping skills to work through adverse circumstances. There were also aspects of social support systems from friends and family.

Appendix VIII - Strategic Framework for Qualitative Research (Patton, 2002)

Design Strategies:

1. **Naturalistic inquiry:** Openness to whatever emerges
2. **Emergent design flexibility**: Openness to adapting inquiry as understandings and/or situations change
3. **Purposeful sampling:** Participants selected because they are rich in information of the phenomenon of interest, not a generalisation from a sample to population

Data Collection and Fieldwork Strategies

4. **Qualitative data**: Thick descriptions, interviews capturing personal perspectives, experiences.
5. **Personal experience and engagement**: Research has direct contact with participants, personal experiences and insights are an important part of understanding the phenomenon.
6. **Empathic neutrality and mindfulness:** Empathic stance means understanding without judgement, showing openness, respect, sensitivity, awareness and responsiveness, being fully present (mindfulness).
7. **Dynamic systems:** Attention is given to process, change is on-going for individuals, families, communities, cultures. Remain mindful and attentive to system and situational dynamics.

Analysis Strategies

8. **Unique case orientation:** Assumes each case is unique and special, being true to respecting and capturing details of the individual cases.
9. **Inductive analysis and creative synthesis:** Immersion in the details and specifics of the data to discover patterns, themes. It begins by exploring, confirming while being guided by analytic principles rather than rules, and ending in creative synthesis.
10. **Holistic perspective**: The whole phenomenon under study is viewed as a complex system that is more than the sum of its parts.
11. **Context sensitivity**: Findings placed in social, cultural, historical contexts. Consider and remain aware of transferability and generalisability – making explicit that findings remain context sensitive.
12. **Voice, perspective and reflexivity**: researcher remains reflective about own voice, perspective. Credibility shown through authenticity, trustworthiness, objectivity – impossible. Finding balance between understanding and depicting the data from participants' views but also recognises complexity of being self-aware (self-analytical and reflexive).

Appendix IX – Participant Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
• Parents from a Black and Minority Ethnic background • Parents who have a child/children with a diagnosis of autism • Parents who are known to the Local Authority or local organisations who support families with CYP with autism • Parents who are willing to speak about their culture and experiences around their child's autism diagnosis - their willingness to participate indicates an interest in the aims of the study (culture, family resilience, autism).	• Parents who require an interpreter • Parents whose child/children are awaiting diagnosis for autism • Parents whose child is not in education • Parents who are involved in other research

Appendix X – Information Sheet

Information sheet for Parents

Title of research: Culture and family resilience: Exploring the views of Black and Minority Ethnic parents of children with Autism

Dear Parents,
My name is Rosabel Ng and I am a trainee Educational Psychologist (EP) on the Professional Doctorate programme in Educational and Child Psychology at the University of East London (UEL). I am also working in -- as a trainee EP. I am inviting you to take part in my research project. I hope this information sheet will be useful in providing background to my research and to help you decide whether you would like to take part. I am happy to go through this information sheet and consent form with you to answer any questions that you may have.

The information is split into two sections:

Part A - Tells you about the purpose of the study and what will happen if you take part.
Part B - This section provides you with more detailed information about the conduct of the study such as confidentiality.
Please feel free to ask me any further questions using the contact details below:

Rosabel Ng
Email (S
Email (U
Phone (

Part A – Information about the study

Who am I?

I am Rosabel Ng, a postgraduate student in the School of Psychology at the University of East London. As well as university work, I am also a trainee Educational Psychologist at --. As part of my studies I am conducting the research you are being invited to participate in. I have experience with working with children with autism and working with parents. In the past I was a teacher in a mainstream primary school and in a secondary special school for young people with social, emotional and communication difficulties. I have worked closely with parents, specialist outreach teachers, speech and language therapists and other professionals to support children with a range of needs.

What is the research?

The research will explore parents' views of children with autism on culture and family resilience. I am particularly interested in how culture might influence having a child with autism by strengthening the family. **Family resilience** focusses on positive aspects of families that draw on shared beliefs that might help a family get stronger as a unit over time. **Autism** is a lifelong developmental condition that affects how people see, hear and

feel the world differently to others. It may affect the ability of one to communicate and interact with others. Different labels are used for autism, such as Autistic Spectrum Disorder (ASD) and Autism Spectrum Condition (ASC).

The aim of this research is to explore your views, experiences and opinions on culture and family resilience and having a child with autism.

My research has been approved by the university's School of Psychology Research Ethics Committee. It follows the standard of research ethics set by the British Psychological Society.

Why is this research being done?

I am doing this research as I'd like to hear about your views on culture and family resilience. This will help schools and Local Authorities to understand aspects of culture and family resilience that may support children with autism.

Why have you been invited to take part?

As the aim is to explore culture, parents from Black or Minority Ethnic backgrounds with a child or children with autism have been invited to take part. You will not be judged or personally analysed in any way and you will be treated with respect. I value your contributions and appreciate the time you have taken to read about the research.

You are free to decide whether or not to participate and should not feel coerced.

What will you have to do?

If you agree to participate, you will be taking part in an informal interview with me. Before the interview, I will go through this information sheet with you and you can ask me any questions related to the study; if you are happy to take part, we will also go through the consent form. If you would like, you may attend the interview with another adult family member.

The interview should last no longer than 45 minutes and will take place somewhere convenient for you such as your child's school. You may take breaks or leave the interview at any time. I will take notes during the interview, but the interview will also be audio recorded. Recordings will be stored on the digital recorder and transferred to a password secure computer. It will then be transcribed (typed up word for word) and stored until I finish my doctorate studies (likely to be by the end of next year). However, all names will be anonymised in the write-up.

What is the time frame?

Interviews can be arranged at a time convenient for you between February-April. The interviews will be analysed over the summer and a summary of the findings will be shared with you at the end of the research in summer 2019. However, if you have any questions before then may ask them at any point.

What are the benefits of taking part?

By taking part in this study, you will have the opportunity to *voice your views and opinions on culture, family resilience and supporting a child with autism*. It is hoped that the findings from this study will contribute to a *better and more positive understanding of culture and autism among teachers, support staff and other professionals working with*

families of children with autism. By focussing on strengths within the family, other families from diverse backgrounds can also be encouraged that their child can move forward positively in life. Promoting cultural awareness and sensitivity around autism will help to build stronger communities that work together to manage autism.

Part B – Detailed information about the conduct of the study

If the information in Part A has interested you, please read Part B before making a decision to take part.

Will the information I provide be confidential?

Yes, your privacy and safety will be respected at all times. Under the Data Protection Act (2018), all data (including interview recordings and transcripts) will be anonymised and kept in a safe and secure place. You will not be identified by the data collected or in any written material.

What are the possible risks of taking part?

There are no risks for taking part. However, if you feel distressed at any stage you may withdraw from the research. There will be a chance for debriefing to take place at the end of the interview.

Do you have to take part?

It is entirely voluntary and you may withdraw at any time.

What will happen if I don't want to carry on with the study?

You are free to withdraw from the research study at any time until the start of data analysis, without any explanation, disadvantage or consequence. However, after starting the analysis of the data, I will not be able to withdraw your interview.

What happens to the information from the interview?

The recorded interviews will be written up as a transcript (typed up word for word with all names anonymised) and kept by the interviewer for the duration of the project. All confidential data will be stored until it has been analysed and the research has been passed by the university. In the research report, the parents will be given a replacement name and any mention of schools, staff names or family members will be anonymised. The interview transcripts will be shared with my supervisor at University of East London. The recordings, transcripts and personal details (consent forms) will be stored securely on a password computer that will be locked away, along with other confidential paper copies, and no one other than the researcher will have access to them. However, if you decide to withdraw before transcripts are analysed, they can be destroyed on request. I do reserve the right to keep and use all data if analysis has begun. The information will be used in the research write up and any quotations selected will be anonymised. At the end of the research project, a summary of the findings will be shared with you as well as other parents, schools and professionals in the Local Authority.

What if there is a problem?

If there are any problems, you can ask me as the researcher or contact my supervisor using the contact details provided at the bottom of this information sheet. You will have an opportunity to debrief at the end of the study. Debriefing provides you with the opportunity

make sure you are ok before leaving the interview. You may contact me afterwards if you have any further questions.

General information about psychological research:

BPS Code of Ethics and Conduct

https://beta.bps.org.uk/news-and-policy/bps-code-ethics-and-conduct

BPS Code of Human Research Ethics

http://www.bps.org.uk/sites/default/files/documents/code_of_human_research_ethics.pdf

Contact Details
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.
Researcher name: Rosabel Ng
Email: --
Email (UEL): u1021590@uel.ac.uk
Phone (--): --

If you have any questions or concerns about how the research has been conducted, please contact the research supervisor:
Dr Helena Bunn (Academic and Professional Tutor)
School of Psychology
University of East London
Stratford Campus, Water Lane, London E15 4LZ
Telephone:
H.Bunn@uel.ac.uk

or

Chair of the School of Psychology Research Ethics Sub-committee: Dr Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ.
(Email: m.finn@uel.ac.uk)

If you would like to take part, please read and sign the attached consent form.
Thank you for taking the time to read about my research project.
Rosabel Ng

Appendix XI- Research Interest from Local Organisation

From: --
Sent: Tuesday, October 24, 2017 1:25 PM
To: RN
Subject: RE: Parent voice: your help needed

Dear RN,

Your email was forwarded to me by one of the Family Support Workers.

I am the Lead Educational Psychologist on Project; I am also interested in your research on the "impact of culture on family resilience" with particular reference to families living with autism. (Project title) is a funded project to support BME families living with autism and your research interest is highly relevant to our Project Outcomes.

I look forward to meeting you soon to further discuss your research area and its relevance to our Project.

I am available on Tuesdays, Wednesdays and Thursdays from 11am onwards.

Regards,

Dr.--

Appendix XII –Poster Advert

[redacted]

Sensory Processing and Motor Skills Development

By

[redacted]

Educational Implications

&

Rosabel Ng – Trainee Educational Psychologist
University of East London

The Views of Black and Minority Ethnic Parents of Children with Autism/ASD

Key Learning

- **Understand Sensory Processing and Motor Performance**
- **Learn about the relationship between Sensory Processing difficulties and conditions such as ASD, ADHD, and Dyspraxia**
- **Understand how the sensory system supports motor skills development**
- **Why children with Sensory Processing difficulties often have motor skills problems**

S [redacted] iates oad \A

Date: Thursday 15th February 2018

Time: 9.30am—1pm

LOTTERY FUNDED

Appendix XIII – UEL Ethics 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: Max Eames

SUPERVISOR: **Helena Bunn**

STUDENT: Rosabel Ng

Course: Professional Doctorate in Educational and Child Psychology

Title of proposed study: What are the views of BME parents (of children with autism) on culture and family resilience?

