An exploration of the experience of Bangladeshi parents of children who have been diagnosed with an Autistic Spectrum Disorder

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ABSTRACT

There is a dearth of research on the experience of South Asian parents with a child with a diagnosis of an Autistic Spectrum Disorder (ASD). Studies have demonstrated that services fail to meet the needs of this population to the same standard as their 'white' counterparts. This is further complicated by the challenge of translating the western concept of ASD to this population where there is no word for ASD in some Asian languages and translations include derogatory words such as 'deformity' 'dumb' or 'fool'. This qualitative study explored the experiences of Bangladeshi parents who had a child with a diagnosis of an ASD. It aimed to explore their subjective experiences of the assessment, diagnostic and intervention process. It also aimed to explore their understanding of ASD from a cultural perspective and to see how this impacted their understanding of their own child's difficulties.

Two fathers and seven mothers with a child with an ASD participated in semi-structured interviews. Data collection and analysis was guided by Interpretative Phenomenological Analysis.

The analysis revealed the importance of the role of culture in participants' understanding of ASD ('The role of culture') which showed it could be a help and/or a hindrance for these families. Participants also described their experience from first noticing that their child was different to receiving a diagnosis of an ASD ('From intuition to diagnosis'). The adjustment to their child's diagnosis featured a great deal in the parents' talk of their experiences ('Process of adjustment to ASD diagnosis) and this varied for parents at different points in time. This seemed to be guided by their ability to cope at these different times ('Coping'). Their religious faith, family and friends provided parents with a great deal of support but they themselves also demonstrated tremendous perseverance, determination and strength in the face of adversity.

The findings are discussed in relation to other research in this area. Recommendations are made for how services and their staff can improve the support they offer these families.

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[1] Hereafter culture will not to be underlined but it can be taken that this thesis is referring to specific culture (small c) versus Culture (big C).

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The parents who agreed to give up their time and participate in this study, your stories moved me deeply.

1. INTRODUCTION

This chapter will outline the literature relevant to this thesis which has investigated the experience of Bangladeshi parents of children with an Autistic Spectrum Disorder (ASD) with a particular focus on how their cultural background impacts their experience. This is the first research study to the author's knowledge in this area. The focus of this chapter will be on the current context of ASD including theories, models, aetiology, policy, assessment and diagnosis in the UK, whilst also considering the historical context. Attention is also paid to cross cultural research, in particular in relation to South Asian[2] families who have a child with a diagnosis of an ASD. It will also consider parental adaptation and coping to the diagnosis, as well as critical appraisals of the mainstream psychiatric literature.

1.1 Literature Search Strategy

To identify the literature around the experience of South Asian and Bangladeshi families who have a child with a diagnosis of an ASD computerised databases were searched (e.g. Medline, PsychINFO, OVID) as well as internet search engines (e.g. Google Scholar). Search items included "autism", "autistic spectrum disorders" and "parent". These in turn were combined with "experience", "South Asian", "Bangladeshi", "culture", "assessment" as well as "family" and "support". A range of both quantitative and qualitative research was identified. These articles were checked for references to previous relevant research. International research was included however papers not published in the English language were not.

1.2 Historical Perspective

The German word autismus was coined by the Swiss psychiatrist Bleuler (famous for his work in the area of 'schizophrenia') in 1911 where he first used the word to describe idiosyncratic, self-centred thinking that led to withdrawal into a private fantasy world (Goldstein, Naglieri & Ozonoff, 2008). In 1943 Leo Kanner

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[2] South Asian is used to refer to people originating from India, Pakistan and Bangladesh. The researcher is unaware of any research that focuses solely on Bangladeshi families living in the UK with a child with a diagnosis of an ASD. The small body of research in this area tends to have broader inclusion criteria where participants are South Asian.

introduced the modern concept of autism[3] where he described a pattern of behaviour he observed in a small group of young children which he termed 'early infantile autism'. He hypothesised that autism was distinct from 'schizophrenia' and represented a failure of development rather than a regression. One year later, Asperger wrote about another behavioural pattern in older children and adolescents, which although different in its details appeared to agree overall with Kanner's accounts (Wing, 1997).

Until the 1970's, autism was considered a form of 'schizophrenia', where in the first and second editions of the Diagnostic and Statistical Manual (DSM) published by the American Psychiatric Association (APA), (1952, 1968) only the term 'childhood schizophrenia' was available to describe children with autism. Autism was first included in the DSM III (APA, 1980) where it was called 'infantile autism' (Goldstein et al., 2008).

1.3 Theories of ASD Aetiology

It is still the case today that diagnoses of ASD lack a unifying theory (Goldstein, et al., 2008). Early theories about the causes of autism were focused on inadequate parenting which resulted in behavioural and emotional difficulties in the child. Bettleheim (1967) argued that unemotional, cold and inadequate parenting led to autistic withdrawal of the child. The recommended treatment of choice was long term non-directive psychodynamic psychotherapy which focused on helping children deal with the presumed central emotional difficulty and provided a substitute parent-child relationship which would meet the warmth and acceptance needs of the child.

Carr (2006) suggests that currently theories of autism fall into three broad categories[4]: 'psychogenic' where psychosocial processes are central in the aetiology of autism, 'biogenic' where theories focus on biological factors as the basis for the condition and 'cognitive' theories which are not concerned with identifying the primary cause of autism but with explaining the patterning of symptoms of specific underlying cognitive deficits.

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[3] The author acknowledges widespread critique of the concept of 'autism' and will elaborate on this below.
[4] Carr (2006) provides a comprehensive review of the literature on the aetiology of ASD.

1.4 ASD Today

1.4.1 Current Context

Today in mainstream psychiatric literature ASD is classed as a 'neurodevelopmental disorder in the category of pervasive developmental disorders' (PDD) (Levy, Mandell & Schultz, 2009, p. 1627). In the DSM-IV-Text Revision[5] (APA, 2000) 'Autistic Disorder' is defined by onset prior to three years and the presence of deficits or unusual behaviours within three domains: reciprocal social interaction, communication, and restricted, repetitive interests and behaviours. ASD is understood to be along a spectrum, along which individuals experience varying degrees of difficulty in these areas. The term ASD is used to include autism, 'Asperger's syndrome' and PDDs not otherwise specified (Levy et al., 2009). Wing (1988) famously characterised ASD within three areas of impairment, social communication, social understanding, and imagination.

Recent surveys suggest that the rate for all PPDs is around 60 per 10,000 (Fombonne, 2003). Some research has challenged the claim of universality of autism among different ethnic groups reporting a low incidence of autism in several Latin American countries (e.g. Peru, Argentina, Brazil and Venezuela) as well as some developing countries (Kenya and India) (Sanua, 1981a, 1981b & 1984). Approximately 60 to 70 per cent of children worldwide who have a diagnosis of autism also have a diagnosis of 'Intellectual disability'[6] (Fombonne, 2003). The greatest risk factor for ASD is being male whereby ASD is diagnosed about four times more often in boys than girls.

1.4.2 Assessment and Diagnosis of ASD

As described above there is currently no single aetiology demonstrated for ASD and the number of children being diagnosed with an ASD is increasing steadily (Fombonne, 2003). Mansell and Morris (2004) noted that the first stage prior to a diagnosis of an ASD is the period of time when parents begin to notice behavioural signs. Howlin and Moore (1997) in their national survey in the UK

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[5] See Appendix I for the full diagnostic criteria for ASD in the DSM- IV-TR and ICD-10.
[6] The construct of 'Intellectual Disability' itself has received a great deal of criticism; for a detailed critique see Rapley (2004).

suggested that this period lasted on average four years but ranged from one year to more than ten years. Additionally Midence and O'Neil (1999) highlighted that this period is often characterised by feelings of self-blame and severe stresses on family relationships. Furthermore parental satisfaction with the final diagnosis appears to be negatively correlated with how long they have had to wait (Howlin & Moore, 1997).

A diagnosis of an ASD is made based on descriptions and observations of behaviour (Lord & Bishop, 2010). According to Baird, Cass and Slonims 'the purpose of assessment is to confirm the diagnosis, seek an underlying cause, assess strengths and weaknesses in the child and associated developmental and mental health impairments (comorbidities), assess family needs, and identify the resources to meet their needs' (2003, p. 491). The National Autism Plan for Children in the UK (NAPC, 2003) provides national frameworks for professionals to help provide a consistent and timely multidisciplinary and multiagency approach to the identification, assessment, and intervention for pre-school and primary aged children. Their guidelines highlight that the process from initial referral to diagnosis should occur within 30 weeks (Dover & Le Couteur, 2007).

1.4.3 Recent Developments in Health Services and Policy in the UK towards Minority Ethnic Groups

This section will start by outlining general developments in the UK followed by a focus on minority ethnic groups. Due to the emphasis of this research on Bangladeshi families research with South Asian participants will be highlighted.

Following the publication of Every Child Matters (DfES, 2003) and Every Child Matters: Change for Children (HM Government, 2004) there has been an increased focus on services provided to families of children with special needs. The NAPC made the recommendation that families of children with autism should have an allocated worker to support the family and provide information (2003). Moreover the Department of Health recently published a guide on autism focusing on recognition, referral and diagnosis of children and young people on the autism spectrum (NICE, 2011).

In 2005 the National Autistic Society (NAS) devised guidelines for the experiences of minority ethnic families. In the guidelines it was noted that ASD is not well understood within minority communities, resulting in the child and their family not receiving the full range of services that they are entitled to. It underlines the need for service providers to have a basic understanding and training in the cultural needs of the established minority communities. They distinguish that it is equally important not to stereotype service delivery on the basis of ethnic background, that the user should be listened to and services matched accordingly.

In another study Hatton, Akram, Shah, Robertson and Emerson (2003) explored the lives of South Asian families in the UK with a child with severe disabilities and highlighted three current policy initiatives which are relevant to them: The National Carers Strategy; The Quality Protects Initiative; and Valuing People. Furthermore in July 2011 a report was collated by the UK Faculty of the Psychiatry of Learning Disability looking at minority ethnic communities and specialist learning disability services. They found that understanding and respect for different family structures is vital. They added that the involvement of the extended family including non-blood relatives may be seen as a collective social responsibility in some communities especially those from South Asia. They highlight the importance of having a culturally competent workforce in these services that allows flexibility to adapt to the knowledge of communities and willingness to learn from them. Moreover they suggest that it needs to be integrated both at the organisational level as well as the individual practitioner level.

1.4.4 The Sharing of the Diagnosis
Woolley, Stein, Forres and Baum (1989) suggest that the way in which a diagnosis is conveyed can have a long-term impact on parental attitudes, on families' levels of acceptance and stress as well as on general coping ability. In particular they found that being told the diagnosis directly, early, sympathetically and privately was important. Other research also points towards an earlier diagnosis reducing parental distress (Quine & Pahl, 1987) yet diagnosis in the UK before the age of three years is still rare (Baren-Cohen et al., 1996). Milner,

Bungay, Jellinek and Hall (1996) not only found that the quality of news breaking and counselling following a diagnosis of disability was important to families but that it also had an impact on subsequent ability to work effectively with the child. Hatton et al. (2003) also note that South Asian parents whose child was being assessed for a learning disability reported that the disclosure process had a huge impact on their understanding of the child's condition and consequently of their child. Moreover parental accounts of their experiences of diagnosis and intervention of ASD in the UK suggest there is continued dissatisfaction (Howlin & Moore, 1997).

Parents have also reported a lack of support provided from services following the ASD diagnostic process such as lack of information and counselling following a diagnosis (Mansell & Morris, 2004). Dobson, Upadhaya, McNeil, Venkateswaran, and Gilderdale (2001) emphasize that the complexity and interaction of the cognitive, social and communicative difficulties associated with ASD make it difficult to explain in a short and concise way. They go on to add that most information available is in English and is white ethnocentric in its design. Furthermore Hatton et al. (2003) noted that few services met the language cultural and religious needs of South Asian families.

1.4.5 Critique
The author acknowledges critique around ASD and is in agreement with Smukler (2005) and Molloy and Vasil (2002) who argue that 'Autism' and 'Asperger Syndrome' are socially constructed. However the author also recognises that at present in both educational settings and in the NHS in order to receive support and interventions a diagnosis is often required. The ethical issues surrounding this will be explored further in the Discussion chapter on page 91.

The conceptualization of ASD has been criticised, in particular the assumption that ASD is a unitary deficiency resulting from one core disability which has a scientific basis (Molloy &Vasil). Several problems have been highlighted with this assumption. Firstly people with labels of ASD describe their experience as individual and diverse. Additionally, Wing's triad of impairment (1988) which is regularly associated with ASD, has been criticised as communication and social

interaction require more than one person and therefore difficulties in these areas should be located between individuals as opposed to within them. The deficit approach is also dehumanising and Smukler (2005) suggests that in order to go beyond deficit models of autism it is necessary to devise a new definition that is not so much based on behaviour but on experience.

Smukler (2005) adds that Theory of Mind (ToM) models of autism are inadequate because they fail to consider what 'autistic' people think and feel. He continues to suggest that the theory is, in effect, 'mindblind' with regard to 'autistic' perspectives. He notes that to avoid enacting the very deficit attributed to their 'autistic' subjects, autism researchers would do well to seek out stories that have been, for the most part, conspicuously absent from autism research: the stories told by people with a diagnosis of autism themselves. Smukler (2005) writes that 'ultimately, the question of who has the privilege to define autism or any category of human difference—is not a scientific, but a philosophical and political one' (p. 25).

Duffy and Dorner (2011) suggest that an explanation for such an interest in autism both from a popular culture perspective and in scientific literature is its status as an essentially narrative condition. 'That is, despite numerous and ongoing efforts to identify and locate a "biological marker" for autism spectrum disorders, autism yet remains symptomatic, diagnosed through the subjective observations of behaviour and affect. This means that diagnoses of autism are essentially storytelling in character, narratives that seek to explain contrasts between the normal and the abnormal, sameness and difference, thesis and antithesis' (Duffy & Dorner, 2011, p.201).

Moreover diagnostic labels such as those present in the DSM-IV-TR (APA, 2000) have been heavily criticised for their 'medical naturalism' which assumes that psychiatric nosology proceeds incrementally with a confidence that there exists a real and invariant external world of natural disease and entities (Hoff, 1995). A number of critics have contended that the lack of clear signs in psychiatry renders all of its functional diagnoses as problematic or mythological (Boyle, 1990; Ingleby, 1981; Pilgrim & Bentall, 1999; Szasz, 1961). Rapley (2004) highlights

that 'the everyday psy (as opposed to medical) use of the term 'symptom' is roughly synonymous with medical term 'sign' (p. 43). He continues to note that 'symptom' in everyday English is immediately hearable as an unequivocal indication of the presence of disease. It is notable that in western cultures most ASD research is funded based on the presence of symptoms (Charman& Clare, 2004) and thus the concept that differences in behaviour which are described as ASD are attributable to diagnosable illness could be considered a construct of ethnocentric thinking about these differences.

Molloy and Vasil (2002) also argue that the medical model approach to developmental disorders is largely counterproductive as once children are labelled they tend to be defined by their diagnosis thereby losing their individuality and limiting other people's expectation of them. Moreover there is a risk that once the diagnostic label is attached all the child's characteristics are filtered through this explanatory mechanism viewing behaviours often as symptoms. Additionally when taking a diagnostic perspective the source of disability is firmly located within the individual and not as a result of the expectations of the social context in which the individual exists (Molloy & Vasil, 2002). Oliver (1990) has written extensively around the social model of disability and has made the distinction between individual and social models of disability challenging the medical model's view that disability is caused by physical entities and 'posits disability as an interpretation of physical differences by discourses invested by social and political power' (Molloy & Vasil, 2002, p. 662).

1.5 Culture and Cross Cultural Perspectives
McHoul (2004) highlights that the noun culture can be used as a mass (big C Culture) or a count noun (small c culture). He adds that if one asks questions about culture (such as what is culture?) whilst referring to it as a count noun one is assuming that it is an 'essence of a thing' (p. 7). He proposes that an answer to such a question is not providing a definition in the form of an analytic proposition but a fragment of historically-specific information in the form of a synthetic proposition. McHoul (2004) also brings attention to Schütz (1962) who distinguishes between first and second order constructs. In this sense McHoul (2004) suggests that if culture is cultural it is necessarily a second order

interpretation in that it has 'interpreted itself before any investigator comes on the scene' (p. 11). He argues that it is the job of anyone investigating culture to interpret the interpretations that people have already made themselves.

McHoul and Rapley (2000) note that where human beings are concerned (as opposed to atoms, planets or cyclones) the investigator is always investigating second order matters, they come pre-interpreted. McHoul (2004) adds that it is 'a fundamental category mistake, then, to treat humanly produced things as 'natural' data; they are not data (givens) but capta (takens) and that one cannot examine second order constructs in the same way as first order constructs' (p.12-13). Moreover McHoul states that 'what we are analysing professionally has already been analysed by those (laypersons, members) whose domain we are (as analysts) already trespassing on (2004, p. 13). Additionally he notes that we can't 'claim to be a member-analysts or participant-observers' (p. 14) by confusing this distinction.

Jonathon Smith, the founder of the methodology of choice in this study describes the 'double hermeneutic' (Smith & Osborn, 2003) in IPA and links this to second-order meaning making. Smith et al. (2009) note that the double hermeneutic suggests that the researcher is making sense of the participant making sense of x. Smith et al. (2009) highlight that this illustrates the dual role of the researcher as both like and unlike the participant. They add that in one sense the researcher is a human being trying to make sense of the world whilst on the other hand clearly highlighting that the researcher is not the participant as he/she only has access to the participants' experience through what they report about it, and this is also seen through the researcher's own, experientially informed lens. Smith et al. (2009) go on to explain that they are suggesting that 'the participant's meaning making is first order while the researcher's sense making is second-order' (p. 36). Smith's double hermeneutic and McHoul's second order interpretations seem to be similar. However McHoul would argue that second order interpretations are a weakness and suggests that they may give rise to political theory. He notes that one should stay at a descriptive level in research making sure that you describe with humility what other people have already interpreted otherwise you are repeating the bad practice of interpreting. On the other hand Smith regards the

double hermeneutic as the central tenet of his theory and does not view this as an obstacle to research.

There are several studies which have demonstrated <u>culture</u> at a more specific level. Jegatheesan et al. (2010a & 2010b) in their qualitative study of three South Asian families in the USA take the view of culture from a specific level referring to culture as a count noun (for other examples see Alexander, 2011; Mandell, Novak & Zubritsky, 2005). The current study will follow in this tradition.

1.5.1 Examples of Cross <u>cultural</u>[7] Research
Due to the emphasis of this research study this section will take a South Asian focus.

Dyches, Wilder, Sudweeks, Obiakor, and Algozzine (2004) stressed that little research exists regarding family adaptation to children being diagnosed with autism specifically, and that most research on the topic emanates from western perspectives. Jegatheesan, Fowler, and Miller state that 'research in the last two decades has contributed significantly to our understanding of ASD, however the research remains limited to western perspectives on autism as pathology' (p. 798, 2010a). Moreover Keen, Reid and Arnone (2010) found a significant association between maternal immigration and the risk of having a child diagnosed with an ASD.

Daley and Sigman (2002) looked at the diagnostic conceptualization of autism among Indian psychiatrists, psychologists and paediatricians. They highlight that beliefs about the cause will often affect models of treatment in autism. They also draw attention to the fact there has been a paucity of studies on diagnostic beliefs and practices of diagnosis in developing countries, adding that little is known about diagnostic procedures in China and India which make up 35 percent of the world's population. Daley and Sigman (2002) reflect that the results hint at ways in which the concept of autism among Indian professionals may be unique. They give the example of the belief that extended families have an ameliorative effect

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[7] Hereafter culture will not to be underlined but it can be taken that this thesis is referring to specific culture (small c) versus Culture (big C).

on childhood problems and that people in India may be more tolerant of differences in their children. Kishore and Basu in their 2011 study in India aimed to understand the early indicators of autism as perceived by Indian mothers. They found that the time lapse between early recognition and diagnosis was much higher than compared to the West. They added that this was in part due to the paucity of resources but also due to other factors such as beliefs that the child would be alright once grown up or a long decision-making process involving a large number of elders in the family. For a South Asian parent living within a western host culture this may create a 'cultural conflict' (Greenfield, Quiroz, & Raeff, 1998) in terms of the understanding of their child's ASD diagnosis.

Trembath, Balandin and Rossi (2005) in their review of the literature emphasised that despite an increasing awareness of the needs of children diagnosed with an ASD, little is known about the impact of different cultural backgrounds and linguistic diversity on interventions. Mandell, Novak and Zubritsky (2005) suggest that treatment decisions of their carers are likely to be influenced by their cultural background. They add that the meaning that parents attach to their children's symptoms and associated beliefs about their symptoms' causes must be understood within the context of parental culture. The use of complementary and alternative medicine among different groups may also suggest important cultural differences in treatment decisions (Levy, Mandell, Merhar, Ittenbach & Pinto-Martin, 2003).

Parental interactions and expectations are also likely to be influenced by differing culturally bound child-rearing practices. This may not only influence the role that parents expect professionals to take but also the role they are prepared to fulfil themselves (Hwa-Froelich & Vigil, 2004). It is frequently suggested that a reason for service under-utilisation by ethnic minorities is that they have differential beliefs about the causes of mental health problems which in turn may lead to help-seeking which may not involve mainstream health services (Yeh, Hough, McCabe, Lau, & Garland, 2004). Moreover Jegatheesan, Miller and Fowler (2010b) in their study of parental beliefs of South Asian families with a child with an ASD underline that if the values underlying the professional practices are

inconsistent with a family's belief then the practices will be rejected as well as other advice and services.

1.5.2 Alternative Conceptions of Diagnostic Labels

Pilgrim and Bentall (1999) highlight that the problem of psychiatric diagnostic inappropriateness can be understood by looking at cross-cultural studies of affect. They add that different societies using different languages use a wide but variable range of words to describe emotional states. They use the term 'depression' to explore this further and give the example that in the Indian sub-continent misery is often expressed through client reports of a fallen or painful heart. Western psychiatrists then claim that these patients are 'really' suffering from depression and they are mistakenly locating their grief behind their sternum. Kleinman (1980) has also suggested that the way in which people experience distress varies across cultures and at different times, within the same culture.

Moreover low attendance from Bangladeshi populations living within a majority 'western' culture has been reported in children's specialist mental health services (Gillam, Jarman, White & Law, 1989; Stern, Cottrell, & Holmes, 1990) and this has been attributed to somatization of emotional difficulties (Parvin, Jones & Hull, 2004), as well as to the population's perception of the causes of unwanted behaviour in children, that unwanted behaviour in children is due to badness, physical illness, or the activity of spirits (Stern et al., 1990). Additionally a study which looked at health beliefs and folk models of diabetes in British Bangladeshis found that illness was generally attributed to events or agents outside of the body rather than to primary failure of an organ within it (Greenhalgh, Helman & Chowdhury, 1998).

