

**The cultural context of caregiving: A phenomenological exploration of the experiences
of South Asian carers caring for children with intellectual/developmental disabilities**

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Abstract

This thesis adopted a phenomenological approach to exploring how culture shapes the experiences of South Asian carers caring for children with intellectual/developmental disabilities in the UK. This was achieved by conducting a series of interviews and focus group discussions with parents and service providers in order to provide first hand and detailed accounts of their experiences. A unique aspect of the research is that it draws on multi and cross cultural perspectives. A striking feature of the accounts was how cultural identity can shape the way in which parents make sense of and cope with disability. In particular, the process of acculturation and the parents struggle to manage two conflicting cultures, was seen to play a significant role in shaping the experiences described. Ultimately, the research has generated important knowledge using participants' lived experiences to enhance our understanding of South Asian carers' culture and in doing so makes recommendations for service delivery.

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I dedicate this thesis to all of the above.

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Key terminology

The following section outlines the key definitions/terminology used throughout the thesis.

Intellectual/developmental disabilities

Often, the terms intellectual and developmental disability are used interchangeably, however there are differences between the two. Firstly, the terminology used varies greatly depending on the country and context it is being used in. For example, intellectual disability is the term favoured by North America, which has replaced the term mental retardation. Conversely, in the United Kingdom (UK) the term learning disability is used in the context of health and social care which, has replaced the term mental handicap. In general, the term intellectual disability is not used in the UK because it tends to focus on intellectual impairment and does not account for impairments to adaptive and social functioning which, according to the UK definition are important.

Regardless of the term used, there are three universally accepted criteria for defining intellectual/learning disabilities which according to the British Psychological Society (2001) are:

- Significant impairment of intellectual functioning (measured by psychometric assessments)
- Significant impairment of adaptive/social functioning (e.g. a persons' ability to cope on a day to day basis, measured by observations)
- Age of onset before adulthood (e.g. impairments acquired during the development period which is below the age of 18).

In the UK, learning disabilities can be classified according to three or four categories which are mild, moderate, severe and profound (Department of Health, 1992). Classification into these categories is dependent upon the severity of the impairment to intellectual and adaptive/social functioning.

Developmental disability is often used as an umbrella term to refer to a range of cognitive and physical impairments that occur during the development period of children (usually up to the age of 18). Developmental disabilities refer to severe disabilities which can be entirely cognitive (e.g. intellectual disability), entirely physical (e.g. cerebral palsy) or both (e.g. down's syndrome). According to the American National Institute for Child Health and Development (NICHD), developmental disabilities are caused by birth defects which lead to physical or cognitive disabilities. There are two main types of birth defects which are, structural or functional abnormalities both of which are present at birth. Structural birth defects refer to problems with body parts (e.g. heart defects and abnormal limbs). Functional birth defects refer to problems with how a body part or system functions. Birth defects can be caused by genetic and chromosomal abnormalities, or environmental factors (e.g. exposure of pregnant women to rubella or drug and alcohol usage). Developmental disabilities can be categorised into four main sub types which are:

- *Nervous system disabilities* - birth defects which affect the functioning of the brain, spinal cord and nervous system, which can impact on intelligence and learning. It can also lead to behavioural disorders, speech and language difficulties, convulsions and mobility disorders. Some common nervous system disabilities include down's syndrome, fragile X syndrome and autism spectrum disorders.

- *Sensory related disabilities* – often go hand in hand with other disabilities and include things such as visual problems (e.g. blindness, cataracts) and hearing loss (e.g. deafness).
- *Metabolic disorders* – birth defects which affect a person’s metabolism and can lead to phenylketonuria (PKU) or hypothyroidism.
- *Degenerative disorders* – these disorders are detected in late childhood, when children show signs of a loss of function and include disorders such as Rett syndrome.

Recently, the term intellectual/developmental disabilities (I/DD) has been introduced by the World Health Organisation (International Classification of Disease 10th revision, ICD-10, 1992). This is the term which has been adopted for use in the thesis as it encompasses a range of disabilities and therefore fits in with the shape of children’s disability services in the UK, which cater for a broad range of cognitive and physical disabilities.

South Asian

In the United Kingdom (UK) the term South Asian refers to individuals of South Asian heritage, usually Indians, Pakistanis, Bangladeshis and to a lesser extent, Sri Lankans, Nepalese and Maldivians (British Sociological Association, 2005). The term South Asian reflects the migratory patterns of this ethnic community into the UK. The term usually excludes people of East Asian heritage (e.g. Chinese, Korean or Japanese) who tend to be defined by their country of origin or as ‘oriental’ as is reflected in the ethnic categorisation in the UK census. This is in contrast to North America and Australia, who use the term Asian to refer to individuals of East Asian heritage (Australian Bureau of Statistics, 2006).

According to the 2001 Census (Office of National Statistics), approximately 4% of the UK's population are South Asian. Indians (1.8%), Pakistanis (1.3%) and Bangladeshis (0.5%) make up the largest ethnic groups. South Asian communities in the UK hold different religious identities which is usually a reflection of their country of origin. For example, Indians tend to be Hindu, Sikh and Muslim religions and Pakistanis and Bangladeshis tend to be Muslim. South Asian communities also speak a variety of languages with some of the most frequently used being Hindi, Punjabi, Urdu and Mirpuri.

Culture

There are a number of definitions and theories of culture. Some theories define culture as a combination of personal values and societal influence that impact on the way in which a group of people understand and interpret the world (Hoecklin, 1993). Such definitions have been challenged as presenting a static view of culture. Alternatively, transactional theorists view culture as a more interactive and dynamic process that is open to change (Kapferer, 1976). Similarly, cultural theorists (Douglas, 1970; Wildavsky, 1987; Thompson, 1996; Gross & Rayner, 1985) suggest that members of one cultural group may become members of another culture or multiple cultures. According to Douglas's (1970) cultural theory, cultures are ways of life supported by or challenged by other cultures, suggesting that cultures are susceptible to change.

According to Shweder (1991), a cultural anthropologist, culture is made up of 'intentional worlds' which in return are made up of 'intentional objects'. These 'intentional objects' include concrete things but also human behaviour. Therefore the intentional world is a world of meaning in which a person lives. Using these concepts Shweder defines culture as:

‘Culture refers to persons, society, and nature as lit up and made possible by some already there intentional world. Intentional worlds are composed of conceptions, evaluations, judgements, goals and other mental representations already embodied in socially inherited institutions, practices, artifacts, technologies, art forms, texts and modes of discourse’ (p. 101)

Shweder further suggests that difficulties arise when one comes to studying the intentional worlds of people. He proposes that one can only study another person’s world from the own vantage point of one’s own world which he calls ‘thinking through others’. This definition fits well with the focus of the current research which aims to explore the cultural context of caregiving through the use of interpretative phenomenological analysis (IPA). In particular, the idea of ‘thinking through others’ fits well with the hermeneutic stance of IPA which focuses on the researcher trying to make sense of the participant making sense of their experiences.