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

Minor amendments required *(for reviewer)*:

No amendments appear to be required.

Major amendments required *(for reviewer):*

N/A

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):* Student number: Date: *(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)
X	LOW

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

Reviewer *(Typed name to act as signature)*: Max Alexandre Eames

Date: 6 Feb 2018

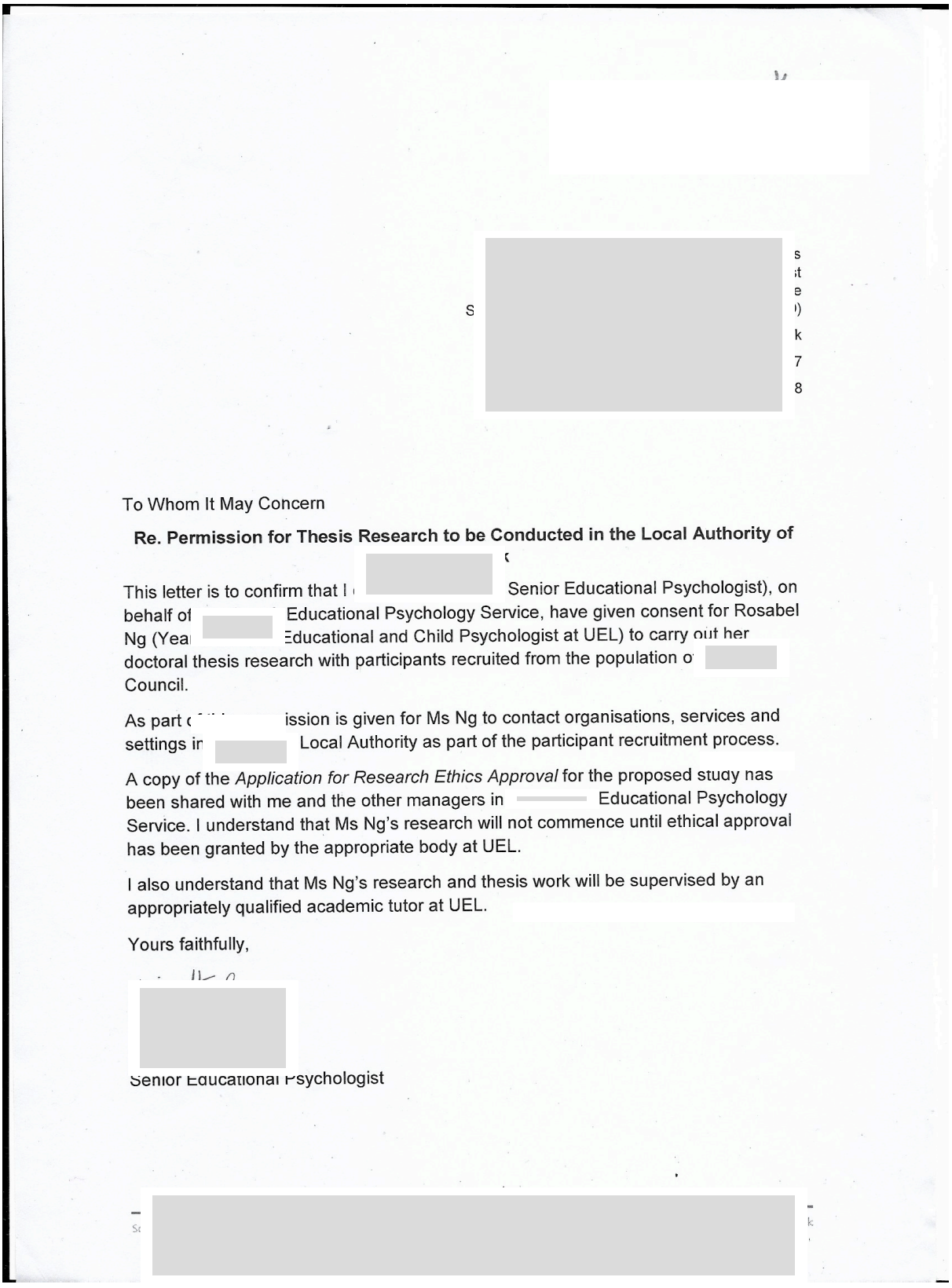
This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

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 XIV - SEPS Approval Letter



To Whom It May Concern

Re. Permission for Thesis Research to be Conducted in the Local Authority of

This letter is to confirm that I Senior Educational Psychologist), on behalf of Educational Psychology Service, have given consent for Rosabel Ng (Yea Educational and Child Psychologist at UEL) to carry out her doctoral thesis research with participants recruited from the population o Council.

As part ission is given for Ms Ng to contact organisations, services and settings in Local Authority as part of the participant recruitment process.

A copy of the *Application for Research Ethics Approval* for the proposed study has been shared with me and the other managers in Educational Psychology Service. I understand that Ms Ng's research will not commence until ethical approval has been granted by the appropriate body at UEL.

I also understand that Ms Ng's research and thesis work will be supervised by an appropriately qualified academic tutor at UEL.

Yours faithfully,

Senior Educational Psychologist

Appendix XV - Consent Form

UNIVERSITY OF EAST LONDON

Consent to participate in a research study

Title: Culture and family resilience: Exploring the views of Black and Minority Ethnic parents of children 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(s) involved 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 seen this consent form, 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 analysis of the data has begun. I also understand that the interviews will be audio recorded but that all names will be anonymised in the transcriptions.

Participant's Name (BLOCK CAPITALS)

…….

Participant's Signature

……..

Researcher's Name (BLOCK CAPITALS)

……..

Researcher's Signature

……

Date: ……..……

Appendix XVI - Debrief Letter

Title of research: Culture and family resilience: Exploring the views of Black and Minority Ethnic parents of children with Autism Spectrum Disorder

Dear Parents,

Thank you for taking the time to take part in my research. This debrief letter is to provide you with details of what will happen to the information you have shared. After the interview, we will also have a verbal debrief but if you have any questions after your participation, please contact me using the details below.

What happens to the information from the interview?

The recorded interviews will be written up as a transcript and kept by the interviewer for the duration of the project. All parents will be given a replacement name and any mention of schools, staff names or family members will be anonymised. The interview transcripts will be shared with my supervisor at University of East London. The recordings, transcripts and personal details (consent forms) will be stored securely and no one other than the researcher will have access to them. However, if you decide to withdraw before transcripts are analysed, they can be destroyed on request. I do reserve the right to keep and use all data if analysis has begun. The information will be used in the thesis write up and any quotations selected will be anonymised. At the end of the research project, a summary of the findings will be shared with you as well as other parents, schools and professionals in the Local Authority.

What if there is a problem?

If there are any problems, you can ask me as the researcher or contact my supervisor using the contact details provided. You will have an opportunity to debrief at the end of the study and contact the researcher afterwards if you have any further questions.

General information about psychological research:

BPS Code of Ethics and Conduct

https://beta.bps.org.uk/news-and-policy/bps-code-ethics-and-conduct
BPS Code of Human Research Ethics
http://www.bps.org.uk/sites/default/files/documents/code_of_human_research_ethics.pdf

For more information and support around Autism:

NEMFLA (Network for Ethnic Minority Families Living with Autism):
http://www.stmichaelassociates.org.uk/services/index.html - nemfla

National Autistic Society:

http://www.autism.org.uk/?gclid=EAIaIQobChMI7un7q8OC2AIVDhHTCh3jZQvrEAAYASAAEgIhcfD_BwE

Contact Details
If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.
Researcher name: Rosabel Ng
Email: u1021590@uel.ac.uk
Phone (----

If you have any questions or concerns about how the research has been conducted, please contact the research supervisor:

Dr Helena Bunn (Academic and Professional Tutor)
School of Psychology
University of East London
Stratford Campus, Water Lane, London E15 4LZ
H. Bunn@uel.ac.uk

or

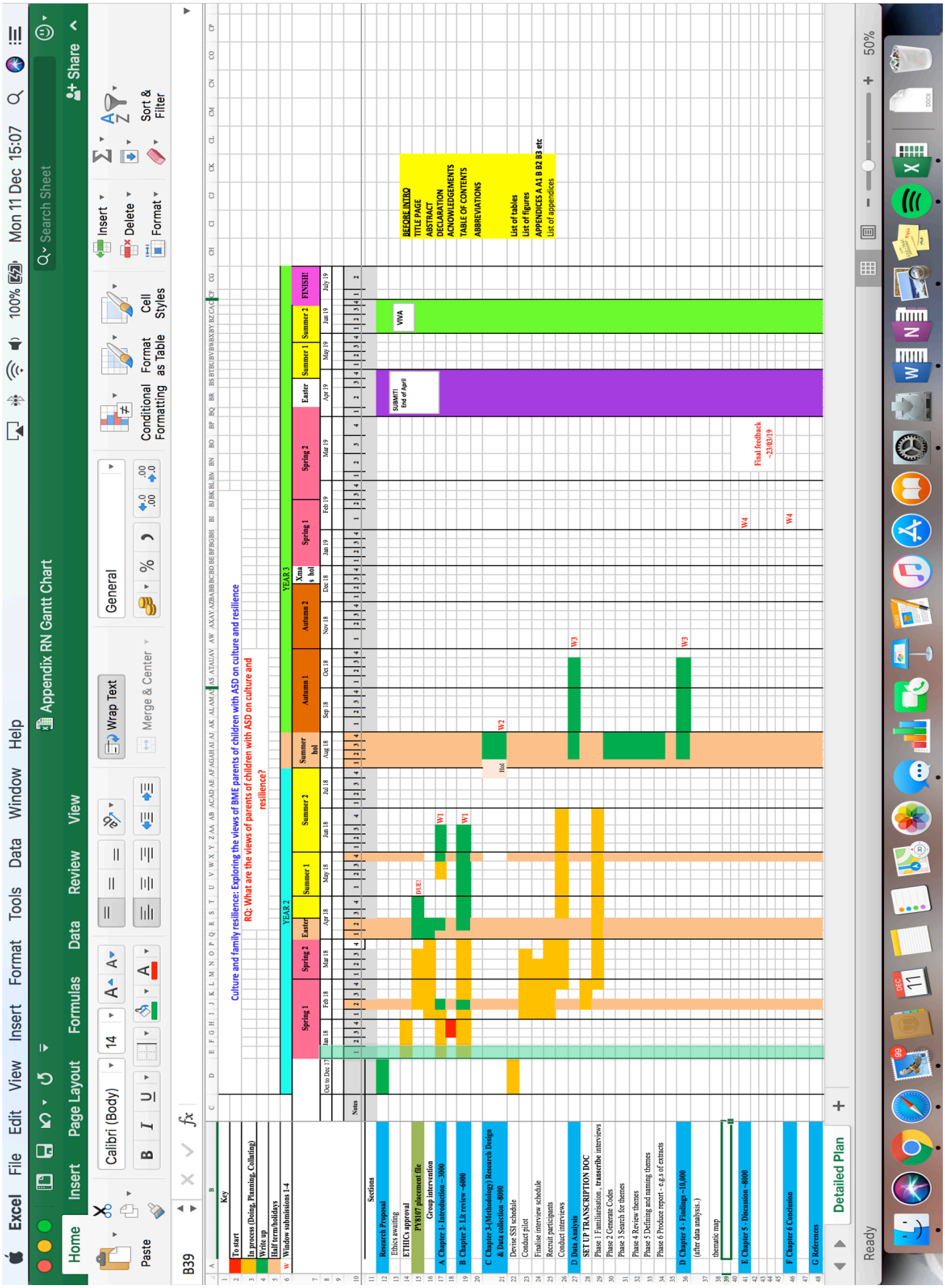
Chair of the School of Psychology Research Ethics Sub-committee: Dr Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. (Email: m.finn@uel.ac.uk)

Thank you again for your valuable contributions, I look forward to sharing the findings when the research has finished.