Studies have demonstrated that disability and the views and beliefs around caring for a disabled family member can vary greatly. In African American culture care-giving for a disabled member of a family is seen as a responsibility to be shared among siblings and extended family members (Pruchno, Patrick, & Burant, 1997). Similarly when Latino mothers of children with severe disabilities believe in their spiritual role as 'sacrificing' they tend to take it upon themselves to raise their families with little organizational support (Skinner, Bailey, Correa &

Rodriguez, 1999). Ellenberger (1968) noted that children who were identified as having many of the same traits as autism in Senegal were known as 'Nit-ku-bon' or 'marvellous children'.

Moreover Groce (1999) highlights that there is a marked variation in how cultures interpret disability. He noted that the lives of individuals with disabilities around the world are usually far more limited by prevailing social, cultural and economic constraints than by the specific physical, sensory, psychological or intellectual impairments. Ingstad and Whyte (1995) emphasise that disability in Euro-America exists within, and is created by a framework of state, legal, economic and biomedical institutions. In non Euro-American countries where this kind of institutional infrastructure only exists to a limited degree, disability as a concept and an identity is not an explicit cultural construct. They go on to note that the 'the meaning of impairment must be understood in terms of cosmology and values and purposes of social life' (p. 10).

1.5.3 The Role of Culture and Acculturation

This section takes a very general perspective whereas section 1.5.4 will focus on the South Asian and Bangladeshi population in the UK.

MacLachlan in his book on culture and health highlights that the term culture has been so widely used that its precise meaning varies from one situation to another (2006). Trompenaars states that 'the term culture refers to groups who share similar norms and assumptions, usually unquestioningly' (p. 21, 2002). MacLachlan emphasises that the pragmatic role of culture is especially pertinent to health. He notes that culture provides a means of communication with those around us and that different styles of communication reflect the customary habits of people from different cultures. A culture which prohibits communication has no way of passing on its 'shared customs' (2006). Judy Ryde writes about being white in the Helping Professions and highlights that 'the focus in the professions is often on a description of 'other' cultures with a baseline of the white, western culture as the norm. Focusing on differences in this way lies at the heart of a

great deal of frustration that black[8] people feel in relation to white people' (p. 112, 2009).

Falicov, who has written extensively about culture, acculturation and immigrants in the USA describes that many immigrants around the world today, more than ever are able to keep up their emotional ties with families and countries through technological advances. She continues to add that 'many immigrant families are challenged by unsettling gender and generation dilemmas that come about through the exposure of family members to the new culture. Many of these dilemmas could be seen as tensions between tradition and modernity' (p. 163, 2007). Acculturation refers to the process of transition that is brought about by the meeting of people's from two cultures. Berry (1997) has researched a framework that considers to what extent a newcomer modifies his or her cultural identity and characteristics when coming to a new country. According to this framework a person decides whether or not to keep his or her original cultural identity and characteristics, and also whether or not to acquire the host culture's identity and characteristics. Integration between the two cultures occurs when the decision is to identify with and exhibit the characteristics of both the original culture and the new host culture.

1.5.4 Social Context: South Asian and Bangladeshi Population in the UK and London

The current study was conducted in an NHS children's disability service in the inner London Borough of Camden and presents findings from UK parents of Bangladeshi origin. The 1991 census suggests that British Bangladeshis account for about 0.3% of the population of England and Wales (Balarajan & Raleigh, 1992). Peach (2006) notes that the population of Bangladeshi Muslims in the UK is very highly concentrated with 84 % living in Inner London and 43% of the London total living in the single Borough of Tower Hamlets. Overspill has occurred into the nearby Boroughs of Newham, Hackney and Camden, but the overall pattern remains astonishingly compact (Hamnett, 2003). The 1991 census

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[8] Ryde (2009) uses the term 'black' to refer to a non-white population.

figures also showed that the Bangladeshi community constituted 6% of Camden's population, making them the largest Black and Minority Ethnic (BME) community in the borough (Balarajan & Raleigh, 1992). The Bangladeshi community is most prominently represented in four wards in the south of the borough, where they represent the following percentages of the ward population Regent's Park 14%, King's Cross 10%, Holborn and Covent Garden 8%, St Pancras and Somers Town 7% (Balarajan & Raleigh, 1992).

In addition the prevalence of a diagnosis of learning disabilities in the UK among South Asians is three times higher than in majority communities (Mir, Nocon, & Ahmad, 2001). Furthermore 19% of the South Asian families caring for family members with learning difficulties had more than one member with a learning difficulty (Mir, Nocon, & Ahmad, 2001). Moreover, Gillberg, Steffenburg, Borjesson, & Andersson (1987) found that urban children with a diagnosis of autism more often than aged-matched children in the general population had immigrant parents from countries other than neighbouring foreign countries.

1.5.5 Discrimination: Ethnicity and Disability

Research has shown that families with disabled children in the UK experience disadvantage and discrimination (Ahmad, 2000). This has contributed to the development of the concept that it is the family as a whole that is disabled by the unjust society in which it finds itself (Fazil, Bywaters, Ali, Wallace & Singh, 2002). Parents and siblings, like disabled children, are also subject to stigma, marginalisation and discrimination (Ahmad, 2000). Fazil et al., (2002) highlight that within this experience two key dimensions are central. Firstly, families with a disabled child in general face greater chances of material deprivation than families without a disabled child. Secondly, against that problematic background, they commonly experience a variety of obstacles in accessing the range of information and services which it is known would have a positive impact on their lives (Beresford, 1994). Moreover Ahmad (2000) argues that these disabling conditions constitute barriers to families with children with a disability exercising their rights and responsibilities as citizens.

Hatton et al. 2003 highlight that South Asian families compared to their White peers, experience pervasive disadvantage and discrimination in terms of housing, education, employment, physical and mental health as well as access to services, adding that Bangladeshi and Pakistani populations are particularly disadvantaged. In Camden it has been noted that although the Bangladeshi community is the largest minority group, the use of statutory community services such as CMHTs by this community is unusually low. Belliappa (1991) and Thompson (1997) showed how factors of social deprivation affected marital and family relationships, making it more difficult for them to provide support to vulnerable members of the family. Moreover Hatton et al. (2003) note that South Asian families with a person with learning disabilities also report low awareness and uptake of specialist disability services. In addition language barriers hinder parental awareness and uptake of services, and services rarely meet the language, cultural and religious needs of South Asian service users.

In their study Hatton et al. (2003) interviewed 136 South Asian parents with children with disabilities across five local authority areas in the UK. In support of other studies they found that parents reported a pattern of pervasive material disadvantage. Moreover housing was generally rated as unsuitable for the needs of the child particularly in terms of lack of space or safety issues and compared to national data, parents in this study were much more likely to report poor physical health across a wide range of physical health problems. Indices of deprivation (DLTR) show that areas in Camden such as King's Cross and Regent's Park are among the most deprived wards in the country. The Bangladeshi community in Camden and Islington specifically, is one of the most deprived BME communities, with 71% being in the bottom income bracket (Noble, Wright & Dibben, 2004). An Association of London Government report (ALG, 2000) also shows that as well as being among the most deprived communities in London the Bangladeshi communities' economic and housing problems all add to stress levels within Bangladeshi families in Camden.

Experiences of and awareness of racism appear to be central to the lives of people from ethnic minorities, and there is growing evidence that these contribute to ethnic inequalities in health (Nazroo, 2003). Findings from the UK Fourth National Survey of Ethnic Minorities suggested widespread experiences of racial

harassment and discrimination among people from ethnic minorities in the United Kingdom where more than 1 in 8 respondents reported having experienced at least one incident of harassment over the preceding year (Virdee, 1990). A survey of Camden's Bangladeshi residents (Camden Equalities Unit, 1996) showed that 62% of the group surveyed felt racial harassment was a subject for concern. One in three households had suffered racial harassment and this had resulted in them making changes to their daily lives. Some 34% of those surveyed only visited the shops at certain times. Ryde (2009) suggests that racial discrimination is better understood if we do not see it as individualistic, but as a culturally determined belief system which is 'woven into the fabric of society and is therefore manifest in the attitudes and assumptions of individuals' (p. 18). The terms 'institutional' or 'cultural' racism are terms in current usage which suggest that racism is entrenched within institutions or within society. Institutional racism was famously brought to public attention in the Macpherson Report (1999) on the murder of Stephen Lawrence.

Ryde (2009) suggests that institutional racism is as prevalent in the helping professions as it is in the police force. Additionally, feelings of under-representation in society may be reinforced by the low representation of BME communities in the health professions. Workforce data from the Camden and Islington Community NHS Trust show that 0.75% of the staff is classified as Bangladeshi, whereas the Camden Bangladeshi population (aged 18 to 64) is estimated to be 4%. Moreover Bangladeshi people are amongst the worst housed in London, with high levels of overcrowding, sharing of facilities, lack of basic amenities and children living above ground level (London Research Centre, 2000). In addition, Bangladeshi children have considerable levels of under-achievement in schools, which is compounded by the their lower levels of fluency in English, as compared with other more established ethnic minority communities (Home Office, 1986).

1.5.6 Research with South Asian Parents with a Child with an ASD
Warner (1999) found that the influence of parents' Bangladeshi background was most noticeable in their feelings about the child's disability. She noted that two of the mothers she interviewed indicated a sense of being blamed for having a

disabled child and another talked about seeking help from a religious person (pir) in Bangladesh. According to Warner, the responses of parents of the two children diagnosed with autism indicated that they did not understand the meaning of a diagnosis of autism and they had difficulty in accepting the severity and the nature of their child's disability. Jegatheesan et al. (2010b) emphasise that Asian families' explanations of having a child with a disability are intertwined with distinct cultural and religious beliefs.

In some Asian languages there is no word for autism and words such as disorder are translated as 'deformity' in information leaflets. Dobson et al. (2001) added that at present within the NHS the information needs for people of Asian descent are not being met to an equal standard with their 'white' counterparts. They stressed the importance of developing information packages for the Asian carers of people diagnosed with an ASD.

Despite the foregoing concerns there remains a dearth of literature on the understanding of the role of culture of parents who have a child diagnosed with an ASD. An increased understanding of their experiences of diagnosis, intervention and services in general, may significantly help to improve these services.

1.6 Coping

1.6.1 Acceptance and Adaptation

Several theories and models have attempted to understand how families cope with stressful situations. Family stress theory (Hill, 1958; McCubbin & Patterson, 1982) offers a useful framework for understanding stressors that these families experience and for identifying the resources of support they utilize in order to adapt positively to those stressors. Bennett, Deluca and Allen (1995, p. 302) note that the theory 'posits that stressors and resources for dealing with stressors interact to influence appraisals of stressors (e.g. causal attributions, sense of control and mastery, and self-esteem). These factors then contribute either to a positive outcome (e.g. family adaptation) or a negative one (family crisis).' The Double ABCX model was the first multivariate model to address the family stress process and to investigate the adaptation of families of children with a diagnosis

of an ASD (Pakenham, Samios, & Sofronoff, 2005). The model includes the severity of the stressor (A), the family's internal demands (B) and the family's definition of the stressor (C) all of which interact to generate or prevent a crisis (X). Moreover Patterson's Family Adjustment and Adaptation Response (FAAR) model (1998) highlights that families engage in active processes to balance family demands with capabilities as these interact with family meanings to arrive at a level of family adjustment or adaptation.

It has been shown that the diagnosis of a child with an ASD can have a significant impact on a family. ASD, of all developmental disabilities, is thought to be one of the most challenging (Brobst, Clopton & Hendrick, 2009; Gray, 2006; Randall & Parker, 1999). In studies investigating the impact on families there has been a particular focus on the negative aspects of this experience such as stress, symptoms of low mood and difficulty in coping where coping has been defined as how one adapts to stressful situations (Taylor, 1983).

Dumas, Wolff, Fishman, and Culligan (1991) found that parents of children who had been diagnosed with an ASD usually reported higher levels of parenting stress and higher affective symptoms when compared to parents of typically developing children. Challenges faced by families may be compounded by stigmatizing reactions from extended family and the public, resulting in social isolation. Myres, Mackintosh, and Goin-Kochel (2009) found that as a result of extended families and the wider community not understanding the behavioural features of children with an ASD parents restricted their social contacts. Gray (1993; 2002) notes that a large proportion of parents of children with a diagnosis of autism felt stigmatized, particularly families of children who exhibited aggressive behaviour. The child's disruptive behaviour coupled with their normal appearance and a lack of public understanding can be burdensome and humiliating for families (Gray, 1993; Ling, Mak, & Cheng, 2010).

In contrast, Davis and Carter (2008) in their study on parenting stress in mothers and fathers suggest that many families show strength in coping and resilience in adjusting to the diagnosis of their child. Moreover, Bailey, Skinner, Rodriguez, Gut and Correa (1999) reiterate that studies on parents' responses to having a

child with a disability are based on the premise that this event leads to negative outcomes and processes. They suggest that when methods other than scales that measure depression, stress or coping are used such as open-ended interviews that allow parents to narrate their perspective, they find that parents also talk about their child's disability in a positive and meaningful way. Additionally some parents show great relief, post diagnosis, that someone has corroborated what they had initially suspected themselves and that this also allows access to the support that is needed (Howlin & Moore, 1997; Sullivan, 1997).

1.6.2 Coping from a Social Rather than an Individual Perspective

As described above having a child with a diagnosis of an ASD can place great stress on parents and their systems. Models of family adaptation, stress and coping acknowledge that the outcomes for parents of children with difficulties are often impacted by the resources which are available to them (Hill, 1958; McCubbin & Patterson, 1982). An important resource is thought to be perceived helpfulness and availability of social support (Beresford, 1994).

Social support has been correlated with improved coping for parents in a number of research studies (Dyson, 1997; Hastings & Brown, 2002). Stainton and Besser (1998) in their study of the positive impact of children with an intellectual disability on the family found that all the families included in their study related an increase in their social networks or community involvement. Most of these associations involved linking in with other families or organisations. Bristol (1987) demonstrated the effectiveness of a modified Double ABCX or FAAR model in predicting successful adaptation to having a child with a diagnosis of autism. She notes that both perceived adequacy of informal social support and coping patterns were related to healthier adaptation. Moreover mothers who had more adequate support from spouses, immediate family, extended family, and other parents reported happier marriages, and were rated by interviewers as having better family adaptation. Other studies have also described that better maternal adjustment was related to higher levels of social support in the general population (Pakenham et al., 2005), as well as specifically among Asian families (Chan, 1986).

Growing attention is being given to media as a source of social support for families. The internet is increasingly being used as a medium to study coping mechanisms for parents with children who have a diagnosis of an ASD (Fleischmann, 2005). Huws, Jones and Ingledew (2001) found in their study that parents of children with autism are using the internet to document and publish their struggles in the public domain, using it as a tool to create links with other parents in similar circumstances thus creating a virtual support group.

1.6.3 Coping from a Spiritual and Religious Perspective
This section will first provide general definitions of religion and spirituality before taking an ASD focus.

There have been a vast number of attempts to define religion and spirituality in the psychological literature over the last century (see Zinnbauer et al., 1997; Zinnbauer, Pargament & Scott 1999; Zinnbauer & Pargament, 2002). Zhang and Rusch (2005) highlight that spirituality is commonly regarded as a broader concept, an individual phenomenon and is characterized as 'personal and subjective' (Zinnbauer et al., 1997, p. 563). Zhang and Rusch (2005, p. 85) continue to add that most religions were created by the followers of a great teacher but that over time, the structure itself has become the focus as opposed to the spiritual teachings and experiences that the 'great teacher' tried to communicate. In 1966 Allport famously distinguished intrinsic religion with extrinsic religion, where the extrinsic believer "uses" religion in a strictly utilitarian sense to gain safety, social standing, or other secular or antireligious goals. In contrast, the intrinsic believer "lives" his or her religion and views faith as an ultimate value in itself (Zinnbauer & Pargament, 2005).

Weisner, Beizer, and Stolze (1991) emphasized that spirituality can help families adjust to this challenge by providing interpretations of their suffering. Tarakeshwar and Pargament (2001) noted that research has pointed to a variety of religious coping methods that serve various ends. For example Pargament, Kennell, Hathaway, Grevengoed, Newman and Jones (1988) have distinguished three different approaches to responsibility and coping in a stressful situation; 1. the self-directing approach, in which the individual relies on self rather than on

God[9], 2. the deferring approach, where the individual places the responsibility for coping on God, and 3. the collaborative coping approach, where the individual and God are both active partners in coping.

Religion is increasingly being reported as an important factor in coping in studies with children with disabilities. Skinner et al. (1999) highlighted that the theme of being a good mother to deserve a child with disabilities was salient among Latino mothers. In fact in their study 76% of Latino mothers who followed Catholic religious traditions viewed themselves as chosen by God, that God gave them this gift because they were worthy. Bennett et al. (1995) in their study investigated the role that religion could play in the lives of parents who had a child with a disability. They noted that prayer, church attendance and several specific religious beliefs were identified as sources of support.

Jegatheesan, et al. (2010b) highlight that there is growing recognition in research on children with disabilities that religious beliefs can play an important role in how individuals interpret and explain disability, as well as offering a source of coping. They comment that the dominant view in the literature around ASD provides an implicit assumption that having a child with an ASD is a profound misfortune. They note that in their ethnographic study of parental beliefs in South Asian immigrant families in the USA that the participants' Muslim faith stressed the child's full inclusion in every aspect of life and called on the removal of social barriers that marginalised individuals with disabilities. They also found that religion was the primary frame within which parents understood the meaning of having a child with autism.

1.7 Current Study
1.7.1 Summary and Justification for the Study
NAS (2005) highlights that ASD is not well understood within minority communities, often resulting in the child and their family not receiving the full range of services that they are entitled to. In western cultures most ASD research is funded based on symptoms (Charman & Clare, 2004). Thus the concept that

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[9] Authors in the psychology of religion take caution when using the term God, highlighting that this is a short hand for their representation of participants' God representation (Zinnbauer & Pargament, 2005).

differences in behaviour which are described as ASD are attributable to diagnosable illness could be considered a construct of ethnocentric thinking about these differences – and this may be positively reinforced, financially. Moreover, Dyches et al. (2004) stressed that little research exists regarding family adaptation to children being diagnosed with autism, and that most research on the topic emanates from western cultural perspectives.

In South Asian communities in the UK the prevalence of a diagnosis of learning disabilities is three times higher than in majority communities (Mir et al., 2001). The NHS does not meet the needs of these families to an equal standard as their 'white' counterparts and there is no word for autism in some Asian languages (Dobson et al., 2001).

The hope for this research is to generate a detailed picture of Bangladeshi parents' experience of assessment in the NHS resulting in a diagnosis of an ASD and of their comprehension of the diagnosis taking into account their cultural background. There has been a dearth of literature exploring the role of culture in this area. An increased understanding of their experiences of assessment, diagnosis, intervention and services in general, may significantly help to improve these services. It seems that the literature provides mixed reports of the experience of families whose child has a diagnosis of a learning disability or of an ASD. However, as Bailey et al. (1999) suggest, the use of qualitative methods may provide an opportunity to get a more balanced view of their experiences, both negative and positive. Very few studies have studied this taking into account cultural context.

1.7.2 Study Aims and Research Questions

Using Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) this study will firstly explore the experiences of Bangladeshi parents of children who have recently been through a multidisciplinary assessment resulting in a diagnosis of an ASD. Secondly it will try to understand the subjective experiences of parents, to explore their understanding of the diagnosis of an ASD from their cultural background and the impact of that on the understanding of their own child's difficulties. Finally it will consider ways in which Clinical

Psychologists and other staff in health services can improve the experience of assessment and diagnosis for these families.

1.7.3 Summary

This introduction chapter examined the current and historical characteristics of ASD. Additionally it focused on experiences of parents whose children have been diagnosed with an ASD and on coping and adaptation to the diagnosis. It also summarised cross-cultural research in this area and included some critique of the dominant psychiatric view. The introduction concluded with a justification for the current study and the study aims and research questions.

2. METHODOLOGY

This chapter will provide a rationale for the choice of methodology used to address the research questions. This will be followed by a description of the chosen method, Interpretative Phenomenological Analysis (IPA) and justification for its use in this research. The main assumptions and drawbacks of IPA will then be considered followed by details of the procedure and eligibility for recruitment of participants as well as an outline of the method of data collection. Finally it will explain the procedure for the transcription and analysis of the results as well as consideration of ethical issues.

2.1 Choice of Methodology

The NHS and the Department of Health have given their support to a medicalised model of clinical work with a focus on 'evidence-based' research and practice. Over the past 40 years the randomized controlled trial, traditionally used to measure the efficacy of medication, has come to occupy a central place in the research community for all health matters, being referred to as the 'gold standard' of research methodology (Roth & Parry, 1997). However despite an emphasis being placed on quantitative methods as described above, the last decade has seen a vast increase in the commitment to and the use of qualitative research methods in the field of psychology (Smith, 2004). Additionally reviews for guidelines, such as those developed by the National Institute for Clinical Excellence are starting to be more open to qualitative methodologies (Willig & Stainton-Rogers, 2008).

Smith et al. (2009) note that a prime reason for choosing a particular qualitative approach should be because it is consistent with the epistemological position of your research question. According to Elliott, Fischer and Rennie (1999) the aim of some qualitative research is to try and get an understanding of people's experiences and actions as they encounter, live through and engage with life situations. On the other hand it has been argued that quantitative methods lend themselves to testing hypothesized relationships or causal explanations, evaluating the reliability, validity and underlying factor structure of psychological measures, and measuring generalizability across samples (Elliott, 1995).

Additionally Yardley notes that qualitative methodology in recent times has been associated with a renewed interest in culture and language and one of the main reasons for employing this methodology is a recognition that our knowledge and experience of the world cannot 'consist of an objective appraisal of some external reality, but is profoundly shaped by our subjective and cultural perspective, and by our conversations and activities' (2000 p.217).

For the purpose of this research it was important to consider the characteristics of the participant group which was to be interviewed. Although the participants in this study speak English fluently, some of the participants may have been educated abroad, such as in Bangladesh, and as a result may have some difficulties with written language and problems with literacy. Additionally the research question was not aimed at generalizing across samples but at understanding the experience of those who were interviewed. Thus it was felt that a qualitative approach that does not aim to generalise across samples or rely on written language was more appropriate for these participants.

2.2 Choice of Method

Following the decision to select a qualitative methodology, several different methods including Grounded Theory and Discourse Analysis were considered. The reasons for not selecting these methods will be considered below.

Grounded Theory generally sets out to generate a theoretical-level account of a particular phenomenon (Smith et al., 2009). Developed by sociologists (Glaser & Strauss, 1967), its approach emphasizes the theory-generative phase as opposed to the theory-verificational phase of induction (Rennie & Brewer, 1987). The aim of the current research is not to develop an overarching theory or model of the participants' experiences of having a child with a diagnosis of an ASD, but to represent a small sample of participants' views. Therefore Grounded Theory was not congruent with the research question.

Discourse Analysis is concerned with how experiences are constructed through language (Wiggins & Potter, 2008). A focus in this type of research is the language used by participants rather than the experiences they are describing.

The current research is interested in the experience of participants and their views; as such this method was discounted.