Acculturation

From a psychological stance, acculturation refers to the change that occurs when individuals from one culture come into contact with individuals from another culture (Graves, 1967).

The most widely utilised acculturation model is Berry’s (1997) acculturation framework. According to Berry’s framework, acculturation is defined across two dimensions which are the degree of ‘participation’ with the mainstream culture and, the degree of ‘maintenance’ of heritage culture. The model suggests that the degree of participation or maintenance can lead to four acculturation strategies:

- *Assimilation* – heritage culture rejected in favour of mainstream culture
- *Separation* – heritage culture retained and mainstream culture rejected
- *Marginalisation* – both cultures rejected
- *Integration* – both cultures are embraced

Acculturation is an important concept to consider when researching South Asian communities as it recognises the changes that can occur across generations. Depending on the types of strategies employed by different generations, acculturation is likely to lead to different interpretations and responses to caregiving and consequently, new challenges for service providers.

CHAPTER 1

An introduction to the literature

Literature search strategy

A literature search was conducted in order to identify a body of literature to inform the rationale for the current research. Rather than asking a specific research question, this literature search employed a conceptual approach to identify relevant literature in relation to South Asian communities in the United Kingdom and intellectual/developmental disabilities. This open approach was adopted to maximise the chances of identifying relevant papers.

Two search strategies were employed to review the literature. Initially the terms presented in Table 1.1 below were entered into the following databases: EMBASE, PsycINFO, Psycharticles, MEDLINE, Web of Science, Applied Social Science Index and Abstracts (ASSIA) and Social Care Online.

When choosing databases care was taken to utilise resources from medical, psychological and social perspectives to increase the chances of getting relevant papers. The searches were limited to titles and abstracts and were restricted to peer reviewed journals, in English. To reflect the recent changes in policy regarding the provision of health care to individuals with intellectual/developmental disabilities, the search was limited to articles from January 1994 to September 2011. The search was conducted by combining the two terms (and the truncated alternatives).

Table 1.1

Literature search terms

Intellectual/developmental disability	South Asian**
Developmental disability*	South Asian
OR	OR
Intellectual disability*	Ethnic
OR	OR
Learning disability*	Culture
OR	OR
Mental retardation	Black Minority Ethnic (BME)
OR	OR
Autism	Pakistani
	OR
	Bangladeshi

** Using these broad search terms encompassed the largest group of South Asians in the UK and enabled me to search for articles relating to other ethnic and religious backgrounds.

*Truncations were used in order to search for information in the databases more effectively.

Duplicate articles were removed and all remaining articles were evaluated as to their relevance to the review and consequently excluded if they did not relate directly to the topic area. A more detailed explanation of the exclusion criteria is provided in Table 1.2. Secondly, the reference lists of the remaining articles were examined to ensure all relevant articles were identified. The total number of articles identified via these search strategies is presented in Table 1.2, which also presents the number of core articles considered in the introduction.

As well as database searches, Google scholar was used to identify other relevant papers using the ‘search and cited by’ facilities. In addition to the core papers, literature which discusses complimentary topics, such as staff experiences of working with ethnic minorities, Government policy and acculturation amongst British South Asian communities, has also been drawn upon to provide supporting evidence where appropriate.

Table 1.2
Number of articles identified within the literature search

	Number of articles
Total articles identified from all databases	427
Articles not relevant*	367
Articles relevant	60
Duplicates	42
Articles identified via reference search	2
Total core articles included in the introduction	20

*The 427 articles identified by the databases were hand sorted and the following exclusion criteria was used to remove irrelevant articles: Non UK ‘Asian’ populations; Irish populations; relating to forensic populations; relating to palliative care; relating to psychiatric difficulties; relating to education; relating to genetics; general learning disability studies not relating to ethnicity (e.g. transitions, drug use and challenging behaviour).

Critical review of core papers

There has been much debate about the usefulness of checklists to appraise the quality of qualitative research and often researchers have reflected on the problems associated with the use of checklists. For example, Dixon-Woods et al. (2004) suggest that there appears to be little consistency between the criteria used to assess the quality of qualitative research. One of the key difficulties in producing a unified set of criteria is the plurality of qualitative methodologies, which often leads to a set of criteria relevant to certain studies but less relevant to others. There also appears to be difficulty in distinguishing between the transparency of reporting and the quality of analysis of different papers (Dixon-Woods et al., 2004). For example, certain papers may have followed the appropriate procedures for a particular approach and provided detailed accounts of the participants and methods used but failed to provide detailed interpretations and insight into the phenomena under investigation. Other studies may demonstrate the opposite qualities. For the current thesis I will draw on Yardley's (2000) guidelines as a means of critically evaluating qualitative research. Yardley's (2000) principles were chosen because they offer wide-ranging criteria and different ways of establishing quality. Additionally, they present criteria which can be applied to psychological qualitative research irrespective of the theoretical orientation of the study and in doing so avoid basing quality of research on a single epistemological stance.

Of the 20 core articles identified, 18 were critically reviewed. The remaining two articles were not included because they were literature review articles rather than empirical studies and therefore the appraisal criteria was not applicable. In order to critically review the papers I drew on the work of Sale & Brazil (2004) and Yardley (2000). Using their criteria for

appraising both qualitative and quantitative studies, I developed the following two checklists for critically appraising the core articles identified:

- *Quantitative checklist* - developed to appraise quantitative studies (see Appendix A, page 244). This checklist is based on the work of Sale & Brazil (2004) and consists of 18 criteria for assessing the quality of quantitative articles. Where articles had achieved the criteria a tick was given and where they had not a cross. Ten of the 18 core papers were quantitative studies and were therefore assessed using this checklist. For each paper the total number of ticks was tallied up to give an overall figure out of 18. Scores were then divided into the three categories below:

Gold (13-18)

Silver (7-12)

Bronze (1-6)

- *Qualitative checklist* - created to appraise qualitative studies (see Appendix B, page 245). This checklist is based on the work of Yardley (2000) and Sale & Brazil (2004). It consists of 15 criteria for assessing the quality of qualitative papers. Eight of the 18 core papers were qualitative and were therefore reviewed in terms of their adherence to the 15 criteria. Where papers had achieved the criteria a tick was given and where they had not a cross. For each paper the total number of ticks was tallied up to give an overall figure out of 15. Scores were then divided into three categories:

Gold (11-15)

Silver (6-10)

Bronze (1-5)

The raw results of the critical appraisal process can be found in Appendix A (quantitative checklist, page 244) and Appendix B (qualitative checklist, page 245). Additionally, detailed summaries of each of the core articles can be found in Appendix C (page 246).