Rosabel Ng

Appendix XVII – Research Time Lines

Gantt Chart:



Data collection time-line:

6th February 2018	Ethical approval gained
15th February 2018	Present research purpose and recruit to parents at local organisation
February/March 2018	Consent obtained from parent and pilot study carried out
March - April 2018	Semi-structured interviews with parents
August – September 2018	Data Analysis
October – December 2018	Findings, Discussion write up

Appendix XVIII – Semi Structured Interview Schedule

Semi-Structured Interview schedule (45minutes)

Research question: **What are the views of BME parents (of children with autism) on culture and family resilience?**

Introductions
Introductions will take place at the start of the interview – the researcher will provide some background to their research interest and go over the purpose of the research. Parents will be given opportunities to go over any questions they may have based on information provided on the **information sheet and sign the consent form.** Parents will be given an explanation of what to expect from the interview such as length of time (around 45 minutes) and that they can take a break if they wish to do so. Parents will be reminded that there will be no right or wrong answers and that the researcher is interested in their views, opinions and experiences. There will be an explanation of informed consent that will take place and parents will be notified that if they feel distressed, they have the right to withdraw at any time. Parents will be informed that there will be opportunities for a **debrief** at the end of the interview if they feel they need one. It will be explained that the interview will be audio-recorded but that in the transcripts, all names will remain anonymous. They will also be informed that notes may be taken throughout the interview which will also be anonymised. Parents will be asked what term they prefer to use to refer to **autism** (Autism, ASD or ASC) and this term will be used throughout.

(Check audio recording equipment)

Clarifying and follow up prompts:
"Could you give me an example of..."
"What do you mean by…"
"How did that make you feel?"
"Can you tell me more about that?"

Warm up question: Remain open, strength-based

Can you tell me about your child?
(siblings, strengths, skills, likes/dislikes)

Main questions:

Belief systems

1. How would you describe your cultural background?
    - Do you have any religious beliefs? Cultural and religious practices
    - If so, what are they? How do they help your family?

2. How is **autism** viewed in your culture?

3. Can you tell me about when your child was diagnosed with **autism**?
    - How was it explained?
    - How did you and your family feel?

1. When your child was diagnosed with autism, do you think your culture helped you cope with the diagnosis? If so, how?
    - What role did values/spirituality/faith have?

2. Has your family changed in any way since receiving the diagnosis? If so, how?
    - Has your relationship with your child changed in any way? If so, how?

3. Has anything changed at home? If so, what has been done differently?

4. How positive do you consider to be as a family after diagnosis? If positive, what do you think has led to your family to feel this way?

Communication/connectedness

8. When you discovered your child had autism, who supported your immediate family in making decisions on what to do next?
    - How did you feel about these decisions?

10. How did you share your thoughts/feelings with your extended family (e.g. grandparents)?
    - How did they feel about the diagnosis?
    - If they provide support or help, how do you think they strengthen your immediate family in raising a child with **autism**?

Organisational patterns

11. What does community mean to you?

12. Can you tell me about support in your community? (may include family/support network)
    - Do you have support with looking after your child and family? If so, who supports you?

13. What help is available in your community? (school, services, explore)
    - Do you have any involvement with help available? If so, how do you help in the community?
    - How did you find out about it?
    - What do you talk about?

14. Do you think they help your family, if so how?

Positive outlook

15. What do you think helps your child and family thrive and be happy?

16. What hopes do you have for your child?

Closing

Debrief: Is there anything else you would like to add? Do you have any questions?

Thank the parents for sharing their views and taking part in the research.

Appendix XIX - Reflective Diary Extracts

Researcher's reflections also drawn upon in Chapter 5

Initial reflections and questions
How do I integrate my research interest into what kind of EP I want to be? Think about transferable skills. How do I want to achieve empowerment throughout the process?
I felt it was important to reflect on the social and cultural contexts of the research. In doing so, I found myself reflecting on my role as practitioner-researcher, being continually aware of my personal and professional background and the impact this had on the research process. This meant reflecting on what kind of EP I wanted to be, the principles I valued and the position I hoped to be taking as I embarked on my journey to becoming a qualified EP. It led me to revisit my core values and beliefs around the importance of community, a sense of belonging and to be flexible and adaptable.

Presenting research idea and recruiting parents at Local Organisation
This felt like a very fulfilling and empowering day as parents from different communities were coming together to socialise and learn new things, all raising children with autism. How did I want to present myself / for them to perceive me? I considered my role as a researcher vs EP and someone who shares their position of supporting BME communities. I tried to be polite, friendly and approachable without being too 'pushy'. Overall enjoyed the process of presenting research purpose and giving them the option to sign up – felt collaborative

Calling parents to recruit
Made sure the time frame was close to when I presented at the local organisation and hoped they would remember me to keep up the rapport. Felt promising that they agreed to sign up but slightly downbeat when I couldn't get through to some of them. Had indications of their organisation e.g. using diary / not. Most seemed pleased when they heard from me and this was encouraging and reminded me of the collaboration involved.

Pilot interview
Felt very reciprocal and equal enjoyment taken from this experience. Parent was light hearted, honest and appeared to feel empowered to share her views and experiences. I tried to engage in Reflection On Action throughout in order to ensure I was maintaining balance between interview mode vs EP – felt that using consultation style facilitated the discussion but that interview questions enabled me to stay on track. Parent commented on asking about weaknesses as well as strengths and this was a very good point and made me reflect on being too swept up in 'positive psychology mode', as parent expressed, reflecting on weaknesses can help think about how you worked towards overcoming them. As first interview – felt empowering, inspired by how parent had persevered and made reference to coping and self-belief.

Carrying out the interviews
Started to notice how parents lit up when asked final question about positive outlook – indicated to me how little they are asked of the positives and what they envisage for the future. It surprised me how open some parents were about painful aspects of their experiences as well as proud moments. I appreciated how honest they were and reflected on how I came across and used the aspect of the 'self' to empower, work collaboratively with them. At times when the interview questions were not interpreted as I had intended, I

thought about how the questions could be rephrased for next time in a way they would understand. It was important not to assume they knew definitions for e.g. culture or resilience and it was about me explaining it in a way they understood so we could establish shared meaning.

Analysis

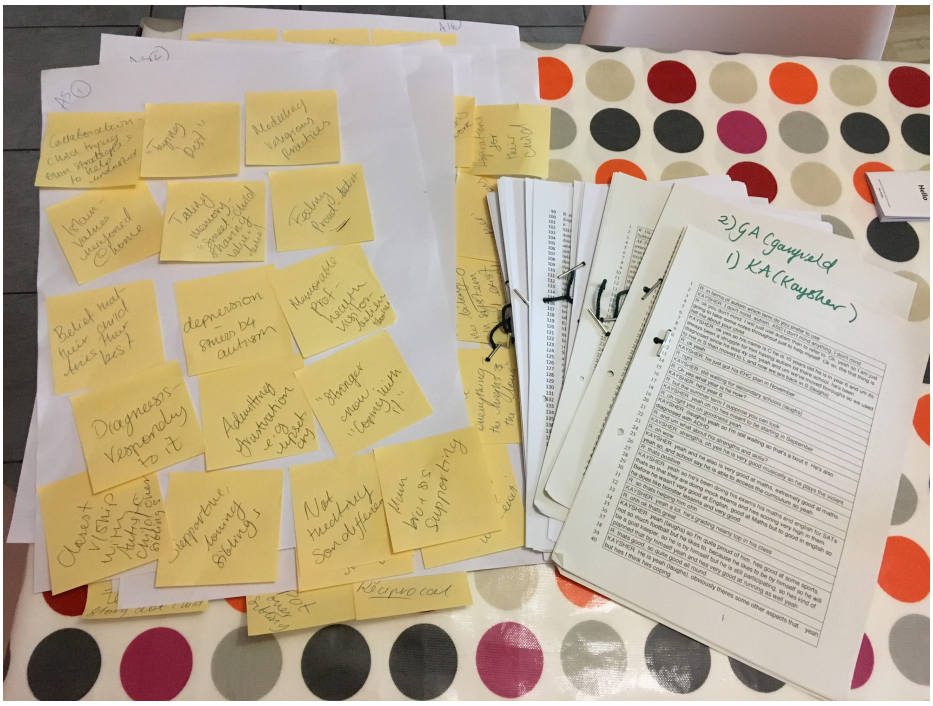
Throughout all stages of the analysis, I tried to remain mindful of what was important to the parents and what they would say or think in relating to sorting codes and themes. Holding in mind their voice helped me to keep in sight the purpose and nature of the research and underpinning paradigms. I needed to be aware of noticing aspects I wanted to see, as opposed to what the data was showing. I noticed a strong theme of perseverance and the importance of exploring what aspects meant to parents such as community.