2.3 Interpretative Phenomenological Analysis[10]

IPA was selected as the qualitative methodology for this study and was initially used for research in the area of health psychology; however it has begun to attract attention in social, clinical and counselling psychology (Smith, 2004). IPA is informed by concepts and debates from three key areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography.

The phenomenological approach was founded by Husserl and further developed by Heidegger, Merleau-Ponty and Sartre. Phenomenology can be described as a philosophical approach to the study of experience where most phenomenologists are interested in what the experience of being human is *like*, in all of its variety, but specifically in terms of the things which matter to us, and which constitute our lived experiences as well as how we might come to understand what our experiences of the world are like. It is concerned with getting an 'insider's perspective' (Conrad, 1987). Husserl was particularly interested in finding a means by which someone might come to accurately know their *own* experience of a given phenomenon. For Husserl phenomenological inquiry focuses on that which is experienced in the consciousness of the individual rather than abstract statements about the nature of the world (Larkin, Watts & Clifton, 2006).

Hermeneutics is the theory of interpretation, and IPA is concerned with how a phenomenon appears, and the analyst is implicated in facilitating and making sense of this appearance. Heidegger differed from Husserl arguing against pre-suppositionless descriptive phenomenology. He suggested that the reader, analyst or listener brings their fore-conception (prior experiences, assumptions, pre-conceptions) to the encounter and cannot help but look at any new stimulus

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[10] This section will draw largely on Smith et al.'s account of IPA (2009) as it provides the most detailed and recent account of this methodology. Other accounts were also taken into consideration (Eatough & Smith, 2008; Flowers, Smith, Sheeran & Beail, 1997; Larkin, Watts & Clifton, 2006; Osborn, & Smith, 1998; Smith, Jarman & Osborn, 1999; Smith, 2003; Smith, 2004).

in the light of their own prior experience. Gadamer, another hermeneutics theorist highlighted that one may really only get to know what our preconceptions are once interpretation is underway. According to Tappan (1997, p651) hermeneutic approaches 'view the knower and the known as fundamentally interrelated, and thus assume that any interpretation necessarily involves an essential circularity of understanding – a hermeneutic circle in which the interpreter's perspective and understanding initially shape his interpretation of a given phenomenon and yet that interpretation, as it interacts with the phenomenon in question, is open to revision and elaboration, as the perspective and understanding of the interpreter, including his biases and blind spots, are revealed and evaluated'. In summary, the hermeneutic circle is concerned with the dynamic relationship between the part and the whole at a series of levels.

Finally, the third major influence on IPA is idiography, which is concerned with the particular. That is it is 'in contrast to most psychology, which is 'nomothetic' and concerned with making claims at the group or population level and with establishing laws of human behaviour' (Smith et al., 2009, p. 29).

IPA suggests that human beings are sense making and experiencing creatures and therefore accounts that participants provide will reflect their attempts to make sense of their experience. IPA aims to know in detail 'what the experience for *this* person is like and what sense *this* person is making of what is happening to them. As part of this, the study may explore in detail the similarities and differences between each case' (Smith et al., 2009, p. 3).

Several studies have used IPA to analyse data from South Asian participants to explore their experiences (Gupta, Johnstone, & Gleeson, 2007; Hatton et al., 2003; Hipwell, Turner, & Barlow, 2008; O'Toole, Ohlsen, Taylor, Purvis, Walters, Pilowsky, 2004; Purewal & Van den Akker, 2009;) as well as specifically Bangladeshi participants (Beck, Majumdar, Estcourt, Petrak & 2010).

2.3.1 Assumptions of IPA

When using IPA there are a number of assumptions upon which it is based. One of the main motivations for the choice of IPA in this research is that it fits with my

beliefs about knowledge and how people experience the world. A main assumption of IPA research is that it is interested in participants' subjective experience of the world rather than the objective 'nature' of it. IPA does not share the positivist view that the 'external world directly determines our perception of it; in fact it does not make any claims about the external world' (Willig, 2008, p. 3). This fits with my belief that there is not one single or unified objective truth, but that individuals experience events in different yet equally valid ways. Thus experiences can vary depending on meanings that events hold for them. In this sense IPA subscribes to a critical realist position (Willig, 2008).

Another assumption of IPA is that access to the experience of participants is not only dependent on what they tell us about their experience, but also on what the researcher then needs to interpret that account. Smith, et al. (2009) note that IPA is engaged in a double hermeneutic, in that the researcher is trying to make sense of the participant trying to make sense of what is happening to them. In this sense IPA analysis requires a reflexive attitude from the researcher (Willig, 2008). In IPA the 'biases' and views of the researcher are made, at least to some degree, explicit. Discussion of how I have been personally reflexive can be found below.

2.3.2 Limitations of IPA

IPA was the analytic method of choice in order to 'give voice' to the participants recruited (Reicher, 2000). However, all analytic systems have shortcomings. Willig (2008) lists several conceptual and practical limitations, drawing upon insights from the discursive rather than the experiential genre of qualitative analysis (Reicher, 2000). Each of these will be outlined below[11]. This will also be returned to in the Discussion chapter on page 97.

Explanation Versus Description

IPA focuses on perceptions, it aims to gain a better understanding of how participants perceive and experience the world from their own perceptions. It is concerned with how the world presents itself to people as they engage with it in

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[11] This section will draw largely on critique provided by Willig (2008).

particular contexts and with particular intentions. Therefore while it is able to provide rich descriptions of participants experiences this type of research does not help in the understanding of why such experiences take place and why there may be differences between individuals' phenomenological representations, it describes and documents the lived experience without explaining it. Historically this has always been the stance of IPA's creator (Smith, 1996), though more recently (2009) he has stated that it is characterised by a 'questioning' herrneneutic in addition to the more familiar 'empathic' hermeneutic. Maintaining an exclusive focus on the descriptions without considering their cause or origin will limit the understanding of phenomena. In order to understand participants' experiences well enough to explain them we need to be aware of the conditions which give rise to these experiences which may be found in past events, histories or the social and material structures within which we live our lives.

The Role of Language

Data generated in this study (and often in IPA) are text. Language is the means by which participants attempt to communicate their experiences to the researcher. There is an assumption within IPA that language provides participants with the necessary tools to capture and communicate that experience. IPA assumes the representational validity of language. Willig however argues that language constructs rather than describes reality, 'that the words we choose to describe a particular experience always construct a particular version of the experience. The same event can be described in many different ways. This means that language can never simply give expression to experience. Instead it adds meanings that reside in the words themselves and, therefore, makes direct access to someone else's experience possible.' (Willig, 2009, p. 67).Therefore an interview transcript tells us more about the way in which an individual talks about experience rather than the experience itself. Willig (2008) highlights that from this perspective, IPA does not engage sufficiently with its constitutive role.

Suitability of accounts

IPA aims to capture the experiences and meanings associated with a phenomenon rather than to identify people's opinions about it. Phenomenology as a social scientific research method relies upon participants' descriptions of their experiences and this in turn raises difficult questions and it can be argued that such descriptions are very hard to produce, particularly for participants who are not used to expressing their thoughts, feelings and perceptions in words. This therefore limits the applicability of this method.

Cognition in IPA

Smith (2009) notes that since its inception IPA has included a concern with cognition. He adds that IPA is compatible with social cognition paradigm because it subscribes to a belief in, and concern with, the chain of connection between verbal report, cognition and physical state and in this sense 'Smith's version of phenomenological method implies a Cartesian conceptualization of the individual as the owner of a set of cognitions which he or she uses to make sense of the world and to act in the world.' (Willig, 2008, p.68).Willig (2008) highlights that from this perspective, an understanding of a person's cognitive register should allow us to make sense of his or her experiences and actions. She continues to note that an emphasis on cognition is not, in fact compatible with some aspects of phenomenological thought as phenomenologists challenge the subject/object distinction implied by cognitive theory.

The present study set out with the aim of 'exploring how participants are making sense of experiences happening to them' (Smith, 2005, p.311). Therefore, the elements of critique set out above were accepted as limitations to, rather than disqualification from, using IPA.

2.4 Epistemological Position

Epistemology is a branch of philosophy concerned with the theory of knowledge and is concerned with 'how we *know* and *what* we can do' (Willig, 2008, p. 2). When conducting research it is important to adopt an epistemological position in order to be clear about the objectives of the research as well as what it is possible to find out (Willig, 2008). Epistemological positions frequently used

within qualitative psychology range from the radical relativist which subscribes to the view that there is no 'pure experience' to the naïve realist which involves the belief that the data we collect provides us with exact information about the world and how things really are (Willig, 2008). There are a range of positions in between these two extremes which include the critical realist position which both acknowledges that the data gathered may not provide access to 'reality' whilst trying to understand what is 'really' going on in the world. A critical realist position underlies this research.

2.4.1 The Researcher in Context[12]

Reflexivity requires an awareness of the researcher's contribution to the construction of meanings throughout the research process as well as an acknowledgement that one cannot remain 'outside of' one's subject matter when conducting the research (Willig, 2008). Nightingale and Cromby (1999) highlight the importance of exploring the way in which a researcher's involvement with a particular study can influence, act upon and inform such research. It is therefore important for the researcher to reflect upon the ways in which their own values, beliefs, experiences interests and political commitments have shaped the research (Willig, 2008).

Supervision from both the Consultant Clinical Psychologist in the team and academic supervisor allowed space to explore my own perspective and position. Additionally I kept a journal which was completed after each interview and throughout the study.

Having outlined the epistemological assumptions underlying the research it is important to identify which identities and experiences I approached this study with as well as my own position in relation to the research. Unlike the participants in this study I am White British and do not have children. Nor do I have experience in my personal life of someone being diagnosed with an ASD. Additionally I am from a middle class background and of further educational attainment unlike the participants interviewed.

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[12] The researcher's reflexivity will be returned to in the Discussion chapter

At the time of conducting the research I was a Trainee Clinical Psychologist in my late twenties. I was on a sixth month placement in the service where participants were recruited but I had no contact therapeutically with the participants who were interviewed. Working in this profession and with families who had had similar experiences to those who were interviewed may have influenced my perception of participants and also their perception of me.

2.5 Participants

2.5.1 Inclusion/Exclusion

Consistent with recommendations for an IPA study, the researcher endeavoured to recruit a sample which was homogenous (Smith, et al., 2009). People that were invited to participate were Bangladeshi parents, who spoke English fluently, of children who have been diagnosed with an ASD in the last 3-18 month period. Participants who required an interpreter were excluded from the study. Participants were identified by members of the multi-disciplinary team and names were passed on to the researcher or the Consultant Clinical Psychologist within the team.

2.5.2 Using IPA with Participants for whom English is not their First Language

The majority of published research using IPA has involved English speaking adults (Smith, 2004). Being able to access participants' experiences is dependent on their ability to articulate them and ensuring participants have strong linguistic abilities could be seen as a prerequisite for research employing IPA (Smith, 2004). However, there has been an increase in studies conducted using IPA which have included participants who do not speak English as their first language (Glasscoe & Smith 2008; Shakespeare-Finch & Wickham, 2009; Coleman-Brueckheimer, Spitzer & Koffman, 2009; Splevins, Cohen, Joseph, Murray & Bowley, 2010). Smith (2004) has highlighted that when working with those who have English as an additional language it is advisable that semi-structured interviews are more structured than in other cases. Although the accounts of their experiences and the meaning that they attach to them may not be as detailed as native English speakers, they may nevertheless enable a researcher to get a closer understanding of their world view, and it would be up to the researcher to

be flexible with their communication to allow participants to give as full a response as possible (Sheppard, 2000).

The researcher considered that the potential challenges of interviewing some participants for whom English was not their native language were outweighed by the potential benefits that this research may offer. The research was conducted in an inner London borough where there is a large population of Bangladeshi families. Additionally in the service where participants were recruited some of the Bangladeshi parents were not native English speakers. It was felt important to give these parents a voice. Unfortunately there was no possibility of using interpreting services to interview parents who did not speak English fluently due to financial restrictions.

2.5.3 Participant Characteristics

Table I contains the demographic details of the participants. All of the participants lived in the London area and unless otherwise stated they lived as a married couple with their children. Out of the 8 parental couples, the parent who spoke English fluently was interviewed. All of the participants also spoke Bengali. No parents requested to be interviewed as a couple and it was felt that being interviewed as a couple may have restricted how openly participants felt they could talk. Pseudonyms for both the child and parent are given in brackets.

Table I: Demographic Details of Participants

Participant Number	Gender of child with diagnosis of an ASD	Which parent interviewed	Age at diagnosis (years)	Age at interview (years)	Number of siblings	Comments
P1	Male (Akash)	Mother (Rupa)	3	4	1	Mother born in UK, father born in Bangladesh, lives with her husband's extended family.
P2	Male (Zahir)	Mother (Kanta)	3	5	2	Mother and father born in Bangladesh, Mother been living in the UK for 15 years.
P3	Male (Kabir)	Father (Arif)	3	4	2	Father was born in Bangladesh, mother born in the UK and is deaf. Older daughter also has a diagnosis of an ASD.
P4	Male (Maruf)	Mother (Anika)	3	3	1	Mother born in the UK, married Bangladeshi man now separated and she lives alone with her two children.
P5	Male (Imran)	Mother (Sreea)	3	5	1	Mother and father both born in Bangladesh, mother has been in the UK since she was 8 years old.
P6	Female (Nahar)	Mother (Sunita)	3	3	1	Mother was born in London, father is from Bangladesh. Her daughter was diagnosed with an ASD four months before the interview took place.
P7	Female (Nishad)	Mother (Dalia)	3	5	2	Both the mother and father were born in Bangladesh but mother has been living in the UK for 16 years.
P8	Female (Priya)	Father (Hasan)	2	3	1	Father came to London when he was 6 years old. His wife was born in Bangladesh and moved here when she married. They live with all of his extended family.
P9	Male (Iqbak)	Mother (Shema)	11	11	1	Mother was born in London, father Bangladesh. They have another son who has a diagnosis of a learning disability.

2.6 Data Collection

Smith et al. (2009) note that the most common form of collecting data in IPA is by semi-structured, individual interviews with participants. This method was chosen here, as one-to-one interviews can be easily managed, allow for a rapport to be developed and give participants a space to think, speak and be heard (Smith et al., 2009). Semi-structured interviews also fit with the model of the relationship between researcher and participant described above in that the participant can in part influence the direction of the research which in turn may allow the interviewer to enter more closely into the psychological and social world of the participant (Smith et al., 2009). At the start of each interview this was explicitly encouraged by explaining that I was interested in the experience of the participants and their own views. Additionally before the end of the interview I asked them whether they wanted to add anything or whether anything had not been talked about which they had expected to be covered.

2.6.1 Recruitment

All of the participants were recruited through an inner city NHS child development and special needs team. The team offers assessments, diagnosis and treatment for children under 18. The researcher initially met with a Clinical Psychologist in the team to discuss the research idea. This was followed by meetings with team managers. The specialist health visitor in the service who makes initial contact with families who are referred to the service agreed to act as the link between the potential participants and the researcher. She made the initial contact with parents and also accompanied the researcher on all of the initial visits to introduce her to the families. It was clearly explained to them at this stage that the research was voluntary and that they did not have to take part.

All parents who met the criteria above were invited to take part in the research. A total of nine families were contacted by the service. The introductory meetings took place in the participants' homes and potential participants were given information about the study both verbally and in writing by means of the information sheet[13]. All seven of the participants who were visited agreed to

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[13] See Appendix II for Participant Information Sheet.

participate. Two other participants were not visited at home but were contacted by telephone and sent information sheets. They also agreed to participate and arrangements were then made for interviews to take place.

2.6.2 Interviews

All interviews were conducted with just the participant and the researcher in a room. Two interviews were conducted in participants' homes[14], one was conducted in a children's centre and six were conducted in rooms at the team base. Interviews were tape recorded for subsequent transcription. Interviews lasted between 45 and 100 minutes.

2.6.3 Interview Schedule

The interview schedule was developed prior to conducting the interviews[15]. Interview questions were open-ended to allow participants to talk about aspects that were salient to them. It also allowed participants to introduce new ideas. Questions were initially drawn from the literature on parental experience of a diagnosis of an ASD as well as cultural aspects of ASD. The researcher also consulted with her academic supervisor in conjunction with Clinical Psychologists and team managers about the content of the interview schedule. Additional cultural consultation took place with a South Asian colleague whose son had a diagnosis of an ASD.

To establish rapport with participants initial questions which were more general (e.g., Tell me about your child) were specifically chosen. Additionally the researcher highlighted that she was interested in both negative and positive experiences for the parents. Initial questions were open-ended deliberately to lessen researcher influence and to allow the participants to talk about a topic with as little prompting from the researcher as possible (Smith et al., 2009).

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[14] The local NHS Trust's lone worker policy was followed for interviews which took place off of NHS premises.
[15] See Appendix III for Interview Schedule.

2.7 Data Transcription and Analysis

2.7.1 Data Transcription

Participant interviews were transcribed[16] verbatim in turn. Participants were assigned a code (P1 through to P9) and any identifiable information was removed. Smith et al. (2009) highlight that IPA requires a semantic record where all the spoken words are included in a transcription. An adapted version of the Banister, Burman, Parker, Taylor and Tindall (1994) format was used.

2.7.2 Analysis

In order to understand the content and complexity of the meanings of the respondents it is important to engage in an interpretative relationship with the transcript. These meanings must be obtained through a sustained engagement with the text and a process of interpretation as they are not transparently available (Smith & Osborne, 2007). Analysis in IPA has typically been described as 'an iterative and inductive cycle'[17] (Smith, 2007).

The transcripts were analysed using IPA according to step by step procedures outlined by Smith et al. (2009) and will be outlined below. Please note that words in the text of the Analysis chapter that appear in italics indicate that they are quotes from extracts.

1. **Reading and re-reading**. The recordings were listened to and the transcripts were read several times in order to become immersed in and actively engaged with the data. This allowed the participants and the data to come to life and allow them to become the focus of the analysis.
2. **Initial noting**. This step examines semantic content and language on an exploratory level. At the centre of the account were a 'descriptive' core comments, which had a clear phenomenological focus and stayed close to the participants meaning. Interpretative comments developed from this to help understand how and why a participant has these concerns. 'Linguistic comments' were concerned with the language used by participants. Finally 'conceptual' comments were more interpretative and took an interrogative

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[16] See Appendix IV for example transcription
[17] The increasing inability of the analyst to approach each successive transcript in a theoretically naïve inductive manner is acknowledged.

form at times. The researcher used different coloured pens for the three tasks.

3. **Developing emergent themes.** Emergent themes were identified within each transcript where the aim was to reduce the volume of the data whilst maintaining its complexity by mapping the connections and patterns between exploratory notes. A table of chronological themes for each participant was used for each transcript.

4. **Searching for connections across emergent themes.** This step involved mapping out how the themes fit together. Mind maps were created that showed both the general and individual themes that the researcher was finding. This allowed the researcher to get a sense of the themes generated across the participants. The researcher used some specific ways of looking for patterns and connections between emergent themes and these are listed below.

   - Through the process of abstraction super-ordinate themes were identified. This involved identifying themes which went together and developing a new name for the cluster.

   - Similar to the abstraction process the subsumption analytic process operates where an emergent theme itself requires a super-ordinate status as it helps bring together a series of related themes.

   - Oppositional relationships were also examined among transcripts where the focus was on difference as opposed to similarity, this is known as polarization.

   - Using contextualisation allowed for me to attend to temporal, cultural and narrative themes in a proactive manner as they frame the more local understandings presented within an interview.

   - Numeration allowed me to take account of the frequency with which a theme was supported.

   - Emergent themes were also examined for their specific function within the transcript.

5. **Looking for patterns across cases.** In order to do this each table of themes was laid out over a large table in order to look across them. The

researcher analysed what connections there were across cases. This was then presented in the form of a table of themes illustrating the theme for each participant.

Specific criteria were used to assess the quality of this qualitative study (Elliott et al., 1999; Yardley, 2000). This will be returned to in the discussion chapter.

2.8. Ethical Issues

2.8.1 Informed Consent

Possible participants were identified by members of the multi-disciplinary team and names were passed on to the researcher or the Consultant Clinical Psychologist within the team. The specialist health visitor in the service and the researcher then met with participants to introduce the research to them. It was clearly explained to them at this stage that the research was voluntary and that they did not have to take part.

If they agreed to participate, an interview time was arranged for at least a week in advance to allow them the chance to reconsider if they no longer wished to participate. They were also provided written information about the study. It was ensured that those with literacy difficulties were offered support by a member of staff or from a family member.

At the interview participants were given the opportunity to ask further questions. They were reminded that their participation was voluntary and that they had the right to withdraw at any time. A consent form[18] was completed prior to commencement of the interview. By signing the consent form participants gave consent to the digital audio recording, consent to the transcription of the interview data and to the inclusion of the interview data in the thesis and publications.

2.8.2 Confidentiality/Anonymity of the Data

The researcher was blind to the medical files of the children of the participants. Any contact information (e.g. telephone number) was passed on by another

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[18] See Appendix V for Consent Form.

member of the MDT. Demographic information (gender of the child, age at time of diagnosis, number of siblings and age at time of interview) was obtained from the parent at the interview.

Participants were notified that the information they provided would be kept secure, both at the initial meeting to present the research and prior to consenting to take part in the interview. Anonymity was assured by assigning each participant a code. These codes, as well as consent forms, were kept in a locked cabinet separate to the digital records, transcribed materials and demographic details. The researcher transcribed all of the interviews. All of the identifiable information contained in the interviews was anonymised. Only the researcher, supervisors and examiners had access to the transcribed material. Data could only be accessed via a password on a computer, and will be erased after five years. After examination of the research has been concluded, all digital records will be erased.

Participants were reminded that although the content of the interview was confidential if they did disclose that they were going to harm themselves or another person a member of the team would be informed. Participants were told before and at the interviews that the clinical care of their children would not be affected by the research. This was also made clear in the Information Sheet.

2.8.3 Ethical Approval

Prior to contacting participants, ethical approval was gained from the Ethics committees at the University of East London[19] and the Local NHS Research Ethics Committee[20] that covered the team where participants were recruited from. The research also received approval from local NHS Research and Development department covered by the Team[21].

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[19] See Appendix VI for University of East London Ethics Committee Approval Letter.
[20] See Appendix VII for Local NHS Research Committee Approval Letter (City Road & Hampstead).
[21] See Appendix VIII for Camden NHS Research and Development Approval Letter.

3. RESULTS

This chapter presents the results of the analysis. The chapter is divided into four sections representing the four superordinate themes and their subordinate themes (see Table II below). The subordinate themes will be detailed using relevant extracts from the transcripts. The titles given to the subordinate themes are taken directly from interview extracts.