Introduction

In this chapter, findings pertaining to the experiences of South Asian parents caring for children with intellectual/developmental disabilities in the United Kingdom (UK) are presented. The chapter opens by exploring the prevalence of intellectual/developmental disabilities within the South Asian community in the UK. The remainder of the chapter aims to explore the ways in which South Asian families' caregiving experiences and understandings of disability are shaped by their culture. This will be done by exploring the research under the following topic areas: conceptualisations of disability, caregiving patterns, the impact of caregiving, barriers to service uptake and acculturation and caregiving.

South Asian populations in the UK and the prevalence of intellectual/developmental disabilities

Research has demonstrated a link between ethnicity and the prevalence of intellectual disabilities. For example, Emerson et al. (1997) collected data regarding the numbers of people with learning disabilities across three Boroughs in North England. They did this using two methods. The first involved identifying Asian people with learning disabilities by reviewing those making contact with services. For example, people who had used or were using adult learning disability services, attended or were attending a school for children with learning disabilities or were considered by the project team to meet the criteria of learning disabilities. The second method involved identifying Asian and non-Asian people with learning disabilities using a case register. Using these methods, Emerson et al. (1997) found that the prevalence of severe learning disabilities in South Asians aged between five and thirty-two to be up to three times higher than in any other communities in the UK.

Additionally, of those families 19% had more than one family member with an intellectual disability. These findings have been criticised by McGrother et al. (2002) who suggest that the study represents a three-fold lower prevalence among white individuals rather than a genuine excess in South Asian individuals. McGrother et al. (2002) also conducted a prevalence study employing a cross sectional design. They used the Leicestershire learning disabilities register to identify South Asian and white adults with a learning disability alongside structured interviews (using assessment batteries). In contrast to Emerson et al.'s (1997) study, they found similarities in the prevalence rates of intellectual disability amongst South Asian and white adults. There are a number of factors that could account for these differences. For example, Emerson and Hatton (2004) suggest that factors such as regional differences, age, ethnic composition and social deprivation of the populations under study may all account for these inconsistencies in the results. They further postulate that differences in the samples studied may have accounted for differences in the prevalence rates. For example, Emerson et al. (1997) studied individuals aged between 0-45 years old whilst, McGrother et al. studied individuals aged between 20-70 years old. Additionally, Emerson et al. used a sample which consisted primarily of individuals from Pakistani communities, whilst McGrother et al. used a primarily Hindu sample, which may have resulted in differences due to ethnicity, culture and social deprivation. Finally, McGrother et al. used an assessment battery which was not tested for reliability and validity across different ethnic and linguistic groups which may have confounded the results. Overall, both the studies have limitations in that they relied on learning disability registers which only account for South Asian individuals who are accessing services which is a limitation given that evidence suggests that South Asians are underrepresented in services (Chaplin, Thorp, Ismail, Callacott, & Bhaumik, 1996).

Recent research also suggests that socio-economic disadvantage and deprivation may be associated with an increased prevalence of intellectual/developmental disabilities amongst ethnic communities in the UK. The 2001 Census (Office of National Statistics, ONS) revealed that ethnic minority groups make up 8% of the UK's population, with South Asians, namely Indians and Pakistanis making up the largest ethnic groups. South Asian communities, in particular Pakistani and Bangladeshi ethnic groups are likely to face substantial inequalities, discrimination and disadvantage when compared to their white counterparts (Acheson, 1996; Emerson, 2010; Fazil, Bywaters, Ali, Wallace, & Singh, 2002; Hatton et al., 2010). For example, between 2005 and 2008, the median household income amongst Bangladeshi and Pakistani households was 42% lower than that of white households in the UK (Hatton et al., 2010). Research suggests that lower socio-economic status is thought to be linked to higher rates of chronic illness amongst the most disadvantaged minority communities in the UK (Acheson, 1996; Nazroo, 1997). Often these inequalities are evident in intellectual disabilities, as disadvantage can lead to poor access to services (e.g. maternity care), which might increase the prevalence of disabilities (Mir, 2001).

More recently, Emerson & Baines (2010) explored the association between ethnicity, socio-economic position of a household, area level deprivation and the prevalence of intellectual/developmental disabilities. The study used school census data in order to collect information on ethnicity (based on religious identity), socio-economic position (based on whether children were receiving free school meals and consequently whether their parents were accessing benefits), area level deprivation (based on postcodes and income deprivation affecting child index) and intellectual/developmental disabilities (based on special education needs statements). The results revealed positive correlations between lower socio-economic

position and higher levels of intellectual/developmental disabilities identification. Higher levels of area level deprivation were also associated with higher levels of intellectual/developmental disabilities identification. Overall, ethnicity was linked to lower rates of intellectual/developmental disabilities identification, with the exception of Bangladeshi and Pakistani groups, who showed higher levels of severe intellectual disability. This may simply be a reflection of the increase in the numbers of this minority group in the UK over the years. However, it may also be due to the fact that South Asian communities caring for individuals with disabilities in the UK are likely to face greater disadvantage than their white counterparts which puts them at a greater risk of having a child with disabilities. A strength of this study is that it made use of a large national sample of children and is therefore likely to provide a more representative picture of the incidence of disabilities.

Research has also postulated that certain South Asian communities may have a greater genetic risk factor for intellectual/developmental disabilities. For example, Morton, Sharma, Nicholson, Broderick, & Poyser, (2002) studied children from different ethnic groups in Derbyshire, England. They found that the incidence of genetic diseases such as Fabry's disease was ten times higher in the Pakistani group than in any other groups. Other studies have also shown a higher incidence of genetic and recessive conditions amongst South Asian groups which are associated with the onset of developmental delays (Bittles, 2001; Saggar & Bittles, 2008; Shaw, 2000). It has been postulated that this may be due to consanguineous marriage practices (within family marriage) amongst certain South Asian communities. However, other factors such as a higher prevalence of social and material deprivation may also be influential (Emerson & Hatton, 2004).