Reflections on the process

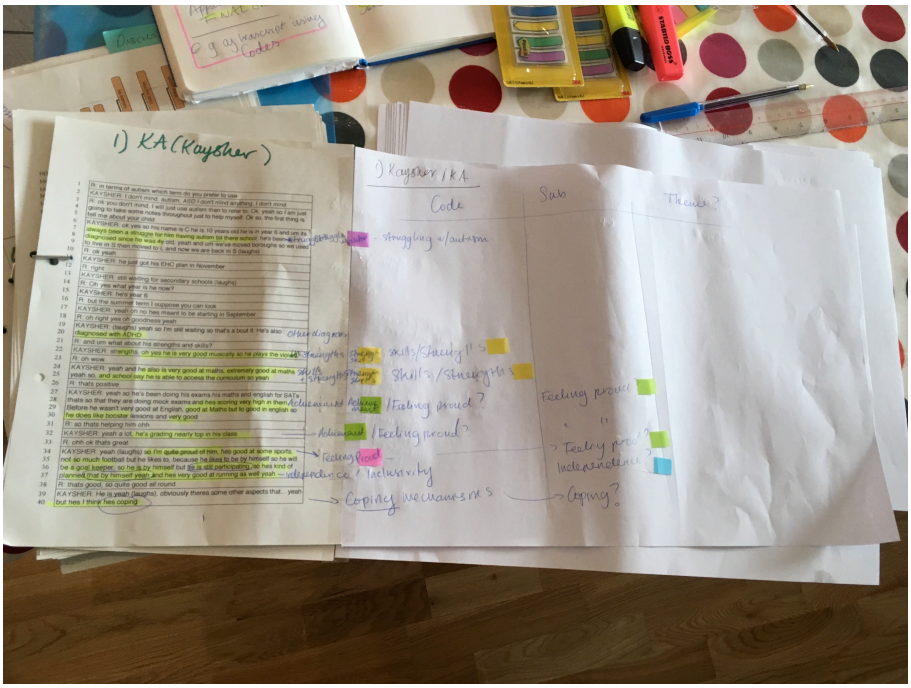
I learned of how resources were internal and external and how they influenced family scripts during their journey of raising a child with autism. I was initially unsure how to respond to negative stories or experienced but I tried to hold this discomfort, and throughout interviews parents naturally steered towards enlightenment, refocussing on what enabled them to thrive. This highlighted to me the importance of listening and acknowledging negative experiences within stories as these are what shaped individuals and families.

Were interviews also a form of intervention? How and why? Therapeutic space to reflect.

Appendix XX - Thematic Analysis Process



Phase 1: Familiarising with the data, re-reading transcripts and noting prominent ideas or concepts

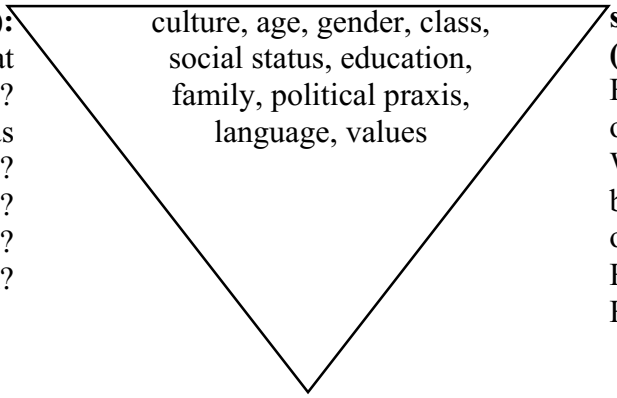


Phase 2: Generating initial codes using colour coding, descriptive words

Phase 3-5: Collating codes into potential sub themes, themes and master themes; gathering all data relevant to each potential theme.

Appendix XXI - Reflexive questions

Triangulated inquiry (Patton, 2002)



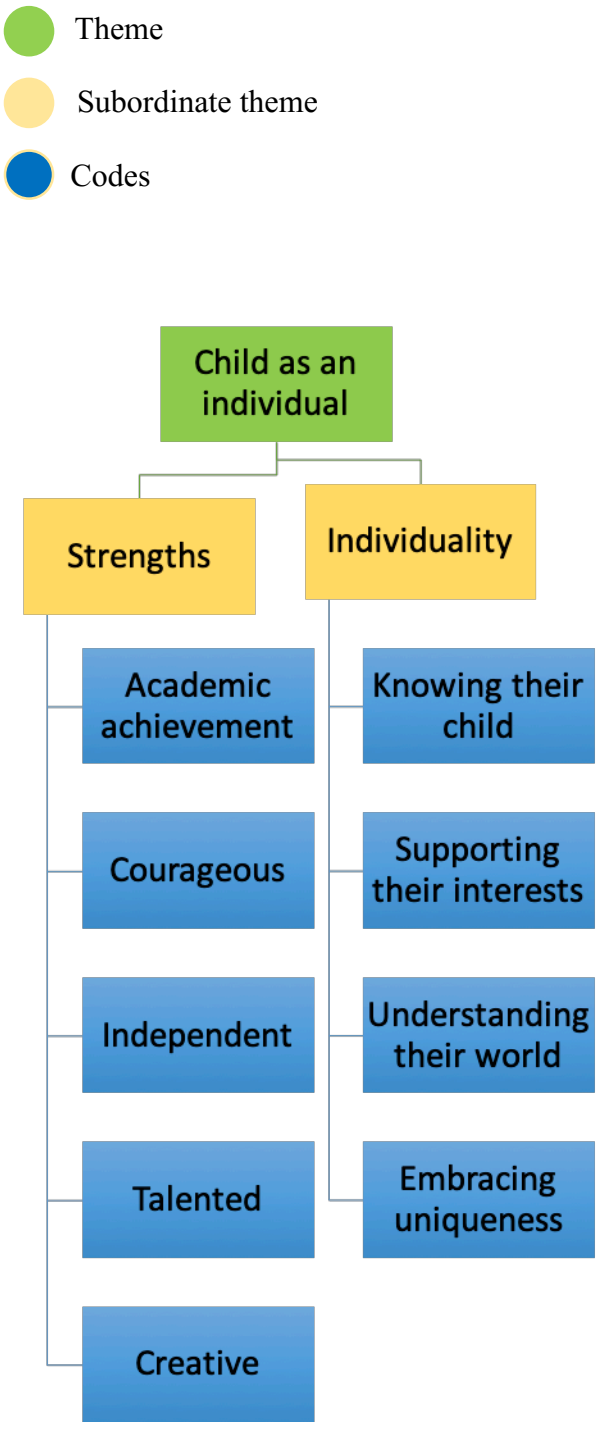
Those studied (participants):
How do they know what they know?
What shapes and has shaped their worldview?
How do they perceive me?
Why? How do I know?
How do I perceive them?

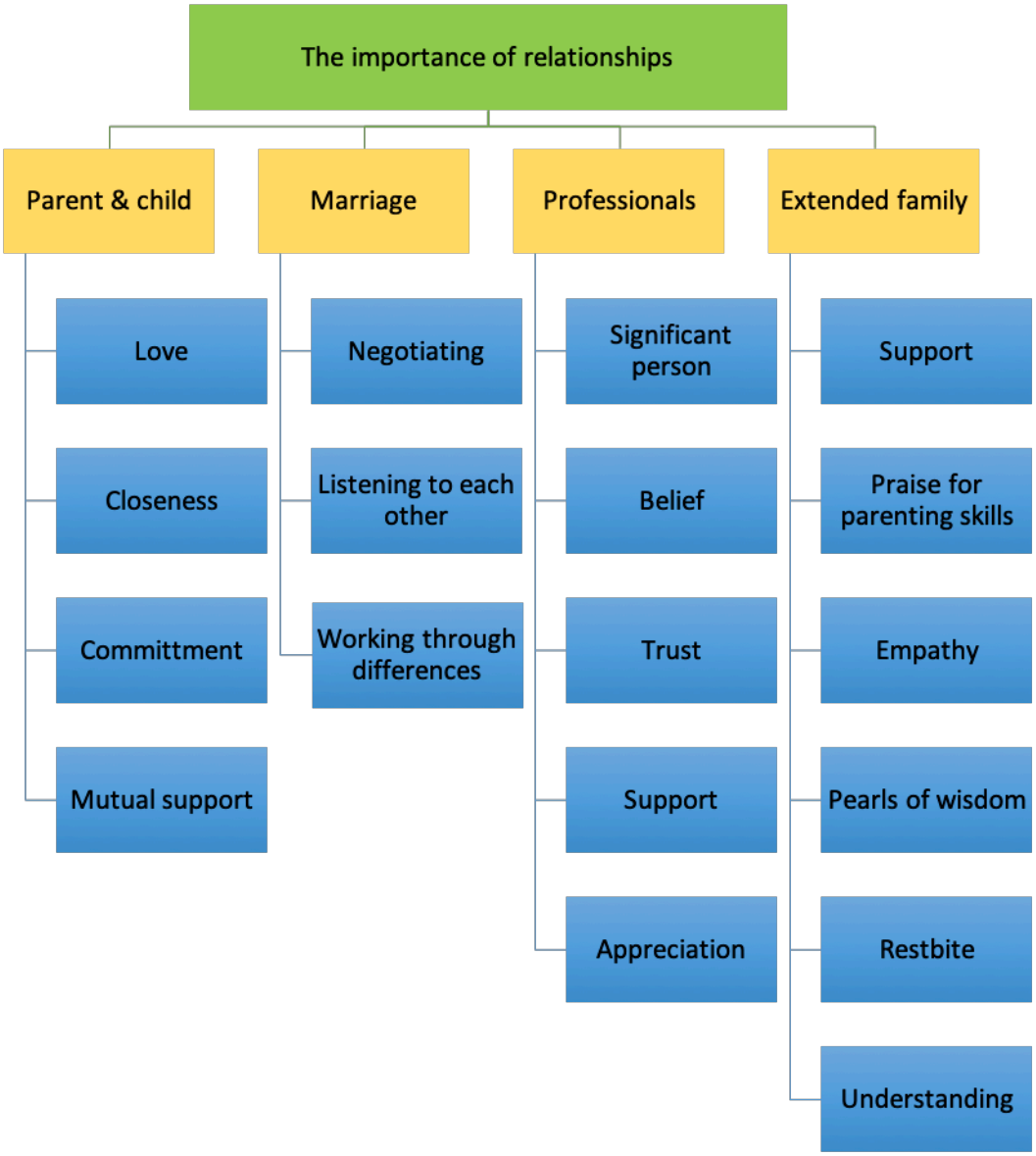
Reflexive screens:
culture, age, gender, class, social status, education, family, political praxis, language, values