Table II: Summary of Themes

SUPERORDINATE THEMES	SUBORDINATE THEMES
3.1. THE ROLE OF CULTURE	3.1.1. It's alright, but I'm not too cultural 3.1.2 They just thought it was something I've done, I've made him like that
3.2. FROM INTUITION TO DIAGNOSIS	3.2.1 I always had a feeling 3.2.2 We had a lot of appointments, it takes time 3.2.3 They are not asking, so I am not telling
3.3. PROCESS OF ADJUSTMENT TO ASD DIAGNOSIS	3.3.1 What's he gonna turn out to be like? 3.3.2 It was heart breaking
3.4. COPING	3.4.1 We believe in Allah, we believe one day she will talk 3.4.2 I needed some support 3.4.3 You know I just looked at him and thought yeah I am quite lucky

3.1 The Role of Culture

Participants were asked to describe their cultural background in the interview. This led to a discussion around the role of culture in the participants' lives as well as in relation to their understanding of their child's diagnosis of an ASD. Subordinate theme 3.1.1 relates to the way in which some participants made sense of their Bangladeshi cultural background whilst living in London. Some participants described a process of acculturation or amalgamation of two cultures, British and Bangladeshi as a way of adjustment. Subordinate theme 3.1.2 relates to the way in which participants talked about their child's diagnosis of an ASD and how this corresponded or did not correspond with certain elements of their Bangladeshi cultural background.

3.1.1 It's alright, but I'm not too cultural

All participants were asked about their cultural background. In response to this some participants commented on a process of acculturation, an integration of British culture and Bangladeshi culture in order to be more congruent with their day to day lives and beliefs about the world, creating their own cultural identity. These participants described feeling some affiliation with their Bangladeshi culture whilst rejecting other segments of it which did not fit with them.

Rupa describes seeing some flaws in her Bangladeshi cultural background and how it influences her in her role as a mother.

> *Um I mean it does (influence me)[22]. I mean I can see a lot of the faults in the culture like the views the ways they think, I mean like I don't agree with it and when it comes to my children I wouldn't be telling them to like be a part of that culture.*

Rupa appears to be acknowledging that there are aspects of her cultural background which influence her as a mother whilst admitting that there are also aspects that she does not agree with. The future seems to be important for Rupa as she is talking about gaining control over the aspects which she will be sharing

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[22] Comments written in brackets have been inserted to clarify participant extracts.

with her children. This aspect of choice and control seems to be important to Rupa. She goes on to note

> *I mean religion as well plays a lot of part you know, teach them what the religion will say you know about respect and manners, I wouldn't really teach them about culture I think it's just ridiculous. You know these cultures these views they hold on to. It's not you know their concepts, it's not right and they lived in the past you cannot live like that in the present, I mean the world has changed.*

Rupa here appears to be frustrated by members of her family who adopt an 'old fashioned' view of culture. She seems to be suggesting that she will be passing down the parts of her culture which are important to her such as respect and manners whilst ignoring concepts she views as outdated. Her strong emphasis on the past versus the present and future seems important for Rupa to justify her views and choices.

Hasan also describes feeling frustrated with his culture.

> *Um you know, sometimes I get fed up with my culture…[23]. I mean it's alright, I mean it's alright but I'm not too cultural, understand what I'm saying? I'm more of a Western, I like the way things are, I don't pray five times a day but I pray um on Fridays, you know I believe in Allah.*

Hasan goes on to describe the parts of 'western' culture that he feels are important.

> *Yeah I still follow everything like we celebrate Christmas, like we don't give out presents but we have traditional lunch yeah. Yeah I mean I think culture don't matter now, you know culture is different, people don't follow culture now.*

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[23] Denotes words which have been cut to ensure that excerpts are concise and clear; care has been taken not toalter participants meaning in anyway.

Like Rupa, Hasan appears to be highlighting that there are some aspects of his Bangladeshi culture which he feels are outdated. It seems that Hasan is suggesting that culture was more important in the past but not in the present. He adds

> *Like my family always, um they're not too cultural, the reason I got married back home is that I wanted my kids to be cultured like me, we both you know that's why we married back home… Don't know I just like both. I don't like fully cultural Bengali, I don't like it.*

However, as seen in the extract above, Hasan does want his children to be *cultured* like him. He clearly states that he likes both western and Bengali cultures. Here he seems to be acknowledging that an amalgamation of both cultures is what makes most sense to him and his identity as well as for his children.

Kanta highlights that her Bangladeshi culture is not that important as she is in England now.

> *I think not very important because we are not in Bangladesh now… My children are growing up in here, so mains things is this culture, my children follow this culture as well.*

It seems that Kanta is describing a process of amalgamation of cultures but also a process of adaptation in order to fit in. It may be that for Kanta her children growing up *here* means that it would be more challenging not to adapt. When asked how she would define her cultural background Kanta noted

> *Not an English culture exactly, um Muslim, British Muslim…We have two cultures, English and Bangladeshi too much for them actually… Main things not exactly British culture… We are Muslims, so we are not Bangladeshi culture main thing is that we are Muslims.*

This extract emphasises the clear decision making that Kanta has been through where she highlights that two cultures would be too much for her children. It appears that Kanta's way of incorporating the two cultures is by defining her family as British Muslims.

Rupa, Hasan and Kanta all appear to be highlighting their views that parts of Bangladeshi/Bengali culture are outdated. There seems to be a strong focus on the future and change mediated through their children and how 'culture' will be passed down to them and defined.

3.1.2 They just thought it was something I've done, I've made him like that

The role of Bangladeshi culture in facilitating or obstructing the understanding of their child's diagnosis of an ASD. Participants' descriptions of cultural discords and accords in relation to this understanding.

Kanta compares support systems that she would have had in Bangladesh with support in England.

> *Here, mother only alone. Mother and father look after only children and in our country is aunty uncle, grannie and everybody live together…So everybody help, so many hands, helpful hands. In this country everybody busy with own work, own business.*

Kanta's use of the metaphor *so many hands, helpful hands* vividly illustrates the amount of support and help she would be getting with Zahir were she still living in Bangladesh. Her direct comparison with England highlights this difference between community and individuals. Kanta is stating that in England people are more focused on their individual lives and needs and that there is less of a sense of community support.

> *We're used to people help and this very hard for me and everything doing with own two hands, so now I am used to it.*

Here Kanta goes on to elaborate on this change and how challenging this was for her. Her description of doing things with her *own two hands* highlights a sense of being alone with her son's difficulties. There is an implication that were she in Bangladesh the cultural norm would be for her family and community to offer support.

Hasan holds a different view to Kanta and describes challenges that he sees with 'his culture's' view of Priya's diagnosis.

> *If she can't talk then people don't understand, people will um, our culture is um, people who follow too too into the culture... They don't understand they're not open minded, you know what I'm saying?… They will think like OK, this person has a disability ah, they're not human, you know what I'm trying to say?*

Hasan is expressing that he sees some people as too focused on their culture; *too cultural* and describes them as not being open minded. His comment that these people may view his daughter as not being human clearly highlights his frustration and anger. He goes on to note that his wife gets particularly upset and preoccupied by these views about their daughter.

> *It's like she's a woman, you know she's a girl she wants to get married one day, you know what I mean?...It's like that she's (his wife) more worried about that, what people say, I tell her like don't worry about her cos by the time she grows up the world's gonna be different. You know people will be different, that's one part I hate about my culture, I don't like culture because of that.*

Again Hasan is looking to the future, hoping that these views which he sees as a large part of Bangladeshi culture will change. He is also stressing his wife's worry about how others will react. Hasan's wife only moved to London recently and it seems that he is trying to protect her and shelter her from these difficult experiences which he too seems frustrated and preoccupied with.

There's a lot of gossips in my culture. Like I'm glad where I live there's not too many Asians… I don't hate Asian people but I just don't like discussing my business and the reason I like western people is because I can talk to anyone, all my friends and they wouldn't be a gossip, you know what I'm saying, that's why I like it.

From these extracts it is clear that Hasan is trying to support his wife with her fears and concerns whilst trying to play down his own concerns to his wife. However it is also clear that he himself is struggling with these views and sees them as incongruent with his beliefs about the world.

Similarly Sreea appears to struggle with the way in which ASD is understood in Bangladesh where she still has a large amount of family and friends.

They're gonna think it's dumb kid… In Bangladesh, like obviously like my family's side and his side of family I made them understand but you know the people like outside they're gonna think the kid is dumb.

Sreea is distinguishing between people on the inside and on the *outside*, family and non-family. It appears that she has some control and influence over those who are close to her and their understanding of ASD, however she is not able to do this to people on the *outside*. The use of the word *made* in order to aid their understanding suggests that it has been hard work and an understanding she has had to forcefully create. The use of the word *dumb* is also quite striking in this passage. I asked Sreea about this in the interview. She explained,

It's like, no one word they have in Bengali is like they call dumb, like that kid, like English word is dumb.

As apparent from the extract above Sreea notes that there is no word for ASD in Bengali and it is translated as dumb. This has clear negative connotations and could explain why Sreea described *making* her family understand as an active process to try and distance them from this view.

Arif described how when he was younger living in Bangladesh that there was a view that ASD was a physical disability.

> *Before when I was little people used to think autism, like someone has no hands no legs.*

I also asked him whether there was a word for ASD in Bengali.

> *Yeah there is a word… Actually some people say the English word, the same, and some people just say actually um, like um actually like a fool. That's what it means, in Bengali, it actually means he's not understanding what he says he doesn't know he's talking, something like that just like fool.*

Dumb or *fool* have strong negative connotations and it is understandable why it may be challenging to aid family and friends in their understanding of the diagnosis when this is their only frame of reference.

Rupa talked in detail about her struggles living with her in laws and their difficulty in understanding Akash's diagnosis of an ASD. She explains that she was consistently blamed for his difficulties and how challenging this was.

> *Yeah I think the role that I was in because I was living with my, well living with my mother in law it's like they had this, I had to be this, you know this um, the daughter in law. I had to be a wife, I had to be a mother. And you know the fact that they didn't understand that if I wasn't able to do these other two roles, and I'm trying to be a mother. It's like they couldn't understand this added to the sort of pressure by blaming or saying it was my fault he was like that or it's something that I might have done that he's behaving like that.*

Rupa here is highlighting the challenges of the different roles that culturally she was expected to fulfil. This added to her family's difficulty in not understanding her son's difficulties and blaming her as a result. She seems to make the

connection between their lack of understanding of his diagnosis being replaced by their own framework to make sense of his difficulties. This led to Rupa holding the responsibility for Akash's difficulties, as she did not spend enough time with him, she did not fulfil her roles. She added

> *So I was like how can you blame me? So it was really stressful. I don't think anyone actually understood what I was going through everyone is just there to judge…Think that was my biggest challenge cos I kept getting that sort of thing oh yeah you made him like that oh you've done something to him. Even after I've explained it to them it was still like yeah, well maybe you didn't spend enough time with him.*

Rupa's use of questioning in the excerpt above highlights her disbelief, frustration and anger at her family placing the blame on her especially when she had tried to explain his difficulties to them. There is a sense that the 'western' explanation of Akash's difficulties as a diagnosis of an ASD did not fit with their understanding.

3.2. From Intuition to Diagnosis

This theme reflects the path that participants describe negotiating which ultimately resulted in their child receiving a diagnosis of an ASD. The first subordinate theme includes the initial process, whereby the majority of parents interviewed recognised intuitively that something was different about their child. The second subordinate theme incorporates their experience of the assessment process which varied greatly. The third subordinate theme explores the experiences that parents' described with regards to the way in which the diagnosis of an ASD was communicated to them by professionals as well as the way in which they themselves communicated, or haven't communicated the diagnosis to others.

3.2.1 I always had a feeling

Dalia, Rupa and Kanta described that they first felt something may be different with their child due to their experience of having older children. They explain that the use of comparison allowed them to notice differences.

Dalia explains a feeling that Nishad was somehow different from her other daughters. It was noticing these differences that led her to seek help from her health visitor.

> *If she watching TV all the time, watching watching if I call her she doesn't respond and that's why I talk to my health visitor and she referred to children centre and they diagnose that she had a problem…Yeah, even I know because I got another two daughters, I know she's having a problem because she's, for my other daughters, different, I feel different for her. That's why I know maybe she's got something.*

Kanta also describes her previous experience as a mother as helping her notice that Zahir was different to her other children. This is what also led her to take Zahir to her health visitor and eventually to a diagnosis of an ASD.

> *I a mother three times so I got own experiences of other three, of other two daughters. I noticed Zahir is different so that's why I went my health visitor to talk about Zahir.*

Shema described having a feeling, an intuition that her son had autism. Despite not having older children it was when she compared Iqbak to other children his age that her intuition was reinforced, that something may be wrong.

> *I always had a feeling that he did have autism… but I wasn't sure what autism was and um just lately he has been diagnosed with autism… Eventually when I saw what other children are doing at their age and he wasn't doing I did realise that there must be something wrong. But I just didn't have no name for it.*

Shema here highlights that although she felt something may be *wrong* with Iqbak, she did not have a name for it. This lack of knowing what is *wrong* seems to be frustrating for her as she ended up requesting support from her son's school.

> *To be honest, um it was me I spoke to the school. I really have a good relationship with the school and I was quite worried because he wasn't doing what other children are doing.*

Sunita and Arif also describe noticing that something was different about their child. However their initial concerns were that there was a physical cause such as deafness. Sunita explains

> *I had noticed, actually mainly I didn't think that she would be autistic, her main problem which was about a year ago, last June, a year back, when I used to call her she never would respond to her name. I used to hoover the house and she wasn't reacting, the first suspicions I thought oh is she deaf? That was the main thing I thought. I thought maybe she's got hearing problems.*

From this excerpt it is clear that Sunita did not think at this stage that her daughter would end up with a diagnosis of an ASD. It may be that having a child who has something physically wrong is easier to understand, deal with and make sense of.

Anika felt very strongly about her intuition that something was not right with Maruf. She describes a process of continually pointing this out to professionals and asking for support.

> *I was kind of shocked at first cos I knew there was some delay with him at the beginning, but I didn't know where to go so I kept asking questions with the health professionals and everything they kept saying it's the age, etc.*

Anika here describes feeling powerless as she had noticed Maruf's delays but did not know how to get support to try and understand them. It seems that she tried several times to get support and is expressing that her concerns were not heard or listened to. She went on to note

> *I just wanted to realise, is it me? Is it me who is noticing this or why isn't the health professionals saying nothing? Why is slow process?... But I just didn't let I go, I kept fighting and I go no, something is wrong with my son there is something there.*

Here Anika is explaining the impact of her concerns not being heard by professionals. This may have led some to give up but for Anika this led her to *keep fighting* and not give up, demonstrating her immense strength and perseverance. It also emphasises the power of her intuition.

3.2.2 We had a lot of appointments, it takes time
Participants were asked in their interview about their experiences of the ASD assessment process. Some participants expressed feeling very pleased with the assessment whereas others expressed finding the assessment process challenging and offered suggestions about how to improve it.

Kanta expressed that she was very pleased with the assessment process and with their on-going care. She notes

> *Yes yes it was OK, the service was good as well and I'm very pleased. I've got so many good workers, in speech and language therapy, occupational therapist, they are all good and helpful as well. I'm very pleased of them.*

It is clear that Kanta felt supported by staff which, when one considers that she described feeling alone (see p. 46-47) and not having the support from her family to care for her son, must have been a relief and reduced some of the pressure of caring alone.

Sunita like Kanta did not find the assessment challenging. She describes feeling ready and prepared for it.

> *The assessment process, um it wasn't hard for me at all because I was prepared, I wanted to do it, especially for my husband he wanted no matter what it is, no matter what people says we just want the best thing*

for her. We want her to have a diagnosis we want to know what exactly wrong with her. Whatever is the best for her. We don't care about the community, we don't care. Um whatever is the best for her that's what we wanna do. And that's why I was like you know, constantly I was coming here just to find out what exactly is wrong.

It seems that Sunita and her husband saw the assessment as a positive thing as it would lead them to answers about their daughter. She notes that they wanted to know *exactly* what was wrong with her. From this description it appears that for Sunita and her husband the most challenging part was not knowing what was wrong, not having a framework to understand their daughter's difficulties. The emphasis on wanting a diagnosis highlights the challenge of not having a name or a label by which they could understand their child. The assessment provided this for them.

Rupa noted that she found the assessment process drawn out and long while also acknowledging the practical benefits of it such as gaining a nursery place for her son.

Um I did actually find it, um, I think there was a lot of appointments… It did take a bit of time. But I think that going back thinking about it. Because after he was referred um they did actually help me get a placement at a nursery.

Rupa added that she felt that she was repeating herself throughout the assessment period and found this frustrating.

Um I think at the beginning I just I suppose there was a lot of assessment a lot of you know, they do ask a lot of questions you do feel like you're repeating yourself saying the same story over and over again.

It may be that Rupa felt she was having to re-tell her story and this may have been frustrating for her if she kept having to say the same thing *over and over*.

She also explains the challenge of having a large number of professionals involved in her care.

> *I mean there are lot of professionals who are involved and it does take a bit of time to get used to that. It took me a while to get used to occupational therapist, speech and language therapist and psychologist and I was just like oh I don't know her name oh I don't know how to meet her, oh I don't know what her profession was. You know it's quite difficult to get that grip together. But I don't know if there is anything that can be changed about that. I think you know when there's professionals involved it takes a bit of time to understand what everyone does… I mean maybe if they give out a sheet with everybody's name.*

Here Rupa's description gives a strong sense that she was finding the assessment difficult. It appears to be highlighting the confusion with having a large amount of professionals involved in the assessment period. She describes finding it hard *to get that grip together* which suggests she found it challenging initially to pull all the information together.

3.2.3 They are not asking, so I am not telling

This theme relates to the communication of the diagnosis of autism and includes the initial communication from professionals to parents, as well as communication within families and to wider contexts such as friends.

Sreea describes not knowing about ASD before her son was diagnosed. She explains how the service helped her understand her son's difficulty

> *No I didn't know before. But after that I find out what is autistic kid… Um they told me and basically they told me autistic kid is meaning special kid.*

Here Sreea is emphasising how she was helped to understand her son's diagnosis by the assessment service. The word *special* seems to be very important for Sreea and she uses this word to talk about her son in further conversation. Earlier on in the interview Sreea describes an incident on a plane

to Bangladesh where a passenger became annoyed with Imran making noises. She explains how her husband made this person understand her son's difficulties.

> *It's in the plane. And my husband makes him understand, he says no, he's special kid he can't understand those kind of stuff.*

It seems that the professionals attempts to create a meaningful explanation of ASD, that her son is *special*, has been an important way for Sreea and her family to conceptualise his ASD as well giving them a way to communicate to others about his difficulties.

Despite initial warning from her GP Anika emphasised that when the autism assessment service tried to tell her that her son may have an ASD she did not feel ready to accept the information due to the recent birth of her daughter and other family stresses.

> *They spoke briefly about that it could be this and that but I mean they were just tryin to prepare me for the time but I think I was just like, I just had a new born I didn't know what to do and I was just worried about him so much like how am I gonna support him I've got a new born as well so I was trying to get you know my um my partner to kind of like bond with my daughter to try and do this.*

There is a sense from the extract above that although the individuals within the service were doing their best to try and support Anika and prepare her for the potential of an ASD diagnosis, they were not able to pick up on the importance of timing and other stresses present for her. It appears that Anika was more concerned with how she would cope with her son on top of these other stresses rather than accepting the diagnosis itself. From this extract it does not seem that the service was able to pick up on this and adapt their processes accordingly.

Sunita did not talk about the communication of the diagnosis of an ASD from professionals but did talk about how she communicated the diagnosis to her

family and friends. She clearly describes a process of choosing only to tell members of her family who will understand.

> *I do talk about it with my family, those who understand, those whose not gonna understand I don't. Cos rather than them making me feel better they're gonna make me feel worse so I don't talk about it. I see who will know who will understand… But some people you know no, no point wasting time. They won't understand… Yes even within my family there are, look I believe like if people don't understand, if someone can't understand don't waste your time, don't bother.*

Here Sunita repeats several times that if she feels a person is not going to understand her son's difficulties then she won't tell them. She highlights that if she were to try and make these people understand it would have an impact on her *make me feel worse*. It therefore seems that this strategy is a way of self-preservation and protection. Sunita goes on to describe the challenges of talking to family in Bengali.

> *When I speak in Bengali I say to them, she's um, it'll take time for her to understand, she's not like my older daughter, she's not like her, she's, I say um for me, she's a little bit behind. For example she is now three and a half but her, I think her mind of understanding is like a fifteen month old...*

The excerpt above highlights the challenges of talking about her daughter's diagnosis of an ASD without having the words in Bengali. It is clear that Sunita has had to be creative in her communication of Nahar's diagnosis by describing her as *a bit behind*. This inevitably implies that she will catch up at some point and may serve the purpose of alleviating concerns temporarily. She continues

> *But, autism they won't know. Not everybody, for example my mum, she won't have a clue what autism is, she won't know what disability is, yes she'll understand, maybe she heard the word of disability but for her, she say if she got a learning difficulty or a learning disability then my mum says*

oh my God she's gonna sit in a wheelchair! So things like that yeah, so I won't bother telling her.

Sunita is vividly describing how some of her family members may conceptualise ASD as a physical disability. To avoid this confusion Sunita makes the choice not to tell her mother about Nahar's diagnosis.

Arif appears to hold a similar view to Sunita that it there is no point in telling people who may not understand about Kabir's diagnosis. He explains

Yeah, they don't really know or see my children, they are not saying how old are they, they are not asking so I'm not telling.

Here Arif is highlighting that he will not divulge information unless he is specifically asked about it. He notes that this seems to work well for him as his friends do not ask more questions. They are happy with the responses he is giving. The excerpt above suggests that Arif may be hiding or keeping Kabir's difficulty a secret from these friends by not exposing them to his son.

Participants described a variety of ways to communicate their child's diagnosis to others with some clearly choosing who they share this information with. The experience of the initial communication from services of the diagnosis of an ASD provided some participants with a useful framework to make sense of their child whilst for others like Anika the service did not seem to take into account other contextual factors of concern.

3.3 Adjustment to ASD Diagnosis

Following their child's diagnosis of an ASD parents described different processes of adjustment to, or non-adjustment to the diagnosis. Theme 3.3.1 relates to the emphasis that some parents placed on their fears for the future of their child whereas others were more focused on their hopes for their child. 3.3.2 shows parental expression of other ways of coming to terms with the diagnosis by fitting it into their own belief system about the world by picking up information about ASD.

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3.3.1 What's he going to turn out to be like?

Understandably, creating their own versions of 'prognosis' was a feature of many parents' 'post-diagnosis' talk. Some of these focused upon cultural markers that participants specifically noted as tied in to their communities.

The importance of speech[24]

Several of the participants emphasised the importance of their child speaking. Hasan describes the significance of Priya being able to speak

> *But it's sad cos the main thing I'm worried about is her speech, I want her to talk you know, if she can't talk then oh my days there's nothing.*

This was a particularly emotional part of the interview for Hasan. He is clearly highlighting the hope he has for his daughter to speak. He elaborates further by suggesting that if she isn't able to speak 'there is nothing'. By using the word *nothing* to describe this Hasan is also inferring that his daughter being able to speak is everything to him. He goes on to say

> *I mean she can't express herself, or her feeling. She can't say someone done something to her… My main concern as I told you is that I don't care how she is, I mean I want her talk, that's the main thing. If she can talk, communicate a bit that's enough for me. I don't want anything else.*

Here we get a sense of why Priya speaking is so important to Hasan. He is clearly worried about his ability to protect her. It may be that this is linked to the way he views his role as a father, as being a protector. Hasan is adamant that this is his main hope for the future, he shows this by repeating this several times and by saying that he doesn't want anything else.