Intellectual/developmental disabilities and caregiving in South Asian populations

According to the 2001 Census (Office of National Statistics, ONS) it is estimated that there are at least 285,000 carers from ethnic minority groups in the UK. However, little is known about the extent of caregiving to children with intellectual/developmental disabilities specifically. Research from the UK suggests that culture plays a significant role in defining caregiving to individuals with disabilities in South Asian communities. Having conducted a literature search, the research appeared to fit four main areas which were conceptualisations of disability, caregiving patterns in South Asian communities, the impact of caregiving and coping and barriers to service uptake, which will be reviewed in the following sections.

Conceptualisations of disability

The way in which parents conceptualise their child's disability will ultimately shape the way in which they respond to the disabilities. British South Asian families have been shown to draw on religious appraisals of disability such as attributing the cause of disability to spiritual and supernatural causes. For example, Fatimilehin & Nadirshaw (1994) conducted interviews with 12 Asian and 12 white British families caring for a family member with intellectual disabilities in order to explore their perceptions and beliefs. They found that when compared to white British families, Asian families held more spiritual/religious explanations about the cause of their child's disability and were more likely to rely on religion as a means of coping. For example, Hindu and Sikh carers were shown to hold beliefs that the disability and their caring role was a process of 'karma', arising due to fate and destiny because of their past misdeeds (Fatimilehin & Nadirshaw, 1994). Using religious beliefs enabled carers to make sense of why their child had a disability and as well as locate their understanding and

responses to the disability within a religious framework. A larger scale study was conducted with over 80 focus groups and over 30 interviews with male and female carers from South Asian communities (Pakistani, Bangladeshi, Gujarati and Punjabi) in the UK (Katbamna, Ahmad, Bhakta, Baker, & Parker, 2004). They demonstrated that carers' perceptions about disability ranged from pessimism to acceptance, with religion playing a central role in enabling some carers to view the disability as "God's will" or a gift from God and others to view it as a punishment from God.

Other, more recent studies have demonstrated that South Asian families may in fact hold multiple beliefs about the causation of disability. For example Dobson, Upadhyaya, McNeil, Venkateswaran, & Gilderdale (2001), using a mixed method design employing both qualitative and quantitative methods, found that South Asians attributed the cause of their child's autism to God's will, magic, mental health problems, illness and physical causes. Similarly, Bywaters, Ali, Fazil, Wallace, & Singh (2003) conducted semi-structured interviews with 19 Pakistani and Bangladeshi families caring for a child with a disability. They suggested that religious and theological explanations are adopted by South Asian families in the absence of medical explanations, thus situating the problem with services that fail to provide ethnic groups with appropriate explanations and accessible information regarding their child's disability. Croot, Grant, Cooper, & Mathers (2008) further suggest that South Asian parents may adopt simultaneous multiple beliefs about the cause of their child's disability. In their study Croot et al. interviewed 16 Pakistani carers of children with disability. They found that the majority of the carers held multiple beliefs about the disability, which focused primarily on theological explanations but also biomedical explanations alongside these. Croot et al. suggest that parents alternate between explanations according to

the situation. They suggest that while parents may initially adopt theological explanations, they may also adopt biomedical explanations when faced with negative ideas from other people within their ethnic communities. A unique factor of these two studies is that the samples included individuals born in the UK, which may have meant that the ability to speak English and generational differences could have also led to multiple beliefs about disability. Unfortunately, this was not explored in detail by the authors. The findings are, however, reinforced by similar research which suggests that a good understanding of medical explanations for their child's disability can help parents to reject and question negative ideas from other people (Hatton, Akram, Robertson, Shah, & Emerson, 2003). This research suggests that families tend to be influenced by a number of different factors. Additionally, religious interpretations of disability are not unique to South Asian communities. Cross cultural studies looking at Mexican, Puerto Rican and African American Christian carers have also highlighted the important role of religion in allowing carers to make sense of disability (Glidden, Rogers-Dulan, & Hill, 1999; Skinner, Correa, Skinner, & Bailey, 2001).

Caregiving patterns in South Asian communities

It is a common misconception that South Asian families have a preference for 'looking after their own' (Katbamna et al., 2004), within family units which is based on the notion that South Asian culture promotes collectivist values which focus on interdependence and support within the family. In reality, for British South Asian families caring for an individual with disabilities the opposite is likely to be true. Research involving South Asian immigrants to the UK has demonstrated that often South Asian families receive little or no support from extended families (Ali, Fazil, Bywaters, Wallace, & Singh, 2001; Katbamna, Bhakta, Ahmad,

Baker, & Parker, 2002). For example, Katbamna et al. (2004) interviewed 105 carers from a range of ethnic backgrounds such as Punjabi-Sikh, Gujarati-Hindu and Bangladeshi and Pakistani Muslim communities. Data generated from focus groups and interviews highlighted that South Asian carers received limited support from family networks which were correlated with the carers' obligation to provide care themselves and negative perceptions about disability amongst the South Asian community.

South Asian families caring for an individual with disabilities may face stigma (in the form of negative attitudes towards disability) from within their own communities which can lead to isolation (Ali, et al., 2001; Bywaters, et al., 2003; Mir, 2003). This can often lead to isolation and rejection of families from communities and can influence family honour and shame (Gilbert, Gilbert, & Sanghera, 2004). This can be a two way process with families avoiding communities whom they perceive to be negative and communities avoiding families with a disability. Amongst the South Asian community there is a strong emphasis on the obligation of families to care for family members themselves, which can lead to negative attitudes towards the use of services such as day centres and respite care (Katbamna et al., 2004). However, it is uncertain whether this is due to cultural preferences or whether it is linked to a lack of trust in western services.

Additionally, like other ethnic communities, mothers in South Asian families are thought to be responsible for the bulk of the care of their disabled child. The burden of caregiving for South Asian mothers in the UK however, is thought to be made harder due to their limited support from services which can lead to feelings of isolation (Chamba, Ahmad, Hirst, Lawton, & Beresford, 1999).

The impact of caregiving and coping

Research suggests that parents of children with intellectual/developmental disabilities are likely to experience significantly more stress than parents of typically developing children (Baker et al., 2003; Dumas, Wolf, Fisman, & Culligana, 1991; Hatton, et al., 2003; Hauser-Cram et al., 2001). A lack of support with caregiving demands can lead to significant social, psychological and physical consequences for the caregiver. Whilst carrying out the literature search it became evident that very few studies have directly explored the consequences of caring on South Asian carers. However, some of the studies did reveal the impact of environmental factors in influencing caregiver well-being.