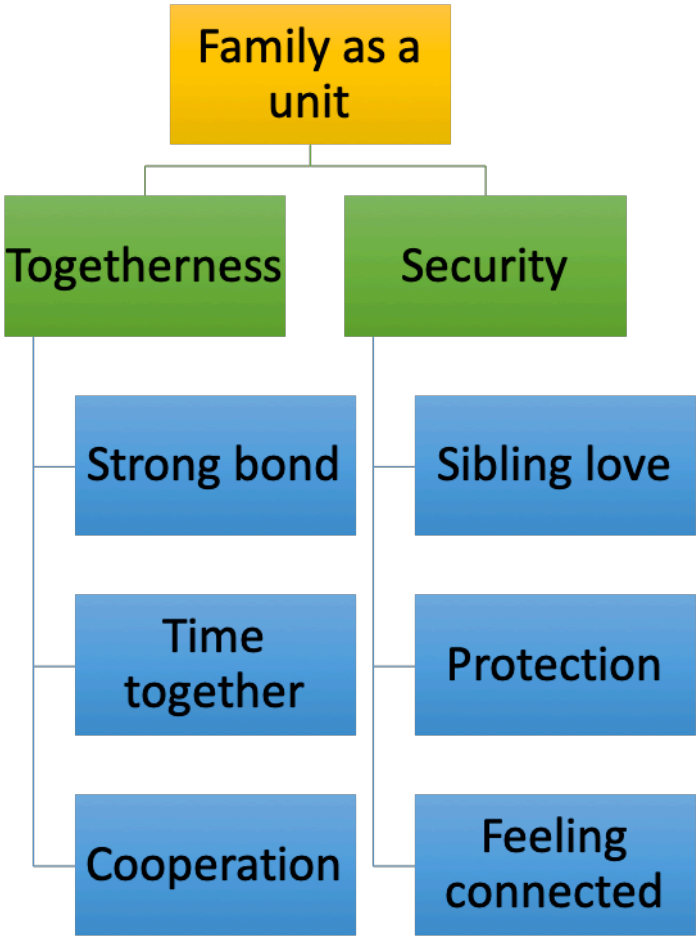
Those receiving the study (readers/audience):
How do they make sense of what I give them?
What perspectives do they bring to the findings I offer?
How do they perceive me?
How do I perceive them?

Myself (as qualitative inquirer):
What do I know?
How do I know what I know?
What shapes and has shaped by perspective?
With what voice do I share my perspective?
What do I do with what I have found?

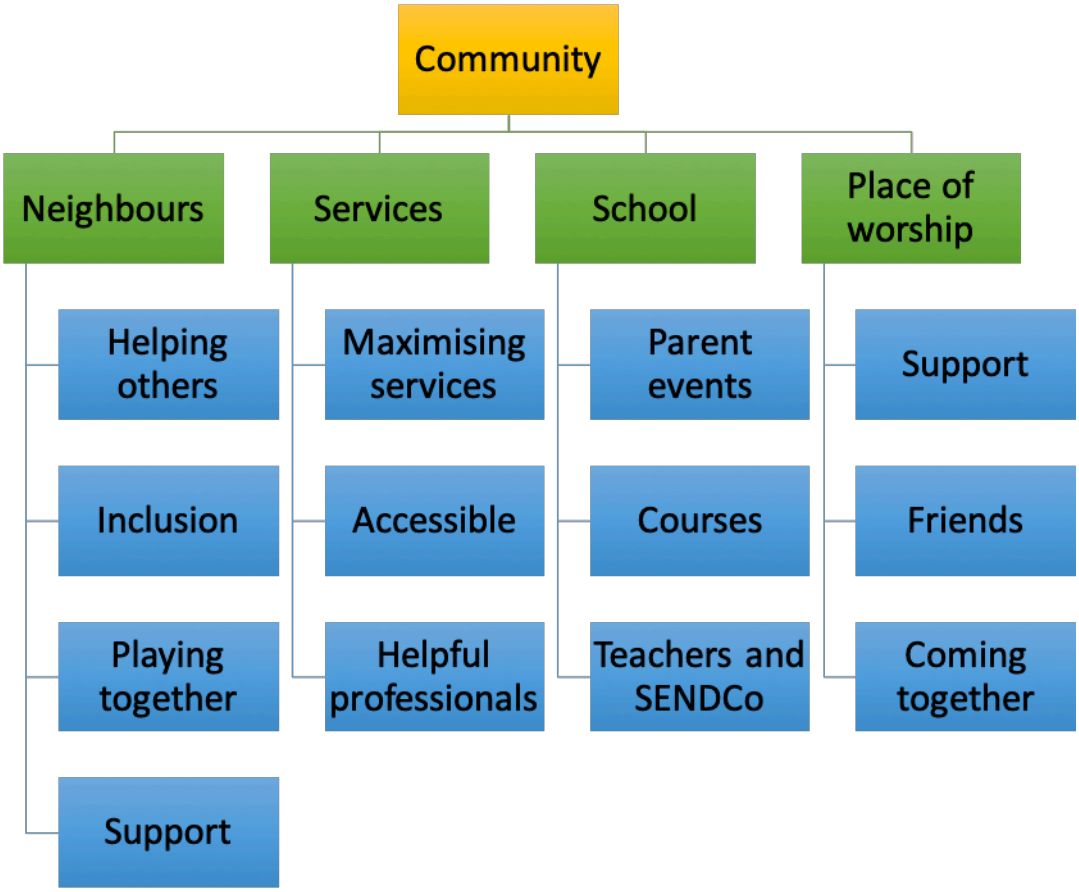
Appendix XXII – Initial Themes, Subordinate themes and Codes formed during analysis

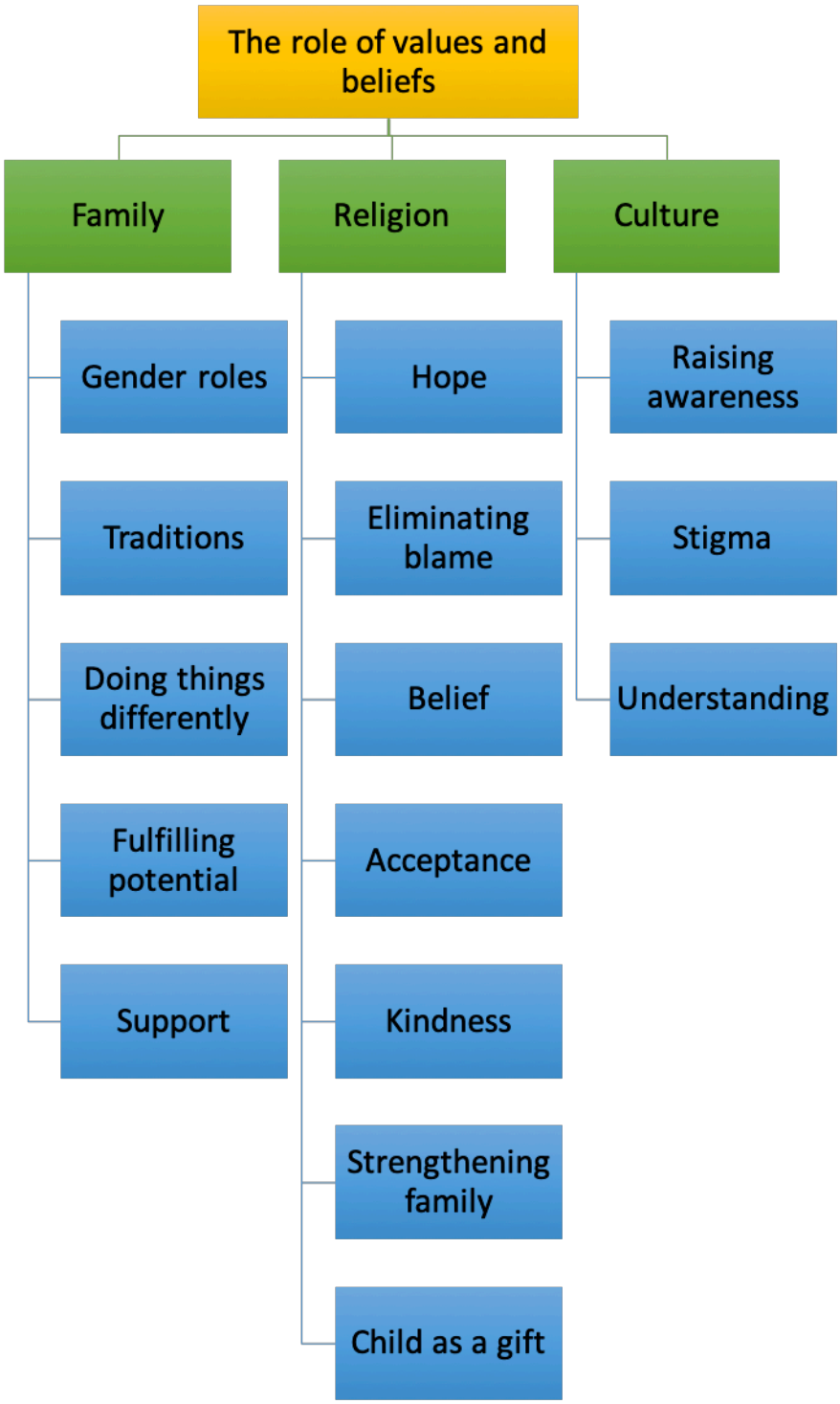


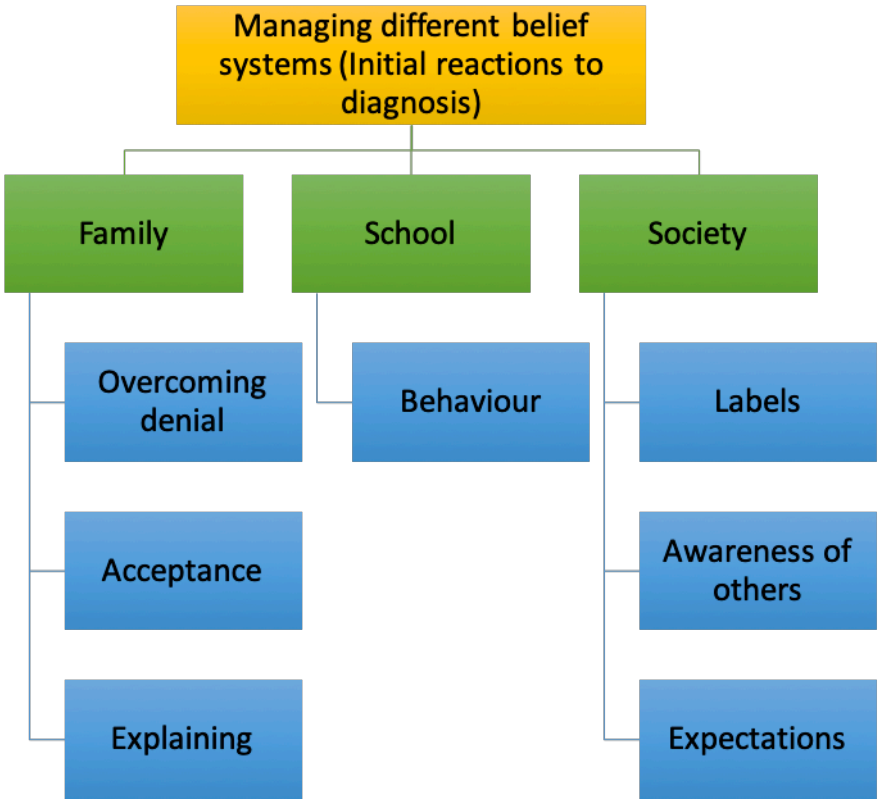

The importance of relationships
Parent & child
Marriage
Professionals
Extended family
Love
Closeness
Committment
Mutual support
Negotiating
Listening to each other
Working through differences
Significant person
Belief
Trust
Support
Appreciation
Support
Praise for parenting skills
Empathy
Pearls of wisdom
Restbite
Understanding