Sreea also notes that she and her family are concerned about Imran's speech. She describes how she tried to reassure Imran's sister.

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[24] The use of the third-level subheadings intend to guide the reader through the subordinate themes, rather than to describe further subordinate themes.

Even yesterday my daughter saying like when is he gonna talk? Because he is turning six. And I said to her, don't you worry about that. I'm the mum, I'm worrying about that, I'm not worrying anymore. He will be talking, slowly, not straight away.

Here Sreea is describing how she herself deals with her son not talking by telling herself and her daughter that he will talk, it just may take time.

It may be that for Hasan, Sreea and Sunita their child not speaking is a clear indicator to them and to others that something may be different about their child. It is possible that one of the functions of their child speaking will mean it is easier to conceal any difficulties they have and allow them to pass as 'normal'.

Who will look after him?
Several participants expressed fears around who would care for their child in the future when they are no longer around.

Sreea describes

I'm sad something, about when he's grows up, if I'm alive or not am I gonna see my son talking or not? When, if he married, who will be the person for taking care of him? I said my daughter, or my son, if my son talk or not talk you have to take care your brother when I'm not alive. You taking care of my son and my son, older, he answer his dad, don't worry Dad, if you not alive or Mum, I'm up to my brother to take care.

It is clear from the extract above that this is something that Sreea has thought about in detail and has made provisions with her family for her son's future. It seems that conversations have taken place within the family about the future and her older son has highlighted that it is his role to take care of Zahir. She continues to note

> *That's autistic kid mother saying that kind of stuff and I know everyone say my son will be a handsome boy and he'll be grown up, nice boy... But I don't know what his future will be when I am not alive? Who will take care of him? Autistic boy? But I'm proud for son, he's autistic I'm not worrying about that.*

Here Sreea is reassuring herself by normalising her fears as the fears that all mothers of children with an ASD have. It may be that her use of questioning suggests these are questions that she is often asking of herself. However it does not take long for her these concerns to reappear. She then continues to reassure herself by noting that she is proud of her son – this seems to be part of her self-talk strategy for managing such fears.

They will grow out of it
Some of the parents interviewed highlighted that they felt their child would grow out of their diagnosis, that they would be symptomless in the future. Sreea describes a time in the future where her daughter is showing Zahir a recording of himself when he used to be 'autistic'.

> *That's what sometime I say to my daughter, can you record his thing, when he grown up he can see or he can show his wife or he can show his son or daughter, he is autistic kid before.*

The use of the word *before* here clearly demonstrates a holding on to a belief that the diagnosis is not permanent.

Sunita holds a similar view by expressing an expectation that her daughter will *be like us*. Her description that there are *a lot* of people who are quiet suggests that she is hoping that that is how Nahar will be viewed by others, and not as someone with a diagnosis of an ASD.

> *But when my daughter grows up I can't imagine how things are gonna be, but as I said I expect her to be like us, because there are a lot of people who is quiet.*

Sunita continues to talk about a daughter of a friend of hers.

> *I have seen my friend's daughter, who I feel she might have been autistic because she sits in her own room, she doesn't like meeting people she only comes out of the room when she feels like it if she knows, she doesn't like social interaction… Maybe 20 years ago or 15 years ago if she came to doctors or met anyone, maybe she was (autistic) but she is living normal life with everybody, no one knows, no problem. So if a girl like her cannot have any problem or any cultural problem then why would my daughter?*

Here Sunita is using the example of her friend's daughter to highlight that she may have met the criteria for the diagnosis in the past, but is fine now. This again highlights Sunita's hope that her daughter will get better and will not have any cultural problems in the future. However later on she goes on to describe her fear that she may not *improve* and the implications this will have within their Asian culture where other people may perceive her as *rude*. Sunita notes that this may be a *bit difficult*.

> *But maybe when she grows up, because she if she doesn't improve or if she is like normally children with autism they don't meet people then yes it's going to be a little bit difficult, like a lot people, like we Asian like a lot of people are coming weekends, your cousins going places meeting relatives or inviting them and then if your child just got in the room then just sit there then for us it is a bit rude people's gonna think, then yes I might have to say this is the problem with her.*

The importance of marriage
Several participants talked about their fears that their children will not be able to get married in the future due to their diagnosis and some talked about this in relation to their cultural background.

Sunita takes a positive outlook on marriage and emphasises that Nahar being quiet in Bangladeshi culture can be seen as a good thing.

Yeah things like this, if I say getting married, yeah every mother in law expects their daughter to be quiet, respectful you know not to talk to too many people, so it might be a positive thing for her.

Sreea on the other hand expresses concern about whether her son will get married. Her use of questioning is powerful here and demonstrates her fear of the unknown.

Cos I'm worried about his future. When he grown up I'm gonna see he's gonna get married? He gonna have kids? How will the kids look like? Is they gonna be normal kid or like him? If he talk then he can say I was autistic kid.

Rupa talked about the difference between male and female roles from a cultural perspective and what that meant for her son's future and the impact it has on the family.

Yeah I think with the, with the culture um, yeah I think what it doesn't fit in is the fact that you know like say where the male is the strong figure, the figure of the like family, the provider and you know to see that that male is, like has um is not able to provide that. Is like something that um is just sort of like as if it lowers your status your, or lowers your it just you know like um it just kind of lowers your level…

She continues and highlights in very strong terms the stigma of having a son who is unable to provide for them.

That kind of like oh no your son, you're not going to be able to get him married. Or your son's not going to be able to provide for you. Or your son won't be able to work and bring money home. You know it's like as if it's a shameful thing like a degrading thing.

Dalia holds a similar view and describes the impact of having a daughter with *problems*.

> *Our culture, um if its girl and they um have problems, the thought is when she's older then then um then she won't get married. That's why they want to keep a secret that she have a problem and then shy, um, that's our culture problem.*

Here Dalia is explaining why people in her culture are more likely to keep their child's diagnosis a *secret* as disclosing it may have implications for their future and whether or not they can get married. It appears that Dalia sees this as a problem on top of the diagnosed *problem*.

3.3.2 It was heart breaking
Reaction to diagnosis
Several participants described feeling very upset when they initially found out about their child's diagnosis. Rupa expressed that she was upset and cried initially.

> *You know I did cry a bit at the beginning*

Both Sreea and Hasan talked more strongly about when they found out. Hasan notes

> *It was heart breaking, cos in my family there is only one daughter you know what I mean, like I have the only daughter of my brothers and sisters…It was difficult, it was heart breaking you know.*

Here Hasan is expressing how difficult it was when he found out his daughter had a diagnosis of an ASD. There is an implication that her being the only girl in the family made it even harder for him. He also describes feelings of anger after finding out. This impacted him both at home but also at work where he found it difficult to interact with customers without becoming frustrated.

First when I found out it did make me really really angry, I didn't wanna go to work, and especially my job is more like customer based, so I got really annoyed with customers.

Sreea like Hasan describes her deep distress when she was told Imran had a diagnosis of an ASD.

Then she said like don't worry, autistic kid not very thingy it's something people have. That time I'm broken my heart and I said what happened?

Sreea went on to describe just how upset she was following the diagnosis and that she spent a long time alone crying.

I came home and my face is like unhappy, crying on my own, then after I get happiness like no, I'll make my heart not soft but hard.

Her description of having to make her heart *hard* and not *soft* is a very graphic description of how she had to toughen up in order to adjust to the diagnosis. The use of the word *make* suggests that this was an active process which required some effort and which perhaps did not come easily.

The impact of the media

Some participants described media influences which helped them make sense of their child's difficulties with some participants referring to films or television series they had seen and others to using the internet as a resource.

Hasan talked about an Indian film he had seen before his daughter was diagnosed which helped him conceptualise ASD.

Also um I watch a film before um my daughter was born, I watch a film, it's about an autistic kid, it's basically this really really good film and if you get a chance to watch it…. It's called Taare Zameen Par… It's with Amir Khan, he's an international star, it's really really good. It's about an autistic kid

and you know the way their mind works, that's when I knew yeah…That's a good film to watch for people who don't know.

However he also expressed not wanting to find out more about her autism.

The thing is since I found out about her autism, I didn't really look it up, I didn't look it up, so what I know is what I hear so I donno, it puts me off when I wanna look into it.
I: What puts you off about it?
I just you know I just think she'll never be normal, you know, that's what I mean. You know it never happened to my family my whole family.

It seems that Hasan avoids finding out more about his daughter's diagnosis as a way of managing his fears about her never being 'normal'. Although it seems that Hasan has come to the conclusion himself that she may never be *normal* it appears that his avoidance prevents this from being confirmed.

Sunita highlights the advantages of having the internet in terms of increasing people's awareness of ASD. She explains that her families' understanding is aided by tools such as the internet compared to 10 or 15 years ago when there was less information available.

But now everywhere if you go on the net there's lots of different sites and everybody nowadays they know… They know how to search they know, um internet, everybody has so they'll believe me.

She goes on to add that in the past her family would have thought she was mad if she tried to explain what ASD was. It seems that this access to information has also reduced stigmatisation.

But if it was ten years back and I was to say oh they would just think oh she's mad. They would have thought what is she talking about… But things are changing, although a little late, things are changing, things have

changed and are changing and I feel from my culture people are more modernised now than before.

There is a sense of relief from the excerpt above, that there has been modernisation in *her culture* although she feels this is perhaps a little late. Sunita may have wondered what it would have been like to have a child with a diagnosis of an ASD when things were less modernised and the impact this would have had on her. She appears to be pleased and relieved at this change which in part may be due to the impact of internet usage and information sharing. In fact Sunita first heard about ASD on an Indian soap drama that she watched before Nahar was born.

> *I used to watch a drama, an Indian drama, I used to watch and it was quite interesting like how an autistic kid, how she grows up… The first few episodes I have seen, and that's when I first heard autism, autistic and how they are.*

Sunita went on to explain that this led her to research more about ASD as she enjoyed learning about new things and also meant that the adjustment period following the diagnosis of an ASD was easier for her.

> *Obviously the internet I used to research on it…I like knowing different things, how things is. That's when I first knew, and then when she was diagnosed I was fully prepared I knew what autism is what they can do what they can't do, things like this.*

This prior knowledge of ASD seemed to be particularly helpful for Sunita.

Family link
Rupa and Arif found that making a family link with their child's diagnosis and a family member aided their understanding as well as their friends and families. Rupa explains

Cos when we look back like my father in law the kind of person he is, he is quite stubborn in his way. He doesn't like to talk to anyone. I mean he doesn't like to socialise at all. Because he was born years ago now back in Bangladesh he wouldn't never have a diagnosis done anyway so you know we were just like you know he probably has that but no one ever picked up on it so maybe um Akash's got it as well due to that. So I think for them there was um you putting all the signs together. You know two and two together thinking yeah it could be.

Rupa had previously described in her interview the struggle she had faced to help her husband's family understand Akash's diagnosis and not blame her. It seems that making the link between similarities with Akash and his grandfather aided this process and was something that the family could relate to and understand. She continues

And even now my mother in law like now when he does play up when he does go into a tantrum they won't blame me anymore they just know he's got a difficulty that's why he is behaving like that… So it really has you know, it's like it's all flipped and it's turned around. It's a lot better it's a lot um it's a lot easier because when you have the family support and when they understand it it's a lot easier.

Here she is emphasising how this framework has completely turned things around for her and her family taking the blame off her and creating a significant shift. Arif, whose wife is deaf, also notes that making a family-link helped with the understanding of Kabir's difficulties for him and his friends.

They (his friends) say what they are thinking. They know about my wife's problems and they think my children have something from mum... I think it is a little due to my wife's problems, because she can't speak and she can't hear. She don't understand lots of stuff.

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It may be that the family link provides a more physical and concrete understanding of ASD compared to other more abstract explanatory frameworks for both Arif and Rupa.

3.4 Coping

All participants described different ways of coping having received a diagnosis of an ASD for their child. Many expressed a deep Muslim faith which seemed to provide parents with a great deal of comfort and consolation. Most participants emphasised the importance of having support, whether from professionals, family or friends, and those who felt they did not have this support highlighted that it would have made things a lot more straightforward. All of the participants described immense resourcefulness, resilience and creativity to deal with their child's diagnosis and related difficulties that arose. Many participants also used comparison as a source of support and comfort.

3.4.1 We believe in Allah, we believe one day she will talk

This theme relates to religious beliefs and faith that participants reported. It describes the role that religion plays in helping some parents and families understand and accept the diagnosis of an ASD.

For most of the participants their religious beliefs seemed to provide them with an important coping system and hope.

Arif described a phase where he questioned why he was given this fate from God.

> *Why God gave me? But I'm not questioning… When they were little I was feeling that way. Why were my children come like this? Why would God give like that? That's actually a little not what I was feeling before, then actually looking and slowly slowly I was thinking that's not a good thing to think. I realised that God knows why he gave me this, he knows. I can't do anything. God knows what happened.*

Here Arif is describing a period when his children were younger when he found it difficult to understand why his children had these difficulties. There is a sense that he feels that what he has been given is unfair, why me? However it is clear that over time he has found comfort in knowing that it was God's choice and that questioning this was *not a good thing to think*. However, it seems that this was a slow process for Arif.

Shema holds a similar view.

> *I believe that everything has a reason and everything is helped by God, you know, everything is done by God, and I believe that whatever, however my son is, it may be a gift for me you know. I believe is if my son is there, he is there for a reason… Maybe God has gave it to me to actually gain a lot more experience, you know I could help other parents in the future and you know obviously help him as well. I mean he has to be there for a reason.*

It is clear that Shema is placing a lot of importance of her son being *here* for a reason. She repeats this several times as if convincing herself. If he weren't here for a reason what would that mean for Shema? Perhaps she would then be left construing all her hard work and challenging experiences are for nothing as opposed to being for a greater good.

Hasan clearly notes that if it weren't for his religious beliefs he would not have coped.

> *If I do you know everything in God's name, religion is a big part of my life…That's why I'm coping, or I would have broke down.*

His use of the expression *broke down* suggests that he would not have managed without his religion. Hasan also noted that he would like to take his daughter to Mecca in the future. '*One day, hopefully. I would probably take my daughter with me.*' Sreea and Dalia both talked in their interview about going to Mecca for their

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children. Sreea explained that she had taken her son there with the hope that his language would come back.

> I went Mecca for my son…For the wish, for come back his talk, but I went there, it's very nice and very thingy, comfortable, my son is very comfortable, he's not doing any bad stuff.

Sreea here is highlighting how at ease Imran was when he went to Mecca and that she noticed a change in his behaviour for the better. Dalia also explained that she went to Mecca to pray for her daughter

> All Muslims, all countries Muslims are going there, lots of people, very crowded, and too hot there but it is a great place
> I: hmm, what did you go there for?
> For praying, mostly for my daughter,

Arif also places a lot of hope in God that he will make his children *normal*.

> But I hope my children one day will become fine. That's what I think everyday. When I am feeling a bit angry or upset then in my heart I say, God one day you will give the children will be fine… One day they will be like normal children, they will come fine, like other children

He goes on to emphasise this

> When I go (to pray) I am just telling, asking every time to God, God please give my children, not one, all of them give good knowledge good mind good things.

Dalia holds a similar view to Arif that in the future Nishad will *be better*.

> Maybe in the future she is better and maybe God knows you can take care of her, that's why he gave you those kind of children, don't be upset and every time pray for God and maybe she is better in the future.

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Some participants spoke about the care they were receiving from professionals versus their religious beliefs as a way of coping. Sreea highlighted that although Imran's school is helpful, God is the most important thing in supporting change.

> *I can see my son changing and I know that in school, the teacher helping around, but mostly its God who is gonna help him changing.*

Arif shares a similar view

> *And like my son with his delayed speech but he keep opening his mouth and trying to speak something. And I say please God…But that's the thing actually, I can't do anything. I know all the professionals give lots of things lots of advice everybody tries, but God knows how to help. God will help and one day he will open his mouth and speak.*

Here Arif is clearly placing the process of change for his son in the hands of God, not in his own or the professionals involved. He is emphasising the powerlessness of himself and professionals by highlighting the power that God has to make changes, and allow his son to speak. However, participants' talk indicated that they and their NHS teams were more than simply caretakers passively awaiting miraculous intervention. Sunita on the other hand does not view religion as important in helping her understand Nahar's diagnosis. She explains

> *No I don't know to be honest, religion is not helping understanding, religion is my thing, this is my duty to pray, as a mother it's my duty to teach them to read Arabic to learn about the religion.*

Here Sunita is clearly distinguishing the role that religion plays in her life and her family's lives. She continues

> *But when it comes to understanding her autism syndrome. Then no. This didn't help me. It actually helped me because I used to work in the GP*

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practice and I have met professionals and I have seen autism kids. When I used to work I have seen a lot of children with difficulties, how their mother reacts.

For Sunita her experience working in a GP surgery and this exposure to other children and families helped her to make sense of and understand her daughter's diagnosis.

3.4.2 I needed some support

This theme relates to the support systems available or not available to the parents and includes professionals, family and friends. All of the participants spoke about their support systems in the interviews. Many of them highlighted the support that they had received from their family and how important this was for them.

Sunita explains that her sister and brother in law are particularly supportive and provide her with some respite.

> *My sister, my older sister and my brother in law they are very understand. They love her to bits, they just love her so much, most of the time if I go somewhere, those are the two people that I can leave, because if my daughter finds her uncle she can, she won't need me anymore. That's how much she loves him. And they understand her very well.*

Here Sunita is placing importance on people being supportive as being able to *understand her very well*. Sunita had previously talked about some family members not understanding Nahar's difficulties (see p. 56-58) and this seems to be important for Sunita as it seems to allow her to rely on them and trust them with Nahar. Hasan also stresses the importance of support from his family

> *Its more easier, with my family around, I always lived with my family, I donno what I would have done if I wasn't with my family, it would affect me more. It's nice cos you know sometimes your mood is off and then my sister will like make a joke at me or you know.*

Hasan is very clear about the importance of the support he gets from his family by stating that he doesn't know what he would have done without them. Hasan is also saying that adjusting to the diagnosis would be more difficult and would have affected him more without their support. Interestingly it seems that Hasan cherishes their ability to notice when his *mood is off* and cheer him up.

Sreea identified her mother as very supportive, particularly in relation to adjusting to Imran's difficulties. She also describes Imran's Occupational therapist (OT) as important in giving her hope.

> *My mum helping me too much. I was breaking down but my mum and the OT gave me hope.*

Hasan also suggests that the support (especially that of a practical nature) that he received from professionals was important.

> *They (professionals) helped with a lot of things, they helped me get the schooling, I got a lot of help and I really appreciate it. I mean I couldn't ask for much, if I was in my country I wouldn't even know.*

He is using comparisons to services in Bangladesh to highlight his appreciation of the professionals *here*. Dalia also notes the support she has received from services and how they have made things easier for her.

> *But she is slowly slowly progressing. Before it was too hard everything, every single thing, very hard for me, doing everything. But now little bit easy because school and you know the disability service. They're helping me and they teach me how to do work with her.*

Dalia here seems to be placing some of the power of change and progress to the work carried out by the service. She adds

> *Biggest support, first the service then school, and my mum and mother in law and my two daughters as well.*

Conversely Anika did not appear to find that the autism assessment service provided her with the support she needed.

> *All this was happening in the process and speech therapist got involved from sure start and they were trying to give me advice, what to do. That's all I wanted some more support but they said no.*

Other participants described their lack of support and how this impacted them. Anika described her husband's lack of support and understanding of their son's difficulty as a huge challenge.

> *And I just wanted his support because I just realise my son is going through something if you can't look after my son or if you don't understand this then you know delay and difficulties you know disability let me deal with him… So it was quite hard at the time.*

She is describing a clear desire for her husband's support and understanding whilst making it evident that his lack of support made it a very challenging time for her. She went on to note

> *It was hard, it was difficult but you know I was just wanted someone at the time, and the dad was there luckily but emotion side he wasn't really supportive at the time.*

Here she is making the distinction between her husband being physically there whilst not being emotionally supportive during the assessment process.

3.4.3 You know I just looked at him and thought yeah I am quite lucky.
All of the participants demonstrated great strength and perseverance through what they often described as a very challenging time. Shema talked about trying

to potty train Iqbak showing a great deal of determination after his school had not succeeded.

> *I just um last year I did a toilet training on him um school they um they done it numbers of time but they said that he wasn't responding so on one summer holiday right I said OK, I am gonna give it a go myself, but school totally they refused they said no, I think you need to give him a bit more time and I said no, I'm gonna see what I can do… I took him to the toilet every half an hour, sometimes half an hour sometimes one hour … So after taking about few times in the toilet then I was so surprised he went into toilet himself.*

It is clear just how proud Shema was of her success at potty training, however it is also evident that this took a great deal of effort on her part. It seems that she was driven to support Iqbak in doing this to make his life more comfortable. She later noted

> *You wouldn't believe it how happy I was when I did the toilet training for my son… I was just so much over the moon, now he has never ever, I have never bought him a pair of jeans, pair of nice jeans because he wasn't able to wear it. It's always either too loose or too tight, you would believe how happy I am just for him to get off the nappy.*
> *I: wow, so have you bought him a pair of jeans?*
> *Yeah it's like now yeah! (laugh). The very next day… You know he loves them.*

Shema was overjoyed in the interview when she was talking about this achievement and being to buy her son a pair of jeans. Anika also demonstrated tremendous resourcefulness by reading books to increase her understanding of Maruf's diagnosis

> *I was trying to you know, read books, trying to get that knowledge to get what is it, what is it…Trying to help him and support him.*

Some participants like Anika described having other social stresses in their lives on top of their child being diagnosed with an ASD. Anika demonstrated a tremendous amount of resilience when she had these other challenges in her life such as the separation from her husband. She talked about finding strength in the face of adversity.

> *I wanted to get the help I needed, that help that support… And really aware this time I go no, these kids are my kids, especially when he was diagnosed I go no, there's, my son has nobody now even the Dad there, we don't know if that's gonna last or not I have to be there for my son, for my kids, I was strong.*

Anika is clearly describing the strength of the bond with her children in helping her find strength in herself. Her clear determination when she stands up to her husband and says *no, these kids are my kids* is very powerful and demonstrates the strength of her resolve at the time. Maruf being diagnosed seemed to propel Anika to find more strength from within. Her instinct to be a mother is also evident here where she talks about being there for her kids.

Rupa on the other hand appears to use comparison to cope with Akash's difficulties.