For example, Hatton, Azmi, Caine, & Emerson (1998) interviewed 54 families of South Asian descent, mainly of Pakistani and Muslim origin, caring for an adolescent with learning difficulties. Using a translated version of the Malaise Inventory (Rutter, Tizard, & Whitmore, 1970) they revealed that South Asian carers had a higher risk for developing psychiatric problems when compared to other UK studies of caregivers to individuals with disabilities. This higher risk factor was attributed to higher unmet needs amongst South Asian groups as well as socio-economic disadvantage. However, it is also important to note that the results may have been affected by the lack of internal validity of the translated measure used which was not accounted for.

These findings have been reinforced by the work of Emerson, Robertson, & Wood (2004) in their comparative study of South Asian immigrant and white families of adolescents with intellectual/developmental disabilities. Emerson et al. (2004) explored the impact of child related factors, ethnicity and socio-economic deprivation on levels of psychological distress

reported by family carers of children with learning disabilities. Information was collected using postal questionnaires and interviews, consisting of a range of measures including the General Health Questionnaire (GHQ-12), used to measure psychological distress. Regression analysis revealed that 47% of the carers scored above the threshold for psychological distress which was associated with the emotional and behavioural needs of the disabled child, ethnicity and the severity of delay in child. However, it is possible that social deprivation, household composition and social support may have also influenced psychological distress as according to the author, the sample was drawn from an area of considerable social disadvantage. The study also received a low response rate (31%) which may have introduced bias in the identification of associations between GHQ scores and other variables. Additionally, where carers were unable to speak English, interviews were conducted by researchers who were able to speak their preferred language. GHQ assessments were translated. However, there is no mention of the validity or reliability of using such assessments cross culturally. Despite these methodological limitations the study still highlights a potential association between ethnicity and increased psychological distress amongst South Asian carers of individuals with disabilities.

Other studies have contradicted these findings. For example, McGrother et al. (2002) conducted a cross sectional study using a learning disability register to identify all South Asian and white adults known to services in Leicestershire. They used structured interviews based on the Disability Assessment Schedule (DSA). Interview data revealed that South Asian carers faced a higher financial burden. However, there were no differences between the two groups in terms of levels of stress and general health status. The results suggest that different families have different ways of coping and adapting to the challenges of caregiving.

The varied findings highlight the need for more research to explore the context of caregiving and how this influences families' adaptations and coping in order to inform service delivery. One of the major limitations of McGrother et al.'s study is that the samples used were variable in their age structures and social and material disadvantage. Although the authors did adjust for age, sex, city/county dwelling and level of understanding the possibility of residual confounding remained.

The notion of coping is important in the caregiving process due to the numerous physical and emotional demands placed on carers. Models of parenting stress have been proposed to understand the adaptations of parents caring for children with intellectual/developmental disabilities. A recent review paper (Hill & Rose, 2010) identified a number of parenting models which have been applied to intellectual/developmental disabilities. These include: the Double ABCX Model (McCubbin & Patterson, 1983); the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984); a Two Factor Model of Psychological Well-Being (Lawton, Moss, Kleban, Glickman, & Rovine, 1991) and; a Model of Parent-Child Interactive Stress (Mash & Johnston, 1990).

The Transactional Model of Stress and Coping is one of the most frequently used across the intellectual/developmental disabilities area. The model assumes that the way in which a situation is appraised will determine how stressful it is perceived to be. Primary appraisals include threat, harm, loss, challenge or benign. After having appraised an event, individuals then use secondary appraisals in order to determine how they will cope, which is often dependent upon the availability of resources. Coping is thought to be combination of both behaviours and emotions which focus on managing the negative emotions associated with the

stressful event. Coping strategies employed are thought to be flexible and new ones can be learned and old ones modified to deal with stressful situations. Some of most commonly used coping strategies include problem focused coping, emotion focused coping, social support, religious coping, and cognitive reframing. Finally, the coping process is recursive in that individuals are likely to evaluate the effectiveness of the coping strategies employed and modify them accordingly. From a western point of view Lazarus & Folkman (1984) suggest two widely used forms of coping, which are problem focused and emotion focused coping. As the name implies problem focused coping adopts a problem solving approach through seeking treatments, interventions, and definitions. Emotion focused coping however, focuses on limiting the emotional distress associated with a stressful event.

Little is known about the specific coping responses of British South Asian families caring for children with intellectual/developmental disabilities. However British South Asians have been shown to attribute the cause of disability to religious, supernatural and spiritual factors (Fatimilehin & Nadirshaw, 1994; Katbamna, Baker, Ahmad, Bhakta, & Parker, 2001; Bywaters et al., 2003; Croot et al., 2008). Religious causal attributions in particular, can provide families with a means of coping with caregiving demands, as it can lead to greater acceptance of the caregiving burden and consequently may enhance a carer's ability to manage stress (Durá-Vilá, Dein, & Hodes, 2010). For example, Fatimilehin & Nadirshaw (1994) found that religious beliefs can help carers to cope with their child's intellectual disabilities because religion has something specific to say about the disability and as a result gives them faith. Muslim carers specifically also discussed the reward they would gain as a result of caregiving, once they had died. Some of the faith associated with religion may be related to the fact that Asian communities have been thought to believe that their children may

be cured through religious interventions (Fatimilehin & Nadirshaw, 1994; Katbamna et al., 2004).

Thomas, Dowling, & Nicoll (2004) found that spirituality could play an important role in enabling parents to grieve and accept their child. For example, they found that for some parents the birth of a child with intellectual disabilities provided reaffirmation of their belief that their child was proof of God's purpose and faith in them as parents. Religious appraisals of the disability allow parents to view their caregiving duties as opportunities rather than burdens, which can be emotionally empowering and enable them to cope.

It is important to note that coping strategies are likely to change dependent on knowledge and exposure to similar people. For example, Lam & Mackenzie (2002) found that mothers who had more knowledge and interacted with other parents with children with disabilities held more positive appraisals and therefore had better coping strategies. Ultimately the ways in which people cope depend on the resources and services available to them, which is discussed next.

Barriers to service uptake

Research has demonstrated that South Asian families caring for an individual with intellectual/developmental disabilities are likely to have poor knowledge about specialist services despite a high awareness of general services such as GPs (Katbamna et al., 2002; McGrother et al., 2002; Hatton et al., 1998; Chamba et al., 1999). For example, Durà-Vilà & Hodes (2009) conducted a survey of teacher self-reports (using case files) of student demographic details, information regarding diagnosis and ethnicity. Data was collected from

242 children with mild/moderate intellectual disabilities across four schools in London.