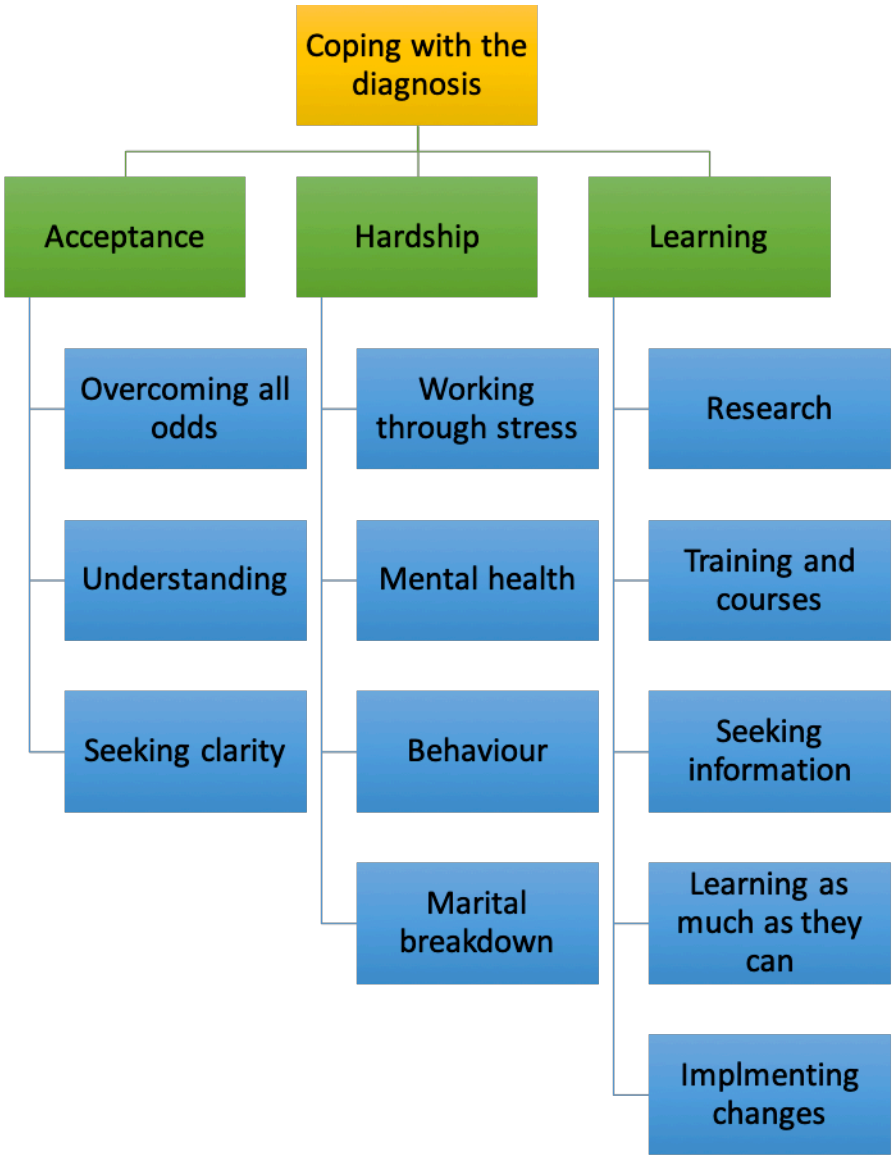

Family as a unit
Togetherness
Security
Strong bond
Time together
Cooperation
Sibling love
Protection
Feeling connected

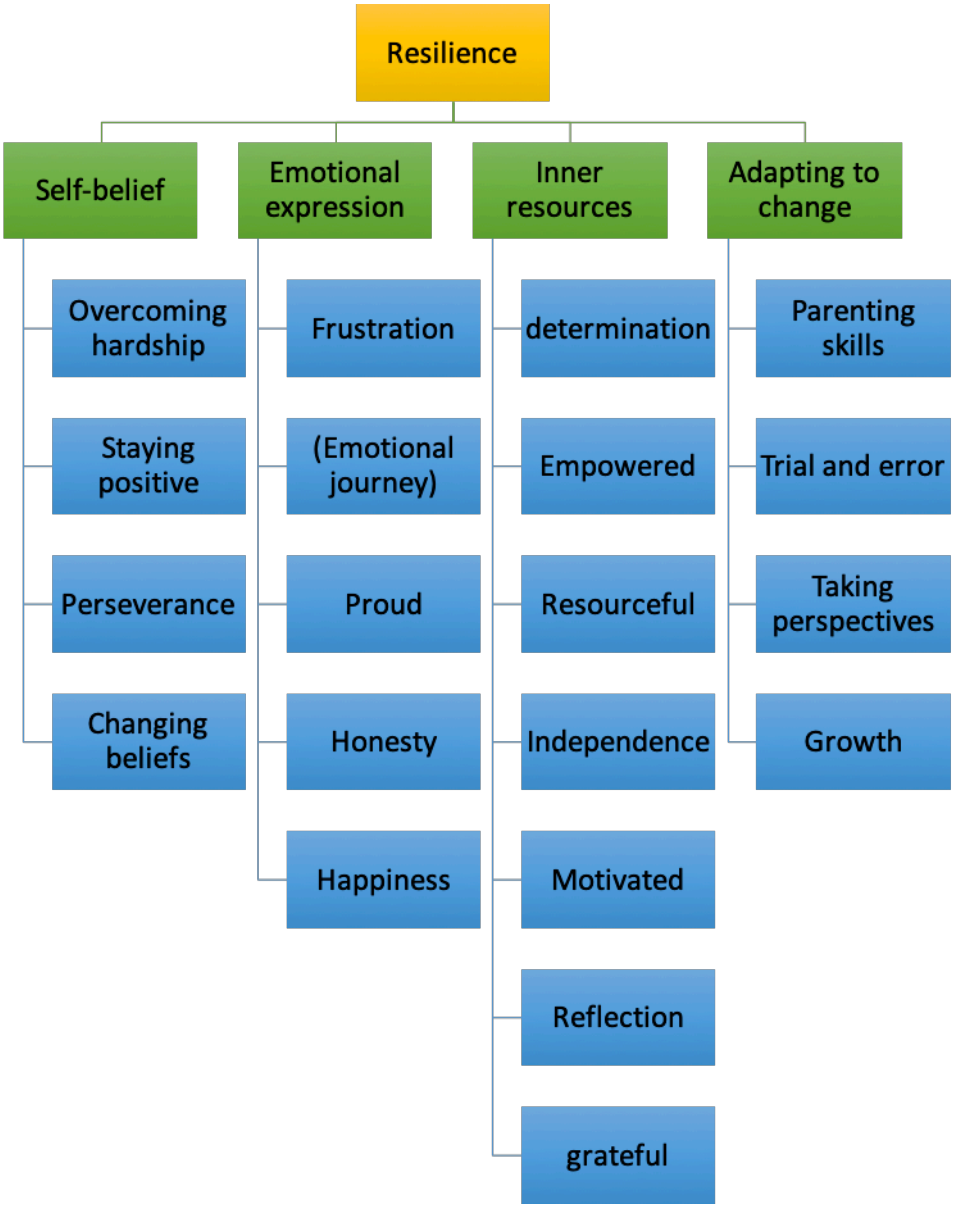
Communication
With their child
With other parents/friends
With professionals
With family
Mutual understanding
Listening to their perspective
Having conversations
Explaining
Sharing stories
Asking for help
Listening to each other
Seeking comfort
Sharing experiences
Support
Clarifying Information
Collaboration
Being open
Appreciation
Trust
Explaining things
Being open
Asking for help
Work towards shared understandig
Regularily