> *You know if he's got something you know you have to deal with it and the truth is I did look at him, and there are lots of children with ASD. Some are a lot worse and some have less and you know I need to appreciate how you know like Akash is.*

Here Rupa is putting her son's difficulties into perspective highlighting that she could be worse off. She continues

> *You know I just looked at him and thought yeah I am quite lucky, there are worser cases and you know. Imagine how it is for the other parents. It must be so much harder for them than it is for me.*

It seems that this technique of comparison to those who are worse off than herself is a strategy to help her come to terms with and cope with her son's diagnosis. Sreea uses a similar strategy she states "*so many people have autistic kid*". She goes on to describe that the OT working with her son also uses this strategy to reassure Sreea and help her cope

> *Then the OT telling me like, don't worry, some children have those kind of stuff. Don't upset. And then I saw so many people coming in and I say oh then it's not only my son. They have more kids diagnosed, autistic kid, I am very happy when I am seeing that.*

Sreea is acknowledging here that she was upset before she was reassured by her OT telling her that she was not the only one. Sreea clearly expresses that knowing that there are other children with a diagnosis of an ASD makes her happy, this may be because she feels less alone.

Sunita continues to be resourceful in her thinking about her daughter by highlighting that she is not embarrassed by the diagnosis and that in fact some children with ASD are very intelligent.

> *But don't feel bad it is nothing to feel bad or embarrassed about, some autistic children are very intelligent.*

Sunita's cup half full attitude where she is focusing on the positive aspects of her daughter's diagnosis seems to be an important factor allowing her to cope well with the diagnosis. Sunita had previously spoken about finding the adjustment to Nahar's diagnosis quite straightforward.

4. DISCUSSION

This chapter will draw upon the current literature and consider how the findings from the analysis relate to each of the research questions. It will also address the implications of the research by making recommendations for future research as well as clinical practice. It will include a critical review and a section on the limitations of the current research. This is the first research study to the author's knowledge which has investigated the experience of Bangladeshi parents of children with an ASD. In particular it is the first study to try and understand how their cultural background impacts their experience.

4.1 What were the experiences of Bangladeshi parents of children who have recently been through a multidisciplinary assessment resulting in a diagnosis of ASD?

The parents in this study described a variety of experiences of the assessment process, as well as a range of experiences before the assessment which in some cases directly led them to the NHS service and a diagnosis of an ASD.

Most of the participants expressed having an intuition that something was different about their child. This was often via comparison to their older children or to children of the same age as their child. Often the differences that they noticed were behavioural. Mansell and Morris (2004) also found that parents tended to become aware of behavioural difficulties associated with ASD first. For some of the participants here, noticing behavioural differences directly resulted in them accessing some kind of support often from a health visitor or GP. A few of the parents described finding this stage particularly hard to deal with and some were blamed by their extended family for their child's behaviour. Midence and O'Neil (1999) have highlighted that this stage is often highly stressful for families and can result in feelings of self-blame or shame. Findings from this study support other research which suggests that for some parents not knowing what their child's difficulty was was the most challenging aspect of the process pre-diagnosis (Midence & O'Neil, 1999; Quine & Pahl, 1987).

Parental experiences of the assessment process varied greatly with some parents finding the experience straightforward and describing feeling prepared for the outcome, whereas others expressed feeling overwhelmed by the amount of appointments and professionals involved in the process. A few of the parents interviewed also described feeling frustrated with having to repeat their story over and over which left them feeling unheard by professionals. Howlin and Moore's (1997) study on the experience of families of autism diagnostic services in the UK found that nearly half were not very or not at all satisfied with the diagnostic process.

Several parents noted that receiving a diagnosis for their child provided them with a sense of relief, that they knew what was 'wrong' with their child. A few described the diagnosis as providing answers to their questions which ultimately led them to receive practical support and help from services. Quine and Pahl (1987) also found that many parents find 'not knowing' how to help their child very challenging and added that a diagnosis was often a relief as it provided some practical guidance. Additionally in another study parents highlighted the need for a 'label', knowing what it is, and therefore what to do to support their child (Midence & O'Neil, 1999).

For other parents receiving a diagnosis of an ASD was heart breaking and devastating. A number of participants described not having heard of ASD until they were told of their child's diagnosis. For some this was seen as helpful as it meant they did not worry unnecessarily whereas others noted it was a shock and it took them a while to adapt to it and make sense of it. Some participants described still struggling to understand what ASD was. They expressed trying to block it out from their minds and not talk about it or gather more information about the diagnosis. This denial seemed to be a way of avoiding the realisation that their child was different to other children but also seemed to make acceptance difficult. Research has emphasised that families' levels of acceptance, stress and general coping are impacted by the way in which a diagnosis is shared (Woolley et al., 1989).

Furthermore the experience of the parents in this study echoes research which has been conducted on the grief process of families with children with disabilities. Studies have supportted that these parents often mourn the loss of the perfect child and themselves go through the stages of grief (Barnett, Clements, Kaplan-Estrin, & Fialka 2003; Ellis, 1989). Here, parents described being at different stages of grief where some were still in denial and others appeared to have accepted the diagnosis. However this process seemed to be a fluid one where they often expressed moving between different stages such as denial and acceptance.

This study has demonstrated that the experiences of Bangladeshi parents pre, during and post assessment are similar to other parental groups studied in previous research. In particular similarities were noted in the descriptions of the different stages parents experienced. For example, an initial intuition, denial that something may be 'wrong' with their child, acceptance, relief, as well as suffering heartbreak and grief at the loss of 'the perfect child'.

4.2 Parental understanding of the diagnosis of ASD from their cultural background and how this impacted the understanding of their own child's difficulties?

Parental experiences in relation to this research question presented both their experiences as well as the experiences of a larger group, which included extended family, friends and for some the local Bangladeshi community. Responses focused less upon the immediate system of the child ('nuclear family') but upon the wider system of the child-and-mother, or of the child-and-parents.

Several parents in this study described a process of adapting their cultural identity to fit with both Bangladeshi and British cultures. This process of acculturation (Berry, 1997; Falicov, 2007) seemed to provide them with their own framework from which they could make sense of their child's diagnosis. One participant was able to reframe their child's diagnosis in a positive light seeing it as a benefit to have a quiet daughter in her Bangladeshi culture as future mother in laws prefer this quality.

For others however it seemed to produce cultural discord among family members and extended communities particularly around the causes of the child's difficulty. Differences in the perception of the causes of unwanted behaviour in children between western and South Asian families has also been commented on in the literature (Stern et al., 1990). Fatimilehin and Nadirshaw (1994) noted that a major influence on attitudes and service utilisation in Asian families was a lack of knowledge about the cause and concept of learning disability, and of the services available. Furthermore Dyches et al. (2004) emphasise that negative appraisals that occur following the realisation that a child is not developing properly in different families from different cultures may be due to the families' interpretation of the cause of the child's diagnosis.

Some of the parents in this study specifically described the influence of culture on the families' understanding of their child's diagnosis. In particular they commented on the influence of their expected roles within the family which seemed to predominantly impact mothers who lived with their husbands' extended family. Two mothers in this situation spoke of being blamed for not fulfilling their roles as mothers effectively and this being seen as a cause of their child's difficulties. They described that providing a genetic or medical explanation of their child's diagnosis to their extended family seemed to be the only way to eventually make their families understand that it wasn't their fault and remove blame away from them. Hatton et al. (2003, p.183) reported similar findings in their study of South Asian families with learning disabilities where they noted 'that a clear understanding of the child's condition gained from the disclosure process was very useful in countering 'lay' understandings of the child, with parents reporting 'medical' understandings to be particularly helpful'. However, Yeh et al.'s (2004) analysis found that ethnic minority parents were less likely to endorse biopsychosocial beliefs often presented by mainstream services.

Research has consistently found that health services do not meet the needs of South Asian families to the same standards as their white counterparts (Dyches et al., 2004; Mandell & Novak, 2005), particularly when it comes to meeting their cultural and linguistic diversity (Trembath et al., 2005). Parents in this study emphasised the challenges that they found with providing information for family

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members in Bengali, and highlighted the lack of it. They also noted that there is no word for autism in Bengali and some parents explained that it is translated into derogatory words such as 'dumb' or 'fool'. This has been echoed in the literature (Dobson et al., 2001; Hatton et al., 2003). Some parents clearly expressed choosing not to disclose their child's diagnosis to family members or friends who they described would not understand. It seemed that for some families the 'western' explanation of ASD did not fit with their own understanding and there was less flexibility for alternative explanations within the health service.

Moreover, 'Lay theories' can be defined as the explanations and descriptions lay people give for various conditions (Furnham & Buck 2003). For example, Gray (1995) in his study on the views of parents of children with a diagnosis of autism found that the parents' explanatory models varied in significant ways from the biomedical perspective of autism. His results also identified gender based differences regarding parental beliefs about the aetiology of the illness. In the present study several participants used a religious framework to understand their child's difficulty with some parents noting that they were chosen by God to gain experience (e.g. Shema p. 70).

The mothers in Kishore and Basu's study in India (2011) of early maternal concerns about children later diagnosed with autism, reported as many as 56 early indicators though very few had a combination of three or more. Additionally, rarely did anyone report early indictors from all the three core domains of autism. They note that findings from their study suggest that autism is truly diverse and the emergence of symptoms or at least the perception of symptoms is not necessary from all the three areas of development. They conclude that 'cultural perspective is very important to identify autism' (p. 162). The present study reinforces this. For example, parents were concerned about their child's language and social development (p.59-60) and several participants spoke of their initial fears that their child may have hearing difficulties which explained this (p. 52-53). But several participants simultaneously saw these immediate concerns as indicative of future shortfall from important cultural norms - would their child be able to get married (e.g. Hasan p. 47) or be able to accommodate to the social events in the family (e.g. Sunita p. 62)?

Almost all of the parents spoke of the importance of religion in understanding their child's difficulty. Two parents emphasised this by speaking of taking their child to Mecca. There are several studies which support this finding and suggest that religion is the primary frame within which parents understand the meaning of having a child with disabilities (Bennett et al., 1995; Zhang & Rusch, 2005) as well as specifically within South Asian families with a child with a diagnosis of an ASD (Jegatheesan et al., 2010b). Research also highlights that families from different cultural backgrounds often seek complementary and alternative medicine as a source of interventions when they have different beliefs and understandings about a diagnosis of an ASD compared to mainstream services (Levy et al., 2003).

Studies have reported that parents of children with disabilities often have deeper questions related to meaning and purpose (Skinner et al., 1999), such as how they make sense of why this disability has happened to their child and how they can reconcile their pain and suffering. Religion often provides the answer to these questions (Zhang & Rusch, 2005). In this study parents also described religion as giving them a means to understand why it was 'their' child who had these difficulties where most of the parents felt that they were selected as they would be able to meet the challenges given to them. The majority of the parents expressed the importance of religion as a way of coping with their child's difficulty. In addition to the 'purpose of life' theme that is mentioned above, the function of a religious approach to the Divine can be (i) to obtain healing, but it can also be (ii) to obtain mercy and forgiveness – or (iii) get punishment – for wrong-doing (Zinnbauer & Pargament, 2005). This seemed to be pertinent for some of the parents interviewed who described feeling blamed by their extended families. For many participants religion seemed to be the most salient aspect of their cultural background and provided a clear explanatory framework for them.

Parents also spoke of religion providing them with strength and resources to deal with any challenges that arise and this has also been supported in the literature (Bennett et al., 1995; Tarakeshwar & Pargament, 2001). For all of the participants who emphasised the importance of their religious beliefs, they also highlighted their spouse sharing their religious beliefs and practices. Studies of religious

coping have shown that shared faith decreases marital distress and enhances the support that spouses provide each other when coping with ASD (Bristol, 1987; Tarakeshwar & Pargament, 2001). A few of the participants in this study described using the deferring religious coping approach, where they placed the responsibility for coping on God whereas others referred to a collaborative coping approach where both themselves and God are both active partners in coping. Studies have consistently indicated that a collaborative coping approach is the most successful style (Zinnbauer & Pargament, 2005). None of the participants spoke of adopting the 'self directing' coping style that is independent of association with the divine.

Prayer was also a clear coping strategy for these parents where several participants made the direct link between prayer and their child getting better in the future. Coulthard and Fitzgerald (2011) also noted in their study that prayer was very important for parents with a child with an ASD. Poloma and Gallup (1991) observed four distinct types of prayer experience; colloquial or conversational prayer (e.g. talking to God as a friend); ritual or recitational (e.g. citing a memorized prayer); meditative (e.g. resting in God or being open and available to the divine); and, petitionary or intercessory (e.g. 'God, please help. . . '). Participants in this study predominantly spoke about engaging in petitionary and ritual prayer.

Although some parents spoke of the lack of support and understanding from their family members others made clear comparisons with the lack of support living in the UK compared to Bangladesh. They described a community approach to dealing with children with difficulties where they would receive support from a variety of people if they were in Bangladesh. This was clearly compared to the UK where an individualistic approach, where ties between individuals are loose (MacLachlan, 2006) was taken and less community support offered. This seemed to be viewed negatively by some parents and for some resulted in isolation. Studies have echoed this finding and suggest that in many cultures strong familial support is a key factor in adjustment and coping (McCubbin et al., 1998) such as in African American (Pruchno et al., 1997), Latino (Bailey et al., 1999; Skinner et al., 1999), and South Asian families (Chan 1986).

The findings from this study are unique in providing a detailed account of the impact of Bangladeshi parents' culture on their experience of having a child with a diagnosis of an ASD. In particular the findings have demonstrated that some of these parents described a process of cultural negotiation in order to make sense of their child's diagnosis. These participants clearly detailed the pros (such as having more family support or it being an advantage to have a quiet daughter in terms of her prospects for future marriage) and cons (such as being blamed for the child's difficulties, being stigmatised as having a 'fool' or a 'dumb kid' and being gossiped about among the local community) that arose from this cultural negotiation. However in parallel with other research of both South Asian and other groups this study found that religion was an important factor in both understanding and coping with their child's diagnosis.

4.3 In what ways can Clinical Psychologists and other staff in health services improve the experience of assessment and diagnosis for these families?

Findings from this study in relation to this research question will be outlined below with links to relevant literature and guidance. The clinical implications section later in this chapter will elaborate further upon these findings.

All of the families in this study noted that professionals did not ask any details about their cultural and religious background apart from simple demographic questions. Interestingly, although most of the participants emphasised that they felt this was not an important area to explore, many spoke of the challenges they faced related to their cultural background, particularly around the understanding of ASD. As previously noted several parents spoke of the challenges of explaining their child's difficulty and diagnosis to family members; some parents appeared to avoid this disclosure to those they felt would not understand or would understand in a stigmatising manner. In particular they commented on the lack of information in Bengali to share with their families. It seemed that some participants in this study were not fully supported by services communicating a clear understanding of ASD which was congruent with their beliefs. MacLachlan

also stresses that 'communication between practitioners and clients from different cultural backgrounds can be highly problematic and prohibit effective healthcare' (2006, p. 162). Furthermore Hatton et al. (2003) highlight that despite current policy initiatives emphasising the importance of providing information for families, the available sources of information such as websites and NHS Direct are unlikely to be used by South Asian families with a child with disabilities. Moreover in accordance with NAS (2005) guidelines for the experiences of minority ethnic families there is a need for service providers to have a basic understanding and training in the cultural needs of the established minority communities. They distinguish that it is equally important not to stereotype service delivery on the basis of ethnic background and the user should be listened to and services matched accordingly.

All of the parents in this study spoke of their anticipatory concerns for the future of their child. A particular worry for parents was whether or not their child's speech and language would develop over the coming years. Several participants spoke of their children 'growing out' of having autism in the future. Others emphasised the role of religion and prayer on the outcome for their child versus professional input, where they highlighted the direct relationship between prayer and their child talking. As the outcome for children with diagnoses of an ASD is variable (Goldstein et al., 2008), it is likely that some of the children in this study will consistently struggle with their language development and some may never talk. This realisation for families could be distressing and may have a detrimental impact on their own religious faith. Studies have shown that some parents can lose their religious faith when faced with such adverse situations (Reilly, Huws, Hastings, & Vaughan, 2008). The results of this study suggest that health professionals could have a role in providing support and realistic expectations for these children. If this is provided in a sensitive and meaningful way this could reduce parental distress in the future. This could be supported and facilitated by having an allocated worker to support the family and provide information as suggested by NAPC (2003) guidelines.

Jegatheesan et al, (2010b) in their study of South Asian families with a child with an ASD found that parents had different perspectives on the role of ASD in their

lives and held a more positive view than professionals. In particular parents objected to a focus on the child's limitations and shortcomings. The authors highlight that even just an acknowledgement by professionals of disability as a sacred obligation could have avoided misunderstandings around assessment and therapy.

Other concerns for the future that several parents expressed were worries about their child getting married as well as what would happen when they were no longer able to care for their child. Concerns about whether their child would be able to get married were present for the mothers and fathers interviewed who had both sons and daughters. O'Hara and Martin (2003) also highlighted that for Bengali parents it was very important to see their child with learning disabilities get married, seeing it as their parental role and responsibility adding that services often struggle with the ethical issues that this situation invariably poses. Several parents also noted specific concerns around who would care for their child once they had died or were no longer able to care for them. A few spoke of clear plans that they had in place such as their other children taking care of their sibling and this had evidently been discussed among the family. None of these parents spoke of the possible support that services would provide in the future and this again highlighted the importance of having the support from family and their community which some parents noted was lacking in the UK. The 2011 report collated by the UK Faculty of the Psychiatry of Learning Disability highlights the need for understanding and respect for different family structures is vital highlighting the importance of having a culturally competent workforce in these services that allows flexibility to adapt to the knowledge of communities and willingness to learn from them. They note that this should be integrated at all levels of an organisation such as the NHS.

Three of the parents spoke about the importance of having someone who had been through the process of an autism assessment. For these parents this person was Bangladeshi but none of them were introduced through the NHS service. The parents emphasised the significance of having someone who had been through the experience to talk to and to share stories and seek advice from.

It is also important for Clinical Psychologists and health care professionals to reflect on the ethical considerations of labelling people with a diagnosis of ASD when there is considerable doubt about the validity of the construct of ASD. Duffy and Dorner (2011) highlight that people with a diagnosis of autism are representing themselves in a variety of forums and venues such as on internet chat rooms and you tube. They add that these narratives expand and enrich understandings of 'autism'. A commitment to including such voices in research and in clinical practice will further understandings of the ways in which identity is socially constructed – whilst all the time recognising that people with a diagnosis of autism are active agents in their own self-definition (Duffy & Dorner, 2011).

Molloy and Vasil (2002) emphasise that it is likely that the labelling of children as having ASD will be increasingly contested as 'scholarship in the field is challenged into addressing the issues of the power dynamics involved in and the social repercussions of such labelling with its implications of deficit and pathology' (p. 669). They go on to suggest that such challenges will only occur if we continue to critically examine diagnostic labels such as ASD in terms of how they are contextualised in our culture as opposed to viewing them as personal pathologies. Services and healthcare professionals working at a diagnostic level should consider these implications for clinical practice.

In common with previous research this study found that services find it a challenge to meet the cultural needs of service users. This was particularly highlighted in the lack of questioning in this area as well as information provided in other languages in this case, Bengali.

4.4 Implications of Research
4.4.1 Implications for Future Research
It would broaden the analytic findings to interview Bangladeshi parents whose child had received a diagnosis of an ASD but were now further along their trajectory with their child. It would be particularly interesting to see if they shared similar views to the participants interviewed in this study or if they saw things differently in terms of how they felt the service met their needs or if they sought alternative interventions.

Although the interest of the service hosting the research was specifically about Bangladeshi parents, the transferability of the present analysis would be substantially improved if similar findings emerged from interviewing participants of other minority ethnicities. It would be of interest to ascertain if they faced similar challenges and difficulties as some of the parents in this study expressed.

As noted this study only interviewed parents who spoke English fluently as there was no possibility of using interpreting services due to financial restrictions. Given the resources, it would be important in the future to interview parents who did not speak English in order to give them a voice as it may be that their cultural background has a greater impact on their experience of having a child with a diagnosis of an ASD. Notably Hatton et al. (2003) have highlighted that it is well documented that people from South Asian communities living in the UK experience substantial inequalities, discrimination and disadvantage and this is likely to be exacerbated in families who do not speak English.

Findings in this study suggested that many of the parents interviewed had hopes for the future, which for some included their child talking and getting married. Conducting a longitudinal study with these parents or a similar sample would be crucial in order to capture adjustment, coping and beliefs around the diagnosis of an ASD over time. Religious coping was clearly reported as important for parents: Pargament's (1997) model predicts an attitude of co-operation with the divine (rather than a polarised relationship) as characteristic of successful coping. It would be important to ascertain if this would be shown to be true for these parents, over time. Moreover, theoretical models of adjustment and coping suggest that the ability to cope with demands varies over time depending on the stressors (Bennett et al., 1995; Hill, 1958; McCubbin & Patterson, 1982). Specifically trying to ascertain how parents adjust their beliefs and/or understanding around ASD if their child does not develop in the way that they would have hoped.

4.4.2 Implications for Clinical Practice

Some of the parents in this study talked about the detrimental impact on them after their child was diagnosed with an ASD for example parents gave descriptions of it being heart breaking and impacting on different areas of their lives such as work and family relationships. As a result services should consider the ethical implications of labelling children with an ASD as this medical model approach can lead to children being defined by their diagnosis and losing their individuality and limiting other people's expectation of them (Molloy & Vasil, 2002). Moreover services should consider who has the privilege to define autism or any category of human difference as Smukler (2005) argues that this privilege is not a scientific, but a philosophical and political one. In addition when taking a diagnostic perspective the source of the disability is firmly located within the individual and not as a result of the expectations of the social context in which the individual exists (Molloy &Vasil, 2002).

Although many of the participants expressed gratitude for the support offered to them by services their main sources of support appeared to come from other areas. These included family support, religious faith as well as support from someone who had been through the same process. Healthcare services could play a role in helping promote this less formal support to families by ensuring that they worked with it and not at odds with it.

As explained previously most of the parents felt that it was not important for services to ask about their cultural background. Despite making this statement several parents spoke of great challenges connected with their cultural background in particular helping their extended families understand ASD. It seems that services could have a role in supporting parents to share information with their families in a way which was congruent with their beliefs and values. In order to do this, professionals would need to have open conversations to try and get a sense of what these beliefs were. Part of the dissemination plan for this study will be to offer such conversations in the form of a brief training event put on to discuss the research findings with relevant staff.

Moreover health services could have a role in offering specific training to interpreting services to avoid any miscommunication or translation of the concept of ASD. Providing this would be crucial as it could alleviate any initial misunderstandings from parents as well as interpreters. It also seems vital that services develop sources of information which are readily available for families in their native languages. In line with the findings from Hatton et al. (2003) it would be important to provide ethnically integrated services that routinely met users' religious and cultural needs rather than having ethnically separate services. They added that the recruitment and retention of South Asian staff throughout mainstream services should be a priority and again this should also be a consideration, particularly in areas of the UK with a high South Asian population.

Some of the parents in this study highlighted the complexity of the assessment process. In particular parents spoke of the large number of professionals involved in their care and noted this was overwhelming for them. As a small but helpful step, one participant suggested that a simple solution of giving parents a list of all the professionals involved in their child's care and an explanation of their job title would have aided this and alleviated some of the confusion.