Results revealed that service uptake (child and adolescent mental health services; community based social services and respite services) was lowest amongst South Asian communities. Regression analysis revealed that ethnicity in particular was a good predictor of respite service usage amongst South Asian groups. The study has the advantage of using a large sample of children. However, it is limited by its reliance upon school case note information which lacks reliability. In order to ensure its accuracy, this information would have needed to be cross checked against service records. Secondly, the study failed to make comparisons across different South Asian groups in terms of ethnicity or religion. Finally, the study cannot identify any specific reasons for the low service uptake amongst South Asian groups because parental beliefs were not explored. However, the authors postulate that South Asian children have lower levels of psychopathology and disruptive disorders (Hackett, Hackett, & Taylor, 1991; Meltzer, Gatward, Goodman, & Ford, 2000) which may have resulted in lower usage of mental health services. Additionally, they suggest that cultural and linguistic barriers may have contributed to lower service uptake amongst this group.

Service awareness is thought to be higher when the degree of challenging behaviour is higher, household incomes are higher, carers have a high proficiency in English or have lived in the UK for a long period (Hatton et al., 1998). Hatton et al.'s (1998) study reported that only 17% of the carers they interviewed felt confident that they would receive help in the event of a crisis. It is a common assumption that the low level of service uptake by South Asian families is counteracted by the support they receive from informal resources such as extended families and friends. However, as mentioned previously this is often a misconception and most

families struggle with caregiving demands with limited or no support (Katbamna et al., 2004; Hatton et al., 1998).

Research has identified a number of barriers to service uptake amongst South Asian communities such as inappropriate resources and facilities, language barriers, negative service attitudes, complex service pathways and discrimination (Chakraborty & McKenzie, 2002; Nadirshaw, 1997). However, it is important to note that difficulties in accessing services is not something which is unique to ethnic communities alone and are often reported by white communities in the UK (Fazil, et al., 2002; Sim & Bowes, 2005). In spite of this, it appears that these difficulties and barriers are exaggerated for South Asian communities, some of which will now be explored in greater detail.

Culturally inappropriate services

South Asian understandings of disability based on cultural and religious beliefs can become an issue when people come into contact with services, as their needs may not be matched (Chamba et al., 1999; Hatton et al., 1998; Hensel, Krishnan, Saunders, Durrani, & Rose, 2005). Parents' failure to engage with treatment plans may be seen as non-compliance, rather than based on a lack of understanding and in return parents may feel judged and unable to identify with health professional views which can lead to poor service uptake (Bywaters, et al., 2003; O'Hara, 2003).

There is a growing body of research on the views and experiences of ethnic minority families when trying to access learning disability services. However, the literature search revealed that very little is known about the service providers themselves and the challenges that working

cross culturally can pose. Much of the literature in the area examines the views and experiences of generic health and social care staff caring for ethnic minority patients and explores their experiences of providing culturally competent care (Hawthorne, Rahman, & Pill, 2003; Katbamna, et al., 2001; Owens & Randhawa, 2004; Richardson, Thomas, & Richardson, 2006; Summers & Jones, 2004; Vydellingum, 2006).

The literature search revealed a small number of studies which looked specifically at cross cultural working in learning disability services most of which employed case study designs. For example, Summers & Jones (2004) used three clinical case studies to provide insight into the issues, tensions and dilemmas raised for a community learning disability team when trying to provide culturally sensitive services. Overall, limited resources and personnel were identified as a barrier to delivering culturally sensitive care. Additionally, conflicts were highlighted between service values of individuality, choice and normalisation which were often seen to contradict with the values and beliefs of South Asian cultures. The study revealed that staff worked with difficult issues such as dealing with death and showing an appreciation for religious beliefs/customs. However, it focused on referrals to clinical psychologists who were all white females. Therefore, it does not precisely reflect the make-up of learning disability services which also include nurses, occupational therapists, speech and language therapists, physiotherapists, psychiatrists and social workers who can be both male and female as well as from different ethnic backgrounds. As a case study design the research is limited in its application and generalisation. However, it does provide an insight into the complexities of working directly with South Asian individuals with a disability including the challenges of exploring service users' religious and cultural beliefs within the confines of how services are delivered. However, the study appeared to pay little attention to the context in which the individuals with disabilities were situated including little attention to working with

the family which, research has shown, can often play a central role in the lives and care of South Asian individuals with disabilities (Katbamna et al., 2004).

Other studies have also explored the difficulties in reconciling cultural and religious perspectives whilst simultaneously trying to provide services. For example, Hepper (1999) describes the challenges raised by the arranged marriage of a Bangladeshi woman with moderate intellectual disabilities. The study revealed the challenges that different cultural perspectives can pose in terms of creating tensions between family responses to disability and professional concerns. Additionally, Hassiotis (1996) described two examples of working cross culturally with Greek and Kuwaiti families, within a psychiatric/clinical setting. Language was seen as a crucial component of the therapeutic relationship. A common theme amongst the families was their expression of grief/disappointment over the loss of the expected child. However, the way in which these emotions manifested was influenced by cultural values and beliefs. When conducting cross cultural work on immigrant families it is important to consider the reasons underlying the migration (e.g. seeking asylum) which could add to the complexity of the family's needs.

Research has also looked at the experiences of staff working directly in primary health care settings. Katbamna et al. (2001) aimed to identify the needs of minority ethnic carers. Using a staff group consisting of seven primary health care teams (GPs, practice nurses, administrative and reception staff and community team members) guidelines to improve cultural competence were developed. The staff agreed on the need to provide information in a way it can be understood, for assessments to identify needs of carers and more collaborative working with community trusts or health authorities. Unfortunately, the study did not mention

the ethnic composition of the group and whether there were ethnic minority staff involved who could represent local ethnic communities and their needs. Additionally, there was no consideration of the costs involved in implementing such guidelines.

Hawthorne et al. (2003) have also explored the perspectives of primary health care workers working with Bangladeshi patients. They used focus groups with 33 professionals (including doctors, practice nurses, nurse practitioners, receptionists, practice managers, health visitors, midwives and district nurses), from a range of ethnic backgrounds (including 6 Indians, 2 Bangladeshis, 1 Pakistani and 1 West Indian) working across four different healthcare centres in Cardiff. The results revealed difficulties with communication and language, feelings of frustration and helplessness and feeling restricted by the rigid nature of primary care service delivery which meant they found it difficult to meet patients' needs. The study has the advantage of using a large, ethnically and professionally diverse sample of service providers. However, it fails to consider the role of age, gender, acculturation, education and religious identity in influencing the experiences and attitudes of the service providers.