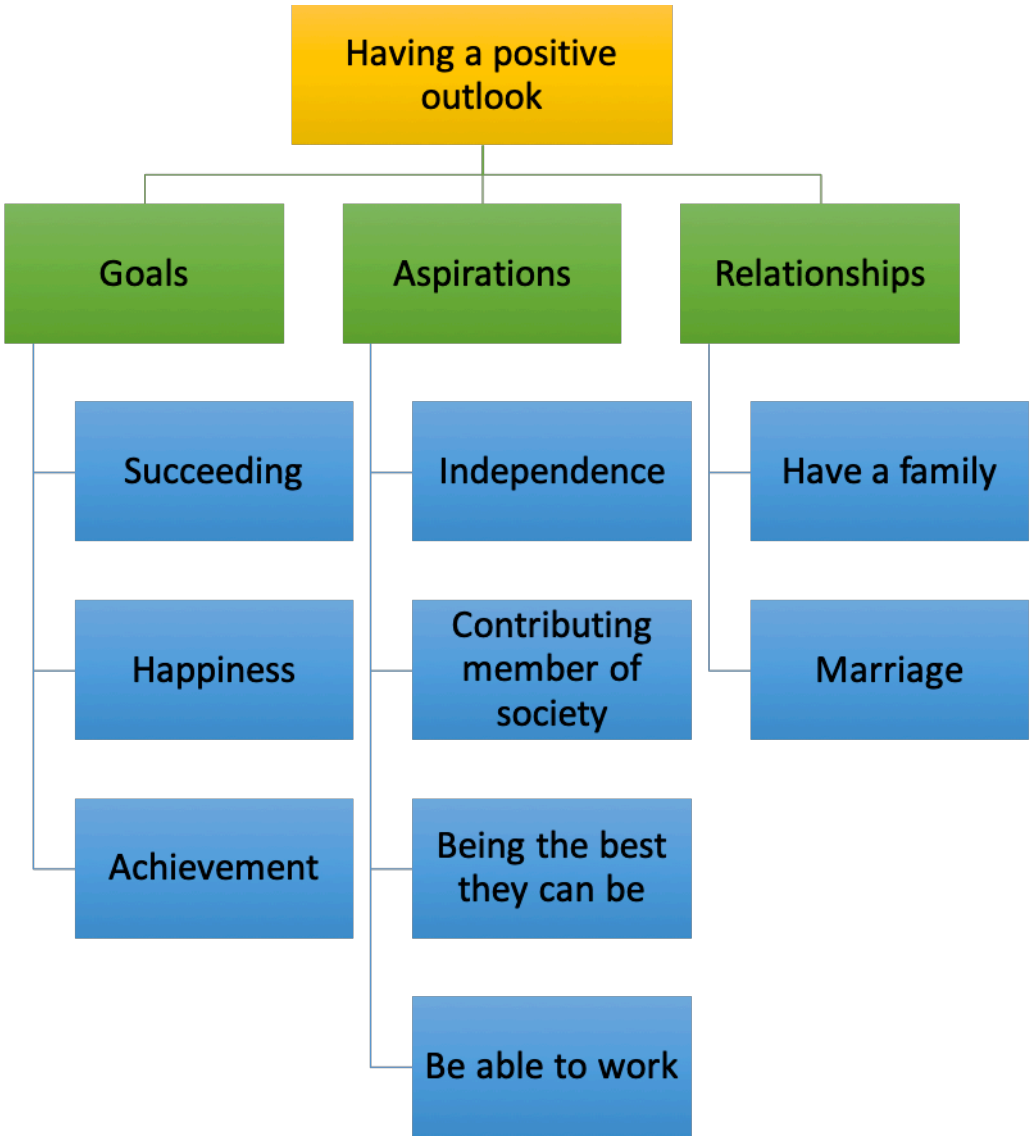

Community
Neighbours
Services
School
Place of worship
Helping others
Inclusion
Playing together
Support
Maximising services
Accessible
Helpful professionals
Parent events
Courses
Teachers and SENDCo
Support
Friends
Coming together


The role of values and beliefs
Family
Religion
Culture
Gender roles
Traditions
Doing things differently
Fulfilling potential
Support
Hope
Eliminating blame
Belief
Acceptance
Kindness
Strengthening family
Child as a gift
Raising awareness
Stigma
Understanding


Managing different belief systems (Initial reactions to diagnosis)
Family
School
Society
Overcoming denial
Acceptance
Explaining
Behaviour
Labels
Awareness of others
Expectations


Coping with the diagnosis
Acceptance
Hardship
Learning
Overcoming all odds
Understanding
Seeking clarity
Working through stress
Mental health
Behaviour
Marital breakdown
Research
Training and courses
Seeking information
Learning as much as they can
Implmenting changes


Resilience
Self-belief
Emotional expression
Inner resources
Adapting to change
Overcoming hardship
Staying positive
Perseverance
Changing beliefs
Frustration
(Emotional journey)
Proud
Honesty
Happiness
determination
Empowered
Resourceful
Independence
Motivated
Reflection
grateful
Parenting skills
Trial and error
Taking perspectives
Growth


Having a positive outlook
Goals
Aspirations
Relationships
Succeeding
Happiness
Achievement
Independence
Contributing member of society
Being the best they can be
Be able to work
Have a family
Marriage

Appendix XXIII - Transcript Example with Analysis of Codes and Subordinate Themes

Transcript	Subordinate themes	Code
R: so the first thing is could you tell me about your children?		
ED: um I've got 4 children, I have twin girls they are 19 and Sm who is 16 and then AA. yeah the twin girls they were diagnosed with autism when they are about 4, 4 and half and Sm was about 2y yeah and it's been...		
R: what kind go strengths do they have and like doing?		
ED: Sm is very, he likes music and, he's a very organised person, he likes things to be in a certain place, a certain routine yeah, you see he always on there. He set in his routine. Er one of the twins, both have autism, one of the twins L, she's very quiet she doesn't mix with people, she is into herself she doesn't like to communicate with others. And the other one K, she is more verbal and she likes verbal, she sings, all of them like music, she sings	Individuality Strengths	Knowing their child Achievement
R: ah that's really nice, and then what kind of difficulties have they have or find hard?		

ED: K, one of the twins as 19y, she finds it hard to dissociate with other people, for example if people are just shouting, nothing to do with her, she has anger that she can't control or even if you are scolding somebody, she cannot dissociate with herself, she just takes it on. She doesn't like being silly and she doesn't understand why and get angry. L us a very, certain things have to be in a certain place, she doesn't like touching messy things, even water the feeling of things touching her - that's one of her difficulties. And she's not verbal, like one sentence, not much. and Sm, he's very verbal now but he's big and tall and doesn't know much about his personal space, so which is beginning to be difficult because he is 16 now and he's not this little boy anymore so you know, tend to go to people and not knowing when to stop can be difficult, so basically that's one of the issues		Knowing their child
R: yeah thank you, er the next few questions are about your background and culture, what is your cultural background?		
ED: in terms if er, we are Cameroonian. I came here as a student and I ended up staying and having the children but they were all born here. the twins were born early at 28 weeks, so we even thought for them they had to stay 4 months in hospital and Sm was a week late but after L was diagnosed. But yes, we are from African but we are born again Christians		
R: what kind of religious beliefs do you have, just Christianity?		
ED: yeah we have Christianity, we believe it wasn't always like that but for the past 12 years we believe in God, and our whole life has turned around from that belief that faith, we strongly strongly believe in that	Religion	Belief
R: and how do you think that has influenced your family?		

ED: oh a lot, a lot. Like I said, it was not always like that, but when I found God, it was 2005, S was 4 and the girls were 6y and I was running into kind of depression because you know, having 3 children with autism but like I said, I found God or more like he found me and err, I begin to believe that He is, that I am not a bad mother, that it is not because of something. One thing for sure, coming from Africa they have family, in laws, it is an African cultural thing that if something is wrong with your children, probably the woman, so having all that so at that time, I did not have the residency so it was all, I was kind of depressed already but then I found God and began to believe that all is not lost and believe there is hope. But even if there was not, it was not the end of life you know, yeah so this is how and why we started going to church and Bible study, reading the words, so yeah that's why it happened. and then I begin to go to church meeting and every meeting with my children and they I began to read the Word to them and believe. It was that hope that I had that made me, bit by bit I began to see them, they were encouraged to sing and join the choice even though not talking. Bit by bit, I began to see change until today	Religion Community Hardship (mental well-being)	Belief Acceptance Strengthening family Support Hope
R: so findings strength for God and the church		

ED: yes yes, and the community because it was it wasn't easy to find people that who accept the children but I found a community who were able to. So Sm was going everywhere and there was no problem and I found something that helped me and um because I believe that this is how I see things now. Back then, it was not like that. Now the way I see things is like ok, because of the fear I've had with God and the children and everything, now I realise my children are ok! They have autism, they don't know it, the problem is not with them the problem is with me. The problem is with the outside who do not know how to deal with them but he is very happy even when he comes and bump into somebody, it is you who might have the problem, he doesn't know. So I had to come to that realisation about myself that there is no point being depressed, because the child is not sick, I mean he doesn't even know what the GP is you know so. But it took me time, and now I know it.	Place of worship	Support Coming together
R: that's great yeah, and you mentioned briefly about how autism is viewed in Africa, so how it is viewed?		
ED: now days, now people have heard more but before it was a taboo, they will say you have given birth to a mad child or something like that. It was a taboo, either witchcraft or something we have done, bad karma thing like that you know	Culture	
R: what do you think has helped get rid of that a little bit?		
ED: God, for me. God and the bible helped me to see that um... there was a bible passage I had to read which was telling me that it was not parents fault that the child was sick, nor the child's fault, God just let it happen and therefore it is glory. And since I got that passage, that message, it was the way out for me. That was my way out	Religion	Hope Belief
R: yeah amazing and when your first child diagnosed at the time, how was it explained?		

ED: the thing is, it did not sink that much and they were twins born early, and been in and out of hospital for a while, so for me it was not terrible because it was for me I've never seen a child born at 28 weeks, yet alone two so they were very tiny and 4months in hospital with oxygen and heart problems and all that, so for me like this delay was part of it all, for me was not I was not distressed because they did not say autism until later as delays here and there. I had appointment with the neurosurgeon every year so it was like consequences of being born so early. But it was with Sm, the pregnancy was fine, I began to see ok there is a problem. But by then I already had diagnosis for the other one. But it was just, for him Sm it just sunk like 'wow'.		
R: yeah and so how did your family feel when Sm came?		
ED: at the beginning everything was fine but after that when he was diagnosed. My own family has been supportive, actually they are and that is the other thing - my family are very supportive, they just embrace these children so they were over to go on holiday with them. They are in France, like every little break the children with go there, my brother sister and Mum and they embrace it and been very good	Family connectedness	Closeness
R: and in terms of when Sm came along, and you found to very difficult, what other ways did your own beliefs help you overcome it? when you were feeling depressed before, obviously you saw strength in God, were there any person beliefs from your family that helped you?	Hardships Religion / Family	Mental health Hope

ED: er, my Mum my Mum was very positive. I will talk about family, my Mum, they have been very positive and very supportive. For them, it was like just the fact that they have a child was good enough (laughs), I think with that help it was very helpful my brother and sister and I'm the big sister and they were treating them like their own children. They were very supportive	Family	Support
R: and then after you received the multiple diagnosis, did you change anything in the home environment, physical and the way you are with them?		
ED: you know when you do things and you don't even realise! it is just that because from that little time with the twins and to Sm, we have been in a routine with the children so I did not even realise anything. As a mother, it was not like I had a child before, so I just did that routine feeding them. I did not know any different, the only thing I did different physically is when they were starting to look for a bigger house because I could understand that now they are not independent as much so need to give them more space, not socialising much so need more room at home to play, looking for somewhere with a garden, So we had to move again to get a bigger property for the girls even to teach them things		
R: ok yeah, and how do you think the relationship with your children has stronger if it has?		

ED: yeah it has because, phew, my relationship with them is very strong as I've been with them from day 1, they see me as er... not as God that's for sure (laugh), but they are very dependent. Even if the Dad calls, because we are not together anymore, the Dad comes before they go they come and ask if I'm ok for them to go. They see me as you know... we depend on each other. We have a very close relationship; we are very close. I find myself when they are in school, I find myself, they go to special school, I can't work as have to be there for them, I find myself being idol when they are not around. Even when I clean the house, I won't be able to do it but as soon as they come in, I find a lot of energy and find myself doing a lot of things	Family	Gender roles Closeness Mutual support
R: so they lift you up		
ED: exactly, even to come here. for me, when they are around like holiday time. Some parents find it stressful but for me, when I have all of them I am ok! We complement each other	Family connectedness	Mutual support and respect
R: ahh yeah that's really nice as well especially with the four siblings that must be quite nice		
ED: I mean its only one of them with autism who is quiet so doesn't really talk to us but that doesn't matter (laugh) but you know because they are getting older they are beginning to fight a lot but still		
R: and the next question is what has contributed to your family being that close?		