It is clear that a concern for all parents was for the future of their child. It seems that services should have a role in giving parents realistic expectations for the development of their child which could avoid parental disappointment and distress in the future though this may have to await research findings to guide best practice.

4.5 Critical Review

4.5.1 Recruitment

As noted in the method chapter the specialist health visitor in the service supported me with the recruitment of participants. A total of nine participants met the criteria for the study and they all agreed to participate. It is notable that having such a high rate of participation is unusual. It is likely that having someone from within the service who had previously met with the participants aided this. Additionally these participants were still accessing the service from which they were recruited and although it was made clear in the information sheets and in

conversations with participants that their choice to participate would in no way affect the care they received, it is possible they may have felt that not participating would have an impact on their child's care. That said, none appeared coerced; all participated in an engaged and enlivened manner.

4.5.2 Issues of Power

Hatton et al. (2003) highlight that South Asian families with a person with learning disabilities report both a low awareness and low uptake of specialist disability services. As described in the Introduction chapter the participants in this study all lived in the borough of Camden where the use of statutory community services by the Bangladeshi community is very low and in addition factors of social deprivation have been shown to affect marital and family relationships, making it more difficult for them to provide support to vulnerable members of the family (Beliappa, 1991; Thompson,1997). These inequalities that these participants are likely to have faced are likely to influence their relationship to the services (Fredman, 1996) and in return their perception of my role.

As a result , it is important to consider the influence that I may have had on the interviews and how freely participants chose to speak. As previously noted I am white and may have been seen by participants as representing powerful institutions such as my university or the NHS. It is clear that within the wider context parental explanations and understanding of their child's ASD diagnosis may be subjugated by academic and professional explanations that occupy a more powerful position (MacLachlan, 2006).

Whilst the current findings represent the experiences of these particular parents they may not be representative of all parents. The study used an homogenous sample within a single autism assessment service. Although I tried to enable parents' voices to be heard within the academic forum, I as the researcher have had control of the data. Moreover I have attempted to be open about the assumptions of IPA notably that access to the experience of participants is not only dependent on what they tell us about their experience, but also that I, as researcher then needed to interpret that account (Smith et al., 2009).

4.5.3 Reflexivity

As previously stated Smith et al. (2009) clearly describe the researcher's role in interpreting the data collected in IPA. It is thus crucial to consider the influences which come from myself as the researcher in order for these to be considered[25]. Throughout the course of conducting this research I kept a record of my experience, thoughts and ideas to assist with this process. I was deeply touched by all of the interviews that I conducted and I found myself in awe of the parents I spoke with who described tremendous strength, commitment and perseverance despite the daily challenges they faced. I have felt a great responsibility to provide a write up of this study which faithfully reflects the experiences they have expressed.

It was particularly interesting to me that religion was significantly talked about by participants in their interviews. Although in hindsight this may seem obvious my personal lack of religious beliefs played a part in my assumption that it would not be widely discussed. In fact in the interview schedule I had only placed a question about religion as a prompt. This suggests that I was able to be flexible and allow the participants' experiences to take precedence over my assumptions as this was a prominent theme in the data.

I have found Ryde's (2009) book particularly helpful when critiquing and thinking about my initial reading of the data I gathered. In particular I was very aware that some of the questions that I had asked participants may have suggested that there is a norm to be different from and their cultural background was 'different' and 'different' to mine (e.g. the question can you tell me about your cultural background). Although like Ryde I feel it is important to acknowledge 'other' cultures it has been just as important for me to consider my own culture, my own cultural assumptions as I have been trying to interpret the participants' experiences from my own perspective, understandings and beliefs about the world. As McHoul (2004) suggests as professionals we are analysing professionally what has already been analysed by 'laypersons'. Moreover whilst analysing the data I was aware that I wanted to stay as close as possible to the

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[25] See section 2.4.1 in the Methodology section for initial details of the researcher in context.

data and I initially struggled between getting the balance between being too interpretative and too descriptive.

One particular difference which I have reflected upon is the idea that often in the white western world the focus is on the individual as the unit of society. I have reflected that this is certainly how I view the world that my values are built on the rights and responsibilities of the individual. As Ryde notes we 'have a clearly defined image of ourselves as complete units, boundaried by our skin' (2009, p. 113).   However this view is by no means universal and for some of the participants this came through in the data. Whilst analysing the data I ensured that I tried to be as open as possible to these views but I did wonder if I was more attuned to participants' talk which was 'different' to my beliefs as opposed to those who perhaps share a 'similar' view to me. I reflected on this in relation to Kanta's descriptions of what I interpreted as the differences between living in the UK and living in Bangladesh (see p. 46-47). Perhaps this stuck out to me in the data for the reasons described above. As a result of this I tried to be aware of this prejudice and look out for 'multiple' perspectives.

4.6 Evaluation of Qualitative Research

Smith et al. (2009) highlight that there is an increasing awareness of the importance of assessing the quality of qualitative research which is largely due to dissatisfaction with using the criteria of validity and reliability used in quantitative research. Guidelines which researchers should consider when conducting qualitative research have been outlined (Elliott et al., 1999; Yardley, 2000). Yardley (2000) provides four broad principles for assessing the quality of qualitative research and I have found that considering these has provided a framework to enhance and ensure the quality of my research. Each of these principles will be addressed in turn and will draw largely on Smith and colleagues' account of assessing the quality of qualitative work (2009).

1. *Sensitivity to context:* Researchers using IPA often demonstrate sensitivity to context very early on in the stages of the research process. The choice of IPA in this study was centred on the need for sensitivity to context through close engagement with the idiographic and the particular. The

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research questions were focused on the contextual aspects of participants' lives with a particular emphasis on their cultural background. Moreover I have endeavoured to show an awareness of both the substantive and theoretical literature in order to orient both the study and its findings. I have also been transparent about my actions and characteristics in order to be aware of how these may affect the study in its various stages. I have also demonstrated a strong sensitivity to the data by including a large number of verbatim extracts to support any arguments being made and thereby allowing the reader to check any interpretations which are being made.

2. *Commitment and Rigour:* Using IPA as the method of analysis meant that I showed a great deal of attentiveness to the participant during the data collection as well as with the analysis of the data. Through this attentiveness I have demonstrated prolonged engagement with the topic as well immersion in the data. Rigour, as defined by Yardley (2000, p.221), refers to the 'resulting completeness of the data collection and analysis. This depends partly on the adequacy of the sample… in terms of its ability to supply all the information needed for a comprehensive analysis'. The sample in this study was selected very carefully to match the research question and was a homogenous sample as far as possible.

3. *Transparency and Coherence:* I have attempted to provide a clear and detailed description of all of the stages of this research process. Moreover I have tried to demonstrate a coherent argument throughout the write up of this study by considerable drafting and re-drafting. I have also shown commitment to providing a good fit between this research and the underlying theoretical assumptions of IPA.

4. *Impact and Importance:* The research aims of this study were drawn together with the hope of providing a piece of research which would offer clear practical and useful findings which could inform services. This has been a thread throughout the study with the hope of improving autism assessment services for service users in the future.

4.7 Limitations

Although it was made clear to participants that the research would be anonymised, and specific information from participants would not be shared with the service, some participants may have been concerned about this and my role within the service. It is possible that this may have limited how freely participants spoke to me about their experiences of the service, in particular any criticism they may have had. Their main concern is likely to have been gaining support for their child and therefore they may have been apprehensive about the impact of the interviews on their child's care. However it is notable that some participants did speak critically about aspects of the service they received and suggested improvements.

It is also important to note that those who agreed to participate in the study were still accessing NHS services. By default this excluded participants who were no longer accessing this service. It is clear that these participants may have very different views and beliefs around ASD as well as the interventions and support offered by mainstream services. As previously highlighted some research suggests people from different cultural backgrounds seek alternative treatments so it is likely that some potential participants were no longer accessing the service where I recruited from (Yeh et al., 2004).

Furthermore this study interviewed both fathers and mothers of children with a diagnosis of an ASD where only two fathers were interviewed. Findings from this study suggest that within some Bangladeshi families there are clearly defined gender roles. Having a more homogenous sample interviewing only fathers or mothers may have led to further findings.

While this study provided rich descriptions of the experiences of participants IPA does go further to help in the understanding of why such experiences take place and why there may be differences between individuals' phenomenological representations, instead it describes and documents the lived experience without explaining it (Willig, 2008). In order for this to take place it would be important for further studies to be aware of the conditions which give rise to these experiences

which may be found in past events, histories or the social and material structures within which we live our lives.

A great deal of consideration was taken with regards to the choice to include participants who did not speak English as a first language[26]. In this study one participant appeared to struggle with their English language in the interview and I had some concerns about the data this interview may provide. However, despite the account of the experiences not being as detailed as some other participants, this participant provided some very rich descriptions of their experiences which have been included in the analysis section. The choice was made to include these participants as the challenges greatly outweighed the potential benefits that this research could offer.

4.8 Concluding statement

This is the first study of its kind to explore not only the experiences of Bangladeshi parents with a child with a diagnosis of an ASD but also with a focus on the impact of their cultural background on these experiences. It will add to the small body of research in this area with the hope of informing clinical services. Parental interviews demonstrated a range of experiences, understanding and coping strategies that these families adopted. Parental reports testified to their tremendous strength and perseverance in the face of great adversity. This study has presented the role of culture to be complex and multi-faceted with descriptions of it being a help, a hindrance or sometimes both when it came to making sense of their child's diagnosis of an ASD.

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[26] See section 2.5.2 for further details

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APPENDIX I – ASD Diagnostic criteria DSM-IV-TR and ICD-10

1. DSM-IV-TR

299.00 Autistic Disorder

A. A total of six (or more) items from (1), (2) and (3), with at least two from (1), and one each from (2) and (3):

    (1) qualitative impairment in social interaction, as manifested by at least two of the following:

        (a) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

        (b) failure to develop peer relationships appropriate to developmental level

        (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (eg, by a lack of showing, bringing, or pointing out objects of interest)

        (d) lack of social or emotional reciprocity

    (2) qualitative impairments in communication as manifested by at least one of the following:

        (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)

        (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

        (c) stereotyped and repetitive use of language or idiosyncratic language

        (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

    (3) restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following:

        (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

        (b) apparently inflexible adherence to specific, non-functional routines or rituals

        (c) stereotyped and repetitive motor mannerisms (eg, hand or finger flapping or twisting, or complex whole body movements)

        (d) persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication or (3) symbolic or imaginative play

C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

299.80 Asperger's Disorder

A. Qualitative impairment in social interaction, as manifested by at least two of the following:

(1) marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

(2) failure to develop peer relationships appropriate to developmental level

(3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (eg, by a lack of showing, bringing or pointing out objects of interest to other people)

(4) lack of social or emotional reciprocity

B. Restricted repetitive and stereotyped patterns of behaviour, interests, and activities, as manifested by at least one of the following:

(1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

(2) apparently inflexible adherence to specific, non functional routines or rituals

(3) stereotyped and repetitive motor mannerisms (eg, hand or finger flapping or twisting, or complex whole-body movements)

(4) persistent preoccupation with parts of objects

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (eg, single words used by age 2 years, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction), and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behaviour, interest, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes 'atypical autism' – presentations that do not meet the criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

The diagnostic criteria for DSM-IV-TR have been reprinted with permission from the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision, (Copyright 2000). American Psychiatric Association.

2. ICD-10

F84 Pervasive developmental disorders

A group of disorders characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communication, and by a restricted, stereotyped, repetitive repertoire of interests and activities. These qualitative abnormalities are a pervasive feature of the individual's functioning in all situations.
Use additional code, if desired, to identify any associated medical condition and mental retardation.

F84.0 Childhood autism

A type of pervasive developmental disorder that is defined by: (a) the presence of abnormal or impaired development that is manifest before the age of three years, and (b) the characteristic type of abnormal functioning in all the three areas of psychopathology: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour. In addition to these specific diagnostic features, a range of other nonspecific problems are common, such as phobias, sleeping and eating disturbances, temper tantrums, and (self-directed) aggression.
Autistic disorder Infantile:

• autism

• psychosis

Kanner's syndrome
Excludes: autistic psychopathy (F84.5)

F84.1 Atypical autism

A type of pervasive developmental disorder that differs from childhood autism either in age of onset or in failing to fulfil all three sets of diagnostic criteria. This subcategory should be used when there is abnormal and impaired development that is present only after age three years, and a lack of sufficient demonstrable abnormalities in one or two of the three areas of psychopathology required for the diagnosis of autism (namely, reciprocal social interactions, communication, and restricted, stereotyped, repetitive behaviour) in spite of characteristic abnormalities in the other area(s). Atypical autism arises most often in profoundly retarded individuals and in individuals with a severe specific developmental disorder of receptive language.
Atypical childhood psychosis
Mental retardation with autistic features
Use additional code (F70-F79), if desired, to identify mental retardation.

F84.5 Asperger's syndrome

A disorder of uncertain nosological validity, characterized by the same type of qualitative abnormalities of reciprocal social interaction that typify autism, together with a restricted, stereotyped, repetitive repertoire of interests and activities. It differs from autism primarily in the fact that there is no general delay or retardation in language or in cognitive development. This disorder is often associated with marked clumsiness. There is a strong tendency for the abnormalities to persist into adolescence and adult life. Psychotic episodes occasionally occur in early adult life.
Autistic psychopathy
Schizoid disorder of childhood

F84.8 Other pervasive developmental disorders

F84.9 Pervasive developmental disorder, unspecified

The diagnostic criteria for ICD-10 have been reprinted with permission from the World Health Organization.

APPENDIX II - Participant Information Sheet

Study title: The experience of Bangladeshi parents of children who have been diagnosed with an Autism Spectrum Disorder

I would like to invite you to take part in my research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. **I will go through the information sheet with you and answer any questions you have.** Please feel free to talk to others about the study if you wish.

Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study. Please ask if there is anything that is not clear.

Researcher name: Stephanie Doig
Email: 0933873@uel.ac.uk
Phone: 0208 223 4174/4567

PART 1

What is the purpose of the study?

There is very little research which has taken into account cultural perspectives when looking at the experience of families where a child has been diagnosed with an Autism Spectrum Disorder (ASD). An aim of this study is to try and understand the role that culture may play in their experience and their understanding of the diagnosis. Having a greater knowledge of these experiences will hopefully help improve the experience of assessment and diagnosis for these families in health services.

You will be asked to answer interview questions about your experience of having a child with a diagnosis of ASD as well as how your cultural background impacts this. The interviews will last approximately one hour. The interview will be recorded and transcribed by the researcher.

Why have I been invited?
You have been invited to participate in this study as you are a Bangladeshi primary care giver whose child has recently been diagnosed with an Autistic Spectrum Disorder.

Do I have to take part?
It is up to you to decide to join the study. I will describe the study and go through this information sheet with you. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?
If you decide you would like to take part in the study I will contact you to arrange a time to meet with you to conduct an interview. During this meeting I will ask you some broad questions about your experiences of having a child diagnosed with an Autistic Spectrum Disorder and how your cultural background may relate to this experience. The interview will last approximately one hour.

I will not access the medical files of your child. I will ask you some basic information in the interview such as gender of your child, age at time of diagnosis, number of siblings and age at time of interview.
The interview will be audio recorded as I will need to transcribe the content of the interview.

What will I have to do?
If you agree to participate a time will be arranged to meet with me where you will be asked some broad questions about your experiences of having a child diagnosed with an Autism Spectrum Disorder and how your cultural background may relate to this experience. This meeting will last about an hour.

What are the possible disadvantages and risks of taking part?
The subject area being discussed may be emotive for you. You are free to leave the study at any time. You are also free to take a break and continue at a later time. If it is felt that you are becoming distressed, you will be reminded that you are free to leave the study at any time or are free to take a break and continue at a later time.

If you continue to show signs of distress I will offer you some contact details for further support. If you are still in contact with MOSAIC NHS services your key worker will be informed that you were distressed in the interview in order to provide you with further support.

Additionally I will ensure that there is a qualified member of staff who will be contactable when I am conducting interviews. In a situation where a participant is highly distressed and support is required immediately I will contact this member of staff for further support and supervision.

The content of the interview is confidential unless I am worried about you or another person in which case a member of the MOSAIC team will be informed.

What are the possible benefits of taking part?
Any benefits to you may be minimal although talking to someone about matters that concern you who is not directly involved in your care may be experienced as helpful. It is unlikely that there will be a direct benefit to you in participating in this study. However, the information you provide will hopefully help develop services by making the necessary adaptations to improve the experience of assessment diagnosis and intervention for families similar to your own.

What if there is a problem?
Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.
Will my taking part in the study be kept confidential?
Yes. I will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

<center>**PART 2**</center>

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

What will happen if I don't want to carry on with the study?
You are free to leave the study at any time. Any data (for example interview recordings or transcriptions) will be extracted from the study and destroyed. This will not affect the care your child receives from Camden MOSAIC.

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researcher Stephanie Doig who will do their best to answer your question.
Stephanie Doig,
University of East London,
Stratford Campus,
Romford Road
Water Lane
E15 4LZ
Telephone: 02082234174
Email: 0933873@uel.ac.uk

If you remain unhappy and wish to complain formally, you can do this.
Details can be obtained from the Secretary of the University Research Ethics Committee:
Ms Debbie Dada,
Admissions and Ethics Officer,
Graduate School,
University of East London,
Docklands Campus,
London
E16 2RD
Tel 020 8223 2976,
Email: d.dada@uel.ac.uk

Harm
In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for

<center>125</center>

a legal action for compensation against Camden PCT but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in this study be kept confidential?
Individual interviews will take place at NHS Camden MOSAIC or at your home depending on which is more convenient for you. Interviews will be recorded using a digital voice recorder and are expected to last roughly an hour. After the interview, you will be given the opportunity to reflect on your experiences of the interview with the researcher. Recordings of the interview will be transcribed. Interviews will be anonymised during the transcription process and any identifying markers removed. Anonymity of data collected will be assured by assigning each participant a code. These codes, as well as consent forms will be kept in a locked cabinet separate to the digital records, transcribed materials and demographic details. The researcher will transcribe all of the interviews. All of the identifiable information contained in the interviews will be anonymised. Only the researcher, supervisors, and examiners (from the University of East London) will have access to the transcribed material. Data will be securely stored on a computer and accessed by a password, and erased after five years. After examination of the research has been concluded, all digital recordings will be erased. The study will be written up for a number of audiences, e.g. thesis, journal article etc. Participants will be offered the opportunity to receive a summary of the results.

What will happen to the results of the research study?
The study will be written up for a number of audiences, e.g. thesis, journal article etc. Participants will be offered the opportunity to receive a summary of the results.

Who has reviewed the study?
Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the
1. The University of East London Registration Board
2. Camden PCT Provider Services
3. NHS Research Ethics Committee
4. University of East London Research Ethics Committee

Further information and contact details
   1. **General information about research.**

For general information about research:

   http://en.wikipedia.org/wiki/Research

For information about Psychological research contact the British Psychological Society

BPS website with Frequently Asked Questions about research:

http://www.bps.org.uk/the-society/code-of-conduct/research-frequently-asked-questions.cfm

2. Specific information about this research project.

Researcher name: Stephanie Doig
Email: 0933873@uel.ac.uk
Phone: 0208 223 4174/4567

Or

Dr Martyn Baker
University of East London,
Stratford Campus,
Romford Road
Water Lane
E15 4LZ
Telephone: 02082234174
m.c.baker@uel.ac.uk

3. Advice as to whether you should participate.

Researcher name: Stephanie Doig
Email: 0933873@uel.ac.uk
Phone: 0208 223 4174/4567

Or

Dr Martyn Baker
University of East London,
Stratford Campus,
Romford Road
Water Lane
E15 4LZ
Telephone: 02082234174
m.c.baker@uel.ac.uk

Or contact your key worker at NHS Camden MOSAIC

4. If you are unhappy with the study

If you have a concern about any aspect of this study, you should ask to speak to the researcher Stephanie Doig who will do her best to answer your question.
Stephanie Doig,
University of East London,
Stratford Campus,
Romford Road
Water Lane
E15 4LZ
Telephone: 02082234174
Email: 0933873@uel.ac.uk

If you remain unhappy and wish to complain formally, you can do this. Details can be obtained from the Secretary of the University Research Ethics Committee:
Ms Debbie Dada,
Admissions and Ethics Officer,
Graduate School,
University of East London,
Docklands Campus,
London
E16 2RD
Tel 020 8223 2976,
Email: d.dada@uel.ac.uk

Thank you for reading this – please ask any questions if you need to.

APPENDIX III – Interview Schedule

Introductions will take place at the start of the interview. Participants will be given an idea of what to expect from the interview (i.e. length of time, informing them they can take a break if they need to). They will be asked to sign and read the consent form. Once this is completed the interview will commence.

Participants will be asked about their child, age, gender, age at time of diagnosis, number of siblings and order of birth.

1. How would you describe your child? Tell me about your child

2. Can you tell me about the time when you first noticed your child may have some difficulties?

   Possible prompts: How did you feel? How did you cope (who talk to/get support from)? What happened next? What did you do? What lead to an assessment at Camden Mosaic?

   3. Can you tell me about your experience of the assessment at Camden Mosaic?

   Possible prompts: Who was involved in the assessment? What did they do/say that was useful/less useful?' 'What did you value/find difficult about what they did/said'? Was there any part of the service which was more/less useful? In what ways did Camden Mosaic respond to your cultural needs?

   4. How would you describe your cultural background? Can you tell me about your cultural background?

   Possible prompts: How culture impacts your day to day life? How culture impacts family life/way you raise your children? Can you tell me about your experiences of being Bangladeshi and living in London? Experiences of cultural fit/mis-fit e.g. Schooling experiences, working experiences, leisure activities, in relation to child- day care, pre schooling/education.

   5. Can you tell me how your cultural background has influenced you as a mother/father/care-giver?

   Possible prompts: In what ways? Views on parenting raising children, views on male/female roles of child, religious beliefs/practices, activities with child, interaction with other parents/families? Can you tell me about your family (extended family, support systems)?

   6. Can you describe your initial reactions to receiving a diagnosis of ASD for your child?

Possible prompts: How did you feel? Who did you talk to? How did you cope with it? In what ways/where did you seek support? Can you tell me about the hopes you have for your child?

7. Can you tell me how your child's diagnosis fits in with your cultural background?

Possible prompts: How do you explain it to family members or members of community? Treatment options: in what ways do they fit/ not fit with culture? Views on alternative treatments? Community's understanding of ASD?