Recent policy drivers have recognised the need to develop culturally sensitive support services for ethnic minority groups (Hatton, 2007; Mir, 2001). Documents such as the National Carers Strategy (Department of Health 1999), Learning Difficulties and Ethnicity: A Framework for Action (Department of Health 2004) and Valuing People Now (Department of Health 2009) make recommendations for improving services for South Asian families. Despite these documents, mainstream services tend to be ill-equipped to provide appropriate services to ethnic families who define and address disability differently from the majority population (Ahmad & Atkin, 1996; Nazroo, 1997; Shah, 1995). For example, the second

national survey of learning disability partnership boards (Hatton, 2007) revealed that services still fail to consider black and ethnic minority communities when planning and implementing disability services.

More recently, cultural diversity policies have emerged in the UK (Papadopoulos, Tilki, & Shelley, 2004). The need to provide culturally sensitive services to ethnic minorities has been recognised as a key component in reducing ethnic health disparities (Bhopal, 2009). In the NHS and public health care services there has been investment in study days, short courses and longer cultural competence training programmes (Papadopoulos et al., 2004). However, literature surrounding the effectiveness of such courses and the experiences of health care professionals working with ethnic families is limited. Empirical studies have developed and evaluated culturally sensitive training programmes, instruments and interventions for healthcare professionals (Papadopoulos et al., 2004; Chevannes, 2002). Most of these studies propose principles for effective cultural competence training which concentrate on challenging ethnocentric beliefs, practices and prejudices amongst staff, rather than simply providing factual information.

To date, very few studies have explored the experiences of staff working directly with South Asian carers caring for a child with intellectual/developmental disabilities. However, the experiences of staff working with South Asian families in generic health services has demonstrated that many health professionals feel ill-equipped to respond to the needs of patients from different cultural backgrounds which can lead to a reliance on generalisations and stereotypes to inform the way they work with such minority groups (Chamba et al., 1999; Vydelingum, 2006). Therefore, more research is required to explore ways in which health

professionals working in learning disability teams address the challenges of working with ethnic communities in culturally a competent manner in order to make recommendations for improving policy and practice for ethnic minority groups.

Discrimination

Failure to provide culturally competent packages of care can lead to South Asian families feeling marginalised and discriminated against. For, example, Azmi, Hatton, Emerson, & Caine (1997) conducted 21 interviews with South Asian adolescents and adults with learning disabilities. They found that 63% felt they had been treated unfairly due to their ethnicity and 57% due to their disability. They also highlighted that day services failed to consider their religious customs and dietary needs. These negative attitudes were sourced to the local community and staff of local services. This has been described as ‘institutional racism’ (Azmi et al., 1997; Chamba et al., 1999) and is thought to be represented by poor quality service provision for ethnic communities. According to Ali et al. (2001) discrimination may be based not only on the disability but also other aspects of the individual’s personal identity. This can be referred to as ‘double discrimination’ and is related to negative views based on race and disability (Azmi et al., 1997). Hatton et al. (2010) found that families’ experiences of racism and discrimination can make them sceptical and cynical about the intentions of service providers and their motivations.

Language barriers

Language is an important means of communication and can greatly affect the relationships between South Asian families and service providers (Katbamna et al., 2002). South Asians in

the UK speak a wide range of languages. However there appears to be no data identifying the number of people speaking a certain language. Language has been identified as a barrier to service uptake and delivery of specialist disability services to ethnic minorities (Raghavan & Small, 2004; Bywaters et al., 2003; Sim & Bowes, 2005). Even for English speaking parents, understanding of medical terms and interventions can be difficult. For example Dogra et al. (2007) found that Gujarati parents and young people tend to assume that mental illness and learning disabilities are the same thing. Additionally, Dobson et al. (2001) found that Asian families in Bradford had limited understanding about autistic spectrum disorder (ASD) and viewed the disorder as being something which could be cured through socialisation.

Language has also been identified as a major barrier in the disclosure process. Hatton et al. (2003) found that of the 152 ethnic families they interviewed, two thirds had received a diagnosis in English (despite having preferences for another language), only one third had received any written information and when compared to their white counterparts, South Asian families received a diagnosis much later. The study also highlighted that poor disclosure related to information not being presented in a culturally or linguistically appropriate manner, impacted on acceptance of the child's condition and uptake of services and benefits. Hatton et al.'s (2003) study has the advantage of using a large and diverse sample of South Asian families originating from a number of countries (including India, Pakistan, Bangladesh and East Africa), and speaking a range of languages (including Urdu, Punjabi, Pashto, Bengali, Gujarati, Swahili and English).

In a more recent study Hatton et al. (2010) compared the impact of caring for a member with learning disabilities on 'majority' and 'minority' families in the UK. The researchers used the

terms 'minority ethnic' (which includes a sample of 5 Muslims, 1 Hindu and 1 Christian carers from minority groups) and 'majority ethnic' (which includes a sample of 5 Protestant Christians and 2 English carers). The study involved fourteen interviews with 'majority' and 'minority' carers and data were analysed using interpretative phenomenological analysis (IPA). They found that the 'minority' carers had less understandings of learning disabilities linked to not being able to use the English language, which the authors termed as reduced 'human capital'. The study has the advantage of being one of the first in the area to employ an open approach to conducting interviews and therefore giving participants the flexibility to raise things that are important to them and, in doing so is likely to reveal new ideas. Additionally, the study used feedback from parents of people with intellectual disabilities in relation to the development of the interview schedule. However, although the study claims to provide a comparison of minority and majority families the data were analysed as one group and therefore a single set of themes were generated to encompass both groups. This is not a standard approach adopted when using IPA, which tends to rely on homogenous samples.

Other studies have also identified language as a primary challenge to delivering culturally sensitive packages of care to ethnic communities. For example Jackson (2007) explored the health beliefs, knowledge and current practice in relation to cultural competence of 75 health visitors working in a primary care setting. The study identified language as a major barrier to service delivery to ethnic groups, which was made harder by inadequate interpreting services. Similar findings have been reported by Richardson et al. (2006) who conducted five focus groups with 28 professionals working with patients with cancer. Language barriers were one of the main factors identified as a challenge to the delivery of culturally competent care. Additionally, the study revealed a scarcity of good quality interpreters demonstrating a good

enough understanding of their area of work and healthcare practice to provide quality interpretations. In such circumstances service providers often prefer to rely on family members as a means of overcoming language barriers in preference to interpreters (Owens & Randhawa, 2004).