ED: for me it is... I would say God because we have time of fellowship in the sense where we sit together and we sing and read the words and I ask each one of them to give something to pray about something, and then I will talk to them and share whether they understand or don't understand you know. We sit at home a lot and go out a lot, go and eat outside and go on holiday, so we tend to make life and do fun things	Religion Family connectedness	Understanding Belief
R: doing fun things yeah, and what about um like church - do you go every weekend?		
ED: we go every time, we go Wednesday, Friday, sometimes everyday as its not far from the house. Like I say it is how I am lifted up and to the point that now because where I go to church is a charity as well, now I am opening a support group where I have other parents who have children with autism. They don't have to join the church but I am just helping them, for example in schooling, some of them coming to depressed. I went to speak at (local organisation) with LO and she said come and speak to those mothers because you are very positive. And I told her I am positive today because of this and that, I am trying to help the mothers, whether administrative or not. I mean it is early days, but 'I've come to the point where like I've said, I am ready to give out what I have to other people. I have come to point where I am not stressed anymore yeah so I have helped another mother, her son is in school now and even the school as even so surprised that she managed to get a plan and she told them I know somebody to go on the internet and find what I need, because the information is there it's when you don't have or know. especially with ethnic minorities, they don't look you see, so that's one of my strengths, I do a lot of research. and because I was it was the children situation that made me stay at home because I had a Masters and um because of the children I had to stay at home. But four years ago Id decided to go back to school and do a counting ACCA, not because I wanted to be an accountant, If I do then fine, but for me it was just that at the end of the day, life is not over. the children are so happy, they live their own like so I cannot be depressed. even for them to tell them	Goals Inner resources Self-belief	Succeeding Empowered Resourceful Reflection Perseverance Changing beliefs

that even if you have been delayed for these years, it is never too late. I was 42 when I decided to go back to university.		
R: yes even my Mum still does courses!		
ED: yeah and to teach them that you can sit down and be reading. It is only with the last child I am trying to learn the curriculum but with the others because they are with special needs it is a bit different		
R: I see yeah, and then um, I guess in terms of making decisions around school or when they were younger, who helped you make those decisions?		
ED: umm I would say that, I did. I made the decisions. I did not know much, but LO (local organisation) helped me a lot. I found a lot of favours for her, she was an EP and at the time she got involved around the time when I was doing the statement and establish it so she was coming round more than she needed to. She was there and we had a speech therapist as well. It was when she was coming to do the assessment for the girls, both of them were there one day and then noticed Sm's behaviour and she know and after they she helped with the arrangements for him. But I would say, even at an early age, because I have not struggled a lot in terms of placement or where to do. because they were born early, they were on the system already. So whenever I go to hospital appointments, if I have any worries about diet or anything, the consultant will call colleague. Even for education the consultation would just call somebody, because I did not have to wait a long time	Professional support	Trust
R: yes, because they are on the system and professionals can help.		

ED: exactly and I did not have to wait. Even when they were two, they had portage and toy library and they try to stimulate the child at a younger age, I had the privilege to be able to attend all that because of the situation that they were on the system since they were born so it was very helpful, which is why I am able to help others because I have been going through all that. Nowadays it is very difficult to get the EHCP Plan		
R: yes and there is a lot of information even as professionals hard to figure out. And in terms of your brothers and sisters, how did they feel after Sm was diagnosed?		
ED: they didn't tell me how they felt but the only thing that I know is that I don't think the Dad was ok. he will not say, but er he was not very much involved, I mean I can say it now its ok (laughs), he was umm, I don't know whether he was dealing with it in his own way but that the problem with African people, it is the woman who has to deal with that situation and that's when I was going into my depression. When I found God, I began to believe again. My family, I don't know how they felt but they were always there and supportive	Gender roles Culture	
R: mm and this bit is about community, what does community mean to you?		
ED: the people in the community? Well for me honestly, today I would tell you that the community is people that I see every day and the people I see every day is my church group. The children they go to choir and we have a lot of social activities and now I do this thing for the parents. the church community and the neighbourhood is what I call community.	Community	Neighbours
R: and that is important. what about support available in your community? you have the church and have you accessed other support services?		

ED: yes, that's liked extended from the community. Yes there are different charities. I was blessed because Sm, I had to fight for him to go to special needs school. for the girls they went to mainstream school and had the help, but for Sm mainstream was not for him. It was a fight you know had to go through the council and at one point, I even took him off school. He was not going for month but finally they agreed for try out. So whenever the plan was coming, annual review, when I had to put the choice down for me there was only one choice. when he was in special needs school I had some people who came from the school and the council and made a list of things available in the community. at that time, I was still new to autism, so I used to go to a lot of support groups like Early Bird, I used to go to a lot but not I don't. At those support groups, there is info about charities that offer help so I had to apply to a lot of them, teaching me how to drive or even holidays with the children, so that was kind of community too.	Community	School Services Courses Place of worship
R: and now looking back at those things you accessed, how do you think it has got you to where you are today?		

ED: oh yes definitely, because those support groups are very helpful. I stopped going because sometimes parents were so negative, they don't mean to be, but thing is I had something plus which was God and that was helping me to hope for better future. so did not want to focus on what my child was doing and that's when I stopped going. at the end it was focussing on him doing this and that, for me I want to know that he can focus on something a minor thing. I took him to a consultation he is retired and I used to do every year for 10 years. he used to tell me, you know academic is not important. If your child knows how to wash plates build a company, he was very supportive, he was an Englishman and very supportive and for me it was focussing on social capabilities of the child, if the child can sweep and focus on that more, don't get down because the child cannot do English - so he has helped me a lot. But looking back, I would still go and do those support groups because they helped, you can get things that you do not see. you can get it. Those support groups are very important, there are loads and loads of information, that if you don't attend you don't see. Especially being part of ethnic minority like I said, not being ashamed to tell others. there is a lady I see recently, my heart was broken, I never know but her son is the same age as my daughter so I saw her when I went to my daughter's school, at parents evening, because although they are sin mainstream school, they have a special needs section. So I saw her but your daughter too as special needs? How come all these years you did not say? She said she was in denial... 19 years! imagine 19 years!	Professionals	Parent support Reflection
R: wow, yes and I guess it is the journey that every parent goes on ups and downs		

ED: exactly and 19 years, she said it is just now that I can accepting it. But this is what I want to have for the support group, for parents you know the earlier you accept it, the better not just for the child. Me personally, I believe that if you are ok your head, then the child is ok. If I am depressed, then there is no hope for my children. But if I am not depressed and ok and I believe I can go out and leave the twins, but if I am down there is nothing. but support groups, as I say, talking about it, especially minority, exposing the problem that it is not your fault. And a lot of marriages break down, especially in ethnic minorities because it's not something that the mother would talk about publicly. So she takes every accusation on top of their child's problems, can get you very down	Hardship Culture	Marital breakdown Stigma / understanding
R: yeah and I guess that how slowly how you can seek different things to build yourself up again		
ED: yes for me the thing that has helped me to build myself up was the support group. Then, it came to the point where the support group was not helpful		
R: yeah because you got what you needed already		

ED: exactly, I was like "is that all is that the end?" and that's when I found God, and from then it has been up and up because for me God is so big you can never get everything so there is always something. every year there is something new you can get from Him. Even for me, even in the hospital because with my children what helped me was that I tried to be very positive. I'm not from here I'm from Cameroon my family is in France, but for me, I'm like I am in London, I may as well use what I have in the U.K. I might as well depend on NHS completely, I cannot be thinking in France it is better cos I'm not in France. So that's what is helping me, believing that ok we are in the UK, the school in the UK has to be good for them and that's how we can function	Resilience	
R: yeah, making the most of what is around you		
ED: exactly, that's how we function		
R: and the last two I guess, so what do you think helps your family thrive and be happy?		
ED: god (laughs) definitely God, yes definitely. because now it's just me and my children, I've been separated for like six years but I am just happier and happier. for me basically it is God, it is God and I can see in God there is so much possibilities.		Being happy
R: yeah and that leads into - what hope do you have in the future for them?		

ED: ohh I mean, it is difficult to explain it to somebody but me I believe because I have God, I pray and receive things for my children. For me I see, my dream, I see a centre where they he helping parents, children, not only with autism but any sort of challenges they might have. I may even see my children working in that centre and then me doing the accounting, which is very hard. In a way it's just to tell the parents that you know, after all this, your life is not over. I mean I stayed at home for 17 years but I can still go to school, I can still achieve something and the only thing that made me to do that was God, it is not even the children even as much as I love them, they have their own life. Even with the girls, I ask what do you want to do? they say I want to sing and do this. it is a bit difficult to let them go as well (laughs) but I have hope. For me, I see him tomorrow being married, have children and working somewhere	Positive outlook Aspirations	Contributing member of society Being able to work Succeeding
R: and a lot of young people do, the autistic school I work for, they have a little cafe and some of the students work there		
ED: the beauty is that because we are here, there is opportunities you know. my consultant was telling me you know Bill Gates is autistic and look where he ended up, it's a matter of looking at what he can do and pushing him	Positive outlook	Belief
R: thank you so much so that's me and it's amazing to hear and journey you've been through		

ED: I mean don't get me wrong, it has not been easy, it is not that it is very rosy every day. I mean there are evenings where you sit and cry or get upset because it's a struggle you understanding. This is a relaxing time but then you have to do all these things. But you cry, you go to bed, you wake up and it's another day! because it is that they do not do to intentionally, they are children they do not realise, so it makes me forget it very quickly. It's different from a child who realises or doing it on purpose. So it makes me appreciate the little things, for example the girls are 19 and have friends with teen boys and girls and I see the headache. you know, everyone has their own challenge but I am grateful - I have developed a grateful heart, that's my strength, I just developed it and learned to love people no matter what, It is not easy it is painful sometimes and you get that abuse sometimes but what can you do	Resilience Emotional expression	Perseverance Determination Appreciation Growth
R: and that's the things the resilience, it's about how you pick yourself up		
ED: I mean in a week you can have one bad day or two sometimes but you have to pick yourself up and try again. After all this, after the twins and Sm and autism and I was depressed and when I found God I become stronger and more confident and confident enough to get pregnant, because the fear has gone, I was fearful that I was going to have another and then she came (youngest) and that's it no autism	Perseverance (resilience) Adapting to change	Strength Reflection Belief Emotional journey