8. We are coming to the end of our time. Is there anything you would like to add?

[Left margin handwritten notes: he's not like other children, but different / childs interests / challenges / everyday life / Challenge / family system / relationships]

51
52 P1: Not as like the other children will *[handwritten: comparing with other children (normal vs abnormal?)]*
53
54 I: Hmm
55
56 P1: um like I was telling you earlier we went to Chessington *[handwritten: help me understand]*
57 yesterday but to him it wasn't no bother, no interest even when *[handwritten: repitition]*
58 he got there *[handwritten: is state saying this is unexpected / abnormal?]*
59
60 I: yeah
61
62 P1: No interest when the rides were there. You know it was just *[handwritten: repitition - he was there, but was he there]*
63 something he was there he was there. *[handwritten: repitition]*
64
65 I: Yeah
66
67 P1: He had his little transformer toy which the whole day he had *[handwritten: how spends days]*
68 that in his hand busy with that. So
69
70 I: yeah ok
71
72 P1: Yeah its quite difficult to get him to be sort of excited you *[handwritten: get him excited/happy]*
73 know to sort of um notice the surroundings he's in? *[handwritten: what does that mean for a mother? → tough]*
74
75 I: Yeah
76
77 P1: Um I don't see him getting that excited. Yeah *[handwritten: repitition emphasis that he doesn't get excited]*
78
79 I: Yeah yeah sure. So so who's at home with Akash? Who lives
80 at home?
81
82 P1: Um He's got his grandparents his father, he's got me his *[handwritten: content @ home]*
83 brother and sister and his auntie *[handwritten: ownership]*
84
85 I: OK And what are his relationships like?
86
87 P1: He's very close to his grandmother.
88
89 I: Mm-hmm
90
91 P1: Very close um he goes to her for everything *[handwritten: what about mum roles? impact on her role]*
92
93 I: Does he? Yeah
94
95 P1: You know whenever he's upset, whenever the feels down *[handwritten: repitition - explains on his relationship with her]*
96 you know it's always his grandmother. Even sleeping you know
97 he'll go sleep near his grandmother. He sort of gets his way with
98 her so he knows, you know? *[handwritten: justification - if that's why that's ok - not as threatening to her role as mother]*
99
100 I: Yeah

2

101
102   P1: She's been there a lot for him I think. Especially since I've *uncertainty*
103   had my baby the little one I haven been able to give him as *shift?*
104   much attention.
105
106   I: Yeah
107
108   P1: So he's you know always with his grandmother a lot of the
109   time he's got a very close relationship with her. *emphasis + repitition*
110
111   I: Oh. and is she um your husband's mother?
112
113   P1: Yes that's right.
114
115   I: Yeah Ok. Ok and then who else is at home?
116

117   P1: He's got his auntie. He's got his grandfather. His *family context*
118   grandfather's quite elderly so he's not able to do much *(members of the home) impact*
119   physically he just bed ridden. *of this*
120
121   I: Mm-hmm
122
123   P1: His auntie he is a bit close to her *suggest wants to be close to her but can't*
124
125   I: Yeah
126

127   P1: but she's sort of um working, cos she's working out and *hesitation*
128   about so you know he doesn't spend that much time with her. *time = closeness?*
129
130   I: Oh ok
131

132   P1: Um you know I would say he's close to his dad as well. *her opinion? Dad?*
133
134   I: Yeah
135

136   P1: His, um yeah he, yeah he he can um I mean with his brother *relationship with sibling.*
137   and sister with his with the baby he's I mean them two I don't
138   know what it is (laugh) but they seem to have this tension *laughter - when talking about*
139   between them. *something difficult*
140
141   I: Hmm *expectation that should still play?*
142

143   P1: They don't know how to play together then even I mean the *relational impact of Akash's condition*
144   baby I feel that he's picked it up from Akash that every time he
145   goes near Akash he will push him away so now he's learnt to *graphic - extensive physical description of violence*
146   push back as well so they'll both, if you've got them sitting near
147   each other they'll just probably be pinching biting pinching
148   fighting, kicking each other. You know you have to separate the
149   two *is that how she sees them arguing as abnormal?* *separate normal*
150

3

151 I: Yeah. And what's that like for you at home?
152
153 P1: Oh, it's quite mad. To be honest. It is quite difficult. Cos
154 yeah I can't keep them near each other. I mean there has been
155 times when X has hurt him quite badly. I mean one time the
156 baby was going up the stairs and Akash up the stairs as well and
157 I think the baby maybe pinched him well I donno what
158 happened but he did actually push him down the stairs and it
159 was actually quite a bad fall. So I am always having to be sort of
160 very weary of where they are and to keep them like apart. Um
161 it's I mean it is quite difficult cos yeah. Even getting them into a
162 car making sure they don't sit near each other cos you know
163 they'll start hitting each other pinching each other pinching each
164 other fighting with the toys. (Sigh). So yeah.
165
166 I: So how do you manage that? What do you do?
167
168 P1: I mean most of the time, I do, I mean if my daughter is
169 around I do have to sort of put her I mean depend on her quite a
170 bit. Get her to like sit between them. Get her to you know to
171 break up the fights. Yeah like Especially if I'm driving.
172
173 I: How old is she?
174
175 P1: Um She's seven.
176
177 I: She's seven. Oh OK.
178
179 P1: So um hey I mean am I quite grateful that I do have a
180 daughter
181
182 I: Yeah
183
184 P1: there cos she's I mean she's very understanding and I think
185 she does understand a lot so she's able to sort of be there to help
186 out
187
188 I: yeah
189
190 P1: when it's needed. So yeah
191
192 I: Sounds like it, certainly
193
194 P1: Yeah. Cos Akash doesn't understand the baby you can't get
195 him to understand
196
197 I: Yeah
198
199 P1: so its end up being her who has to take on that role really.
200 So yeah

4

I: Um. Ok. I'm just interested really in when you first noticed
Akash had difficulties, when you noticed something wasn't
quite right.

P1: Um, I mean as a baby I think he was, he was fine up to the
age of one I would say.

I: hmm

P1: About one and half he seemed alright. But as he started
getting nearer to the age of two. I mean we did sort of notice he
just didn't want to play with any of his cousins, anyone else. He
just always wanted to like sit by himself in a room. I mean like
if you put him in the room like if you put him in the living room
with a like cartoon he likes he will just sit and watch that.

I: Yeah

P1: If anyone came and went in like his cousins and want to play
he won't want to join in.

I: Ok

P1: and one thing I mean everyone, I mean my sisters and
everyone did always say to me whenever you call Akash's name
he wouldn't respond.

I: Yeah

P1: And even if they were sitting near him calling him and
calling him

I: Yeah

P1: he just wouldn't look at them so they you know say why is
that he never like looks at us or never responds to us? But I
didn't pick up on any of that to be honest I just thought yeah Ok
maybe he just doesn't want to um but then as he got reached two
I mean it continued and I think I did notice he wasn't saying any
words it was very difficult to get him to repeat after you, you
know he wouldn't be interested in singing along to songs and I
used to be like. Cos I mean I I cos my daughter when she was
about 1 and half 2 she would watch the cartoon pick up the
songs, look through books and she'll repeat after you so I sort of
notice that with x he didn't have any of that so I did think oh
that's a bit strange

I: yeah

5

134

Communicates
language.

251 P1: why is he not say anything. Um but I think yeah that as soon
252 as he got to two and about two and a half I think I was pregnant
253 at the at time and he started to play up
254
255 I: hmm
256

family
transitions

257 P1: um cos I was working and I left cos I went on maternity
258 leave and I was at home with him and I just noticed he just
259 became very difficult to manage to deal with. Um his behaviour.
260 I mean he was always restless he was jumping around a lot
261
262 I: hmm
263

Communication 264 P1: he was kicking he was I mean every little thing he wanted to
265 say or couldn't say or he wanted and I didn't understand him it
266 used to go into a tantrum
267
268 I: hmm
269

Communication 270 P1: he would be kicking, crying, I couldn't understand
271 anything,
272
273 I: yeah
274
275 P1: I couldn't understand what was wrong with him so it was
276 quite difficult and I think me being pregnant I was at the sort of
277 the last stage
278
279 I: Yeah
280
281 P1: so I was quite heavy I didn't haven't have as much strength
282 as if I wasn't pregnant
283
284 I: yeah course
285

guilt
coping

286 P1: I probably would have been able to manage it a bit better. So
287 I kind of yeah didn't know what was going on anymore. I
288 couldn't really deal with it.
289
290 I: Yeah, how did you cope at that time?
291
292 P1: Um?
293
294 I: How did you yeah?
295
296 P1: I think he just went into tantrums a lot.
297
298 I: hmm
299

Handwritten margin notes: compare with sibling – what normal/expected / when first noticed something not right / transition in family – pregnancy – work pattern – changes / (with him) – find it hard to cope/deal/manage / a lot to cope with → all over the place / what does that mean / (both he can't understand + she can't understand) / further as under? / biographic – violent + aggressive – lack of understanding – frustration / tough time these she she. / vented my letter as well as pregnancy / → guilt – needed a lot of strength to cope / guilt / too much going on – and can't cope / (not coping) / Challenging behaviours

6

135

300 P1: He had a lot of tantrums. He would jump. I mean I think he
301 would get bored and all that he would do was just jump jump
302 jump
303
304 I: Yeah
305
306   P1: and I was just like I couldn't stop. He used to jump on the
307 sofa's he would jump he would get up onto like the tv stand.
308 Jump on the bed he'd jump from the windowsill he would just
309 jump it's like he had no fear in him.
310
311 I: Hmm
312
313 P1: He didn't notice the fact that he might hurt himself he
314 would jump. He would just jump.
315
316 I: mm-hmm
317
318 P1: He would to my mother in law like his grandparents room.
319 He would get onto the chest of drawers and jump from there. So
320 every second I was like what is wrong with him you know why
321 is behaving like this?
322
323 I: Yeah
324
325 P1: If I was to sit near him he would just kick me. It was
326 difficult but he wouldn't sleep he wouldn't go to sleep and I
327 used to be very tired and found it quite a hard time putting him
328 to sleep. He would kick kick kick like throughout the night and I
329 used to have to hold into bed to put him to sleep, it was a very
330 difficult, very stressful, very emotional time
331
332 I: Sounds like it
333
334 P1: Time. I mean I just didn't get him at all.
335
336 I: Yeah. Who supported you through this?
337
338 P1: Um my husband was there but I don't think my husband
339 actually he, just um I mean he works full time and then when he
340 doesn't work he is at home but he does go out with his mates or
341 whatever it is that he does. So he was at that time, I don't think
342 he really noticed it. Even though I told him. He just thought it's
343 just a stage he's going through. He'll come out of it. I don't
344 think anyone really. I mean. I did think or feel. You know given
345 my husband and his grandparents they just thought it was
346 something that I've done I've made him like that. He's a spoilt
347 child. It was just really difficult cos I
348
349 I: Yeah. How did that make you feel?

emotional
reaction.

impact on
mother

initiation

Smearing
(challenging)

lack of
understanding
of behaviour

coping

350
351　P1: I mean I was quite. I mean to be honest I was very sort of
352　emotional, very down I think when I look back at it now I
353　always say to myself I was probably in this depression mode
354　which I didn't even know.
355
356　I: Hmm
357
358　P1: But yeah I think I was very depressed at that time
359
360　I: Hmm
361
362　P1: because I just felt like everyone is blaming me instead of
363　supporting me. And yeah and sorry
364
365　I: yeah
366
367　P1: the other thing which was extremely difficult he used to do
368　with really made my life difficult was he used to um like pooh in
369　his nappy but if he was in his room and he suddenly poohed in
370　his nappy by the time I came to see himhe would put his hand in
371　his nappy
372
373　I: yeah
374
375　P1: he would smear it on the walls, smear it on the floor. And
376　that just sort of really yeah that sort of being pregnant being
377　having to clean that up all the mess that he, it wasn't just once
378　twice he did that. It's just like the amount of times he did it. Oh.
379　It was just disgusting.
380
381　I: yeah
382
383　P1: it was smelly it was horrible.
384
385　I: Yeah
386
387　P1: That was really. It was like. I just couldn't understand it. It's
388　like why would you, why you do that? You know he used to
389　take off his nappy and play with the oh it was just really
390　horrible. I think it was yeah that time. It was just a really
391　horrible experience
392
393　I: It sounds like a really stressful time actually
394
395　P1: Yeah it was
396
397　I: Especially being very pregnant as well.
398

'depression mode' impact

emotional strain - impact of
blame + lack of understanding?

repetition - achanagement
that 'was' depressed
every

blame vs support.
sense of isolation

- pooh
shitty
what it was
like for
her.

- last straw?

emphasis on how
disgusted.

what broke the
camels back?

disgust / graphic / horror.

- why?
disgusted
too much @ that time
+ t+ stress

- a lot to deal with

8

137

Left margin annotations:
cultural roles

blame

blame
abandonment

framework of understanding

comparison

Main text:

399 P1: Yeah I think the role that I was in because I was living with
400 my well living with my mother in law its like they had this, I
401 had to be this. You know this um, the daughter in law. I had to
402 be a wife, I had to be a mother. And you know the fact that they
403 didn't understand that if I wasn't able to do these other two
404 roles.
405
406 I: Yeah
407
408 P1: And you know the fact that they didn't understand that if I
409 wasn't able to do these other two roles and could I'm trying to a
410 mother. Its like they couldn't understand this added to the sort of
411 pressure by blaming or saying it was my fault he was like that or
412 it's something that I might have done that he's behaving like
413 that.
414
415 I: Hmm
416
417 P1: You know and one thing I did get cos I was working
418
419 I: Hmm
420
421 P1: well I was working part time well it was 2.5 days a week
422 but because I left him and I didn't give him enough attention
423 that's' why he's you know, why he's been like that. And I didn't
424 give him enough attention
425
426 I: Hmm.
427
428 P1: That s why he's delayed in his speech he's delayed in his um
429 in his um you know. I mean that's why his behaviour is the way
430 it is.
431
432 I: Hmm
433
434 P1: And I mean I was just like urgh hey. Cos you know cos
435 when my daughter, when I had my daughter I was working full
436 time and I didn't spend hardly anytime with her but my daughter
437 was fine she didn't have any problems
438
439 I: Hmm
440
441 P1: and I was saying to them but I'm only working 2.5 days
442
443 I: yeah
444
445 P1: and I spend a lot more time with him than I did with my
446 daughter but he's you know I don't know why his speech is
447 delayed.
448

Right margin annotations:
- role within family - in laws
- multiple roles - not being able to fulfill them to level expected
- self failure
- family not understand roles → blame
- parent blamed → roles/blame (bless)
- Asking for my understanding? female + working?
- abandoned him?
- idea that she left / enough attention → blame
- blame - explanation of why like this
- share of reference for tony to understand why like this
- comparison / justification
- they step fine
- blessed argument
- defensive / defending self
- contrasts justify + explain actions
- why?

449 I: Hmm

450

451 P1: I mean I haven't chosen. You know it's like I didn't do
452 anything to say yeah I don't you to you know speak I want you
453 to be the way you are.

454

455 I: Yeah

456

457 P1: So I was like how can you blame me? So it was really
458 stressful. I don't think anyone actually understood what I was
459 going through everyone is just there to judge

460

461 I: Sure

462

463 P1: And it makes it very difficult

464

465 I: It sounds it. And was there anyone you were able to turn to
466 and talk to about these issue

467

468 P1: To be honest there was my sisters and they were very
469 helpful, I mean they were ones that supported me. I mean they
470 were the ones that picked it up as well but I just didn't want to
471 hear it. I was like what are you talking about there's nothing
472 wrong with him. I don't even understand what ASD was? I
473 didn't hear of it to be honest. But my sister cos they studied in
474 uni and stuff you know they have worked with um other
475 children with it so they sort of picked up the symptoms.

476

477 I: Oh ok

478

479 P1: But um. Yeah and I think yeah you know afterwards, you
480 know I suppose yeah once I sort of read about it yeah it actually
481 did make it a lot clearer and um Yeah I think once it was
482 diagnosed and just knowing like. I think it was yeah it was so
483 much help, it just made it clearer It just gives you an
484 understanding. Instead of not. Cos I didn't understand him at all.

485

486 I: Hmm

487

488 P1: You know I just. Um. Yeah I mean yeah he was at that stage
489 of hitting. So he'd

490

491 I: Yeah

492

493 P1: hit any child that came near him. He couldn't play with his
494 cousins cos he, any toy that he had he would just whack them.
495 Um you know cos if he was two there was another one, cos his
496 cousins they are all of similar age. But the way he would hit
497 them would be quite dangerous. It would always be on the head

10

139

APPENDIX V – Consent Form

<u>UNIVERSITY OF EAST LONDON</u>

I have the read the information leaflet relating to the above programme of research in which I have been asked to participate 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 researchers involved in the study will have access to the data. It has been explained to me what will happen once the experimental programme has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me.

Having given this consent I understand that I have the right to withdraw from the programme at any time without disadvantage to myself and without being obliged to give any reason.

Participant's Name (BLOCK CAPITALS)

…………………………………………………………………….

Participant's Signature

……………………………………………………………………………..

Investigator's Name (BLOCK CAPITALS)
…………………………………………………………..

Investigator's Signature

……………………………………………………………………………

Date: …………………………

APPENDIX VI - University of East London Ethics Committee Approval Letter

SCHOOL OF PSYCHOLOGY
Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.
uel.ac.uk/psychology

UEL
University of
East London

Doctoral Degree in Clinical Psychology
Direct Fax: 0208 223 4967

June 2011

Name of Student	Stephanie Doig
Title of Research Project	An exploration of the experience of Bangladeshi primary care givers of children who have been diagnosed with an Autism Spectrum Disorder

To Whom It May Concern:

This is to confirm that the above named student is conducting research as part of the requirements for the Professional Doctorate in Clinical Psychology. The Ethics Committee of the School of Psychology, University of East London has approved their proposal and they are, therefore, covered by the University's indemnity insurance policy. . This policy should normally cover for any untoward event provided that the experimental programme has been approved by the Ethics Committee prior to its commencement. The University does not offer "no fault" cover, so in the event of untoward event leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the above named is a student of UEL the University will act as the sponsor of their research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Kenneth Gannon PhD
Research Director

Dr Martyn Baker   020 8223 4411   M.C.Baker@uel.ac.uk   Dr Nimisha Patel   020 8223 4413   N.Patel@uel.ac.uk
Dr Maria Castro   020 8223 4422   M.Castro@uel.ac.uk   Prof Mark Rapley   020 8223 6392   m.rapley@uel.ac.uk
Dr Sarah Davidson   020 8223 4564   S.Davidson@uel.ac.uk   Dr Neil Rees   020 8223 4475   N.Rees@uel.ac.uk
Dr Kenneth Gannon   020 8223 4576   K.N.Gannon@uel.ac.uk   Dr Rachel Smith   020 8223 4423   r.a.smith@uel.ac.uk
Dr David Harper   020 8223 4021   D.Harper @uel.ac.uk   Dr Robyn Vesey   020 8223 4409   r.vesey@uel.ac.uk
Dr M Jones Chesters   020 8223 4603   m.h.jones-chesters@uel.ac.uk Ruth Wacholder   020 8223 4408   r.wacholder@uel.ac.uk
Dr Paula Magee   020 8223 4414   p.l.magee@uel.ac.uk   Administrators 020 8223 4174/4567 c.wickham@uel.ac.uk/ j.chapman@uel.ac.uk

Stratford Campus, Water Lane, Stratford, London E15 4LZ
Tel: +44 (0)20 8223 4966   Fax: +44 (0)20 8223 4937   MINICOM 020 8223 2853
Email: mno.davies@uel.ac.uk

APPENDIX VII – Local NHS Research Committee Approval Letter

NRES Committee London - City Road & Hampstead

South West Research Ethics Centre
Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0117 342 1339
Email: ubh-tr.CityRoadHampsteadREC@nhs.net

13 May 2011

Miss Stephanie Doig
Trainee Clinical Psychologist
Camden and Islington Mental Health NHS Trust
University of East London,
Stratford Campus, Romford Road
Water Lane
E15 4LZ

Dear Miss Doig

Study title: **An exploration of the experience of Bangladeshi primary care givers of children who have been diagnosed with an Autism Spectrum Disorder**
REC reference: **11/LO/0209**
Protocol number: **n/a**

Thank you for your letter of 05 April 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Committee held on 16 May 2011. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

The Committee strongly recommended that the Participant Information Sheet states that the project has been reviewed by the City Road and Hampstead REC.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

142

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date	
Covering Letter		11 February 2011	
Evidence of insurance or indemnity		10 February 2011	
Interview Schedules/Topic Guides	1	11 February 2011	
Investigator CV		11 February 2011	
Other: Peer review by University of East London		27 January 2011	
Other: Peer Review by NoCLoR		02 February 2011	
Other: Supervisor CV		09 February 2011	
Participant Consent Form	1	11 February 2011	
Participant Information Sheet	2	08 April 2011	
Protocol	1	11 February 2011	
REC application		14 February 2011	
Response to Request for Further Information		05 April 2011	

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

> Notifying substantial amendments
> Adding new sites and investigators
> Progress and safety reports
> Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

11/LO/0209	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

Dr David Slovick
Chair

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments*
	"After ethical review – guidance for researchers" *(via email)*
Copy to:	*Dr Ken Gannon*
	Mr Pushpsen Joshi, NoCLoR-North Central London Research Consortium
	NHS Camden Provider Services

APPENDIX VIII- Camden NHS Research and Development Approval Letter

NHS

**North Central London
Research Consortium**

Research Operations Unit
3rd Floor West Wing
St Pancras Hospital
4 St Pancras Way
London
NW1 0PE

General Enquiries: 020 3317 3756
Office Fax: 020 3317 3760

16th May 2011

Miss Stephanie Doig
Trainee Clinical Psychologist
Camden and Islington Mental Health NHS Trust
University of East London
Stratford Campus, Romford Road
Water Lane
E15 4LZ

Dear Miss Doig,

Title: An exploration of the experience of Bangladeshi primary care givers who have been diagnosed with an Autism Spectrum Disorder

LREC Ref: 11/LO/0209

R&D Ref: 11PC20

I am pleased to confirm that the above study has now received R&D approval, and you may now start your research in **NHS Camden**. May I take this opportunity to remind you that during the course of your research you will be expected to ensure the following:

- **Patient contact:** only trained or supervised researchers who hold the appropriate Trust/NHS contract (honorary or full) with each Trust are allowed contact with that Trust's patients. If any researcher on the study does not hold a contract please contact the R&D office as soon as possible.
- **Informed consent:** original signed consent forms must be kept on file. A copy of the consent form must also be placed in the patient's notes. Research projects are subject to random audit by a member of the R&D office who will ask to see all original signed consent forms.
- **Data protection:** measures must be taken to ensure that patient data is kept confidential in accordance with the Data Protection Act 1998.
- **Health & safety:** all local health & safety regulations where the research is being conducted must be adhered to.
- **Adverse events:** adverse events or suspected misconduct should be reported to the R&D office and the Ethics Committee.
- **Project update:** you will be sent a project update form at regular intervals. Please complete the form and return it to the R&D office.
- **Publications:** it is essential that you inform the R&D office about any publications which result from your research.
- **Ethics:** R&D approval is based on the conditions set out in the favourable opinion letter from the Ethics Committee. If during the lifetime of your research project, you wish to make a revision or amendment to your original submission, please contact both the Ethics Committee and R&D Office as soon as possible.

Please ensure that all members of the research team are aware of their responsibilities as researchers. For more details on these responsibilities, please check the R&D handbook or NoCLoR website:
http://www.noclor.nhs.uk

We would like to wish you every success with your project

Yours sincerely,

Mrs Angela Williams
R&D Manager