Acculturation and caregiving in British South Asian communities

The term “South Asian” is a complex one. There is a tendency to assume that South Asians are a homogenous group, who share cultural practices and beliefs. In reality they are a culturally diverse and heterogeneous group. South Asians are made up of a number of sub groups such as Indian-Punjabi, Indian-Gujarati, Pakistani-Mirpuri and many more. Each group has their own languages, religious practices and migration histories. Within each group, there is often great variation in terms of education level, financial status and social status. This heterogeneity of ‘South Asians’ is likely to impact on the experiences of caring for a child with intellectual/developmental disabilities and individual positions on cultural and ethnic identity tend to be more complex and may be influenced by multiple practices. Acculturation (exposure to two cultures) is another cause of diversity amongst British South Asians. However, very little is known about how this process influences caregiving experiences.

The idea of psychological acculturation was first introduced by Graves (1967) and refers to change that occurs when individuals from one culture come into contact with individuals from another culture. There are two main approaches to exploring acculturation which are unidimensional and bidimensional models (Berry, 1997; Gordon, 1964). What makes the two approaches distinct is how they view the relationship between the heritage culture (culture of

birth) and the mainstream culture (new culture). The unidimensional model views acculturation as a continuum whereby cultural identity changes over time and results in values and behaviours from the heritage culture being replaced by the mainstream culture (Gordon, 1964). One of the first unidimensional theories viewed acculturation as a continuum with two extremes consisting of the heritage culture at one end and the host culture at the other end (Gordon, 1964). Gordon proposed that assimilation into the host culture leads to an eventual dilution of the values and behaviours of the heritage culture. Critics have argued that this approach is inflexible and in reality individuals may progress along the acculturation continuum at different rates and take on different cultural identities along the way (Triandis, Kashima, Shimada, & Villareal, 1988).

In contrast to viewing acculturation as a continuum, bidimensional models view heritage and mainstream cultures as being independent and likely to vary in the degree of influence they have in a person's cultural identity (Berry, 1997). Bidimensional models propose that acculturation can lead to multiple identities and is likely to be influenced by an array of factors including cultural values, attitudes and behaviour, but other factors such as occupation or religion. The most widely utilised bidimensional model is Berry's (1997) acculturation framework. According to Berry's framework acculturation is defined across two dimensions which are the degree of "participation" with the mainstream culture and the degree of "maintenance" of the heritage culture. The model suggests that the degree of participation or maintenance can lead to four acculturation strategies:

- *Assimilation* – heritage culture rejected in favour of mainstream culture
- *Separation* – heritage culture retained and mainstream culture rejected

- *Marginalisation* – both cultures rejected
- *Integration* – both cultures are embraced

A recent study compared the effectiveness of both the unidimensional and bidimensional models of acculturation using a sample of 164 Chinese graduates (both first and second generations) living in the US and a series of measures (Ryder, Alden, & Paulhus, 2000). The results revealed that bidimensional models led to more valid understandings of acculturation, and in keeping with Berry's acculturation framework (1997) suggest that there are two dimensions to acculturation (participation and maintenance) which could be measured reliably, showed validity and were independent of one another.

There is little research exploring how individuals from ethnic minority groups in the UK make sense of and handle their relationship with two cultures. The limited research available has focused on acculturation in South Asian groups who form the largest ethnic minority group in the UK. Most studies draw on Berry's (1997) acculturation framework to explore differences in acculturation strategies and identity formation in first and second generations. For example, research has shown that first generation South Asian's favour 'separation', whereby they maintain their South Asian cultural heritage and reject British influence (Anwar, 1998; Robinson, 2009; Shaw, 2000). Conversely, second generations are more likely to 'integrate' into British culture whilst still maintaining some degree of their ethnic identities, thus demonstrating bicultural identity (Azmi, et al., 1997; Ghuman, 2003). As well as exploring the effects of acculturation on ethnic identity formation, other research has also explored the influence of acculturation on mental health, suggesting a positive association between the two (Bhugra, 2001, 2004). These studies suggest that intergenerational conflicts

between adolescents and parents, also known as the ‘culture conflict’, can increase risk factors for psychological problems (Anand & Cochrane, 2005). Although acculturation has been explored in the areas outlined above, very little is known about how acculturation in South Asian communities influences caregiving experiences. However, it is likely that acculturation adds to the diversity of South Asian groups in the UK and is likely to lead to different caregiving experiences and create differing service needs amongst its members.

To date it seems, only one study has explored the impact of acculturation on families caring for individuals with developmental disabilities. McCallion, Janicki, & Grant-Griffin (1997) used qualitative focus groups with African, Chinese, Haitian, Hispanic/Latino, and Korean Americans to explore the issues of caring for a person with developmental disabilities. They found that families demonstrating higher levels of acculturation did not experience language barriers, had better service uptake and relationships with services and were less likely to subscribe to religious or cultural explanations and responses to disability. Little is known about the impact of acculturation on South Asian groups caring for people with intellectual/developmental disabilities in the UK. Two studies have looked at the way in which South Asian disabled youth explore their identities. Using interviews with a range of young disabled South Asian (Muslim and Sikh) individuals these studies demonstrated the complexity of coming to terms with multiple identities including the disability and ethnic identities (Hussain, Atkin, & Ahmad, 2005; Hussain, 2005). Results demonstrated that in most cases participants held strong religious and cultural identities, especially females.

Much of the remaining literature has explored the experiences of less acculturated, first generation South Asian carers demonstrating poor English proficiency, and preferring

‘separation’ strategies of acculturation which promote the retention of heritage cultural values and beliefs. This research suggests that South Asian families tend to attribute disabilities to religious or supernatural causes, seek out religious or cultural treatments, held collectivist values which promote caring within family units (Fatimilehin & Nadirshaw, 1994; Katbamna et al., 2001; Bywaters et al., 2003).

Although these studies do not directly explore the phenomenon, they indicate that acculturation may influence the experiences of South Asian families caring for children with intellectual/developmental disabilities. For example, research has identified that not being able to speak English acts as a barrier to service uptake and the delivery of specialist disability services amongst South Asian groups (Bywaters et al., 2003; Raghavan & Small, 2004; Hatton et al., 2003). This is in keeping with research exploring general service usage amongst other ethnic minority groups such as Latinos in the US which suggests that increased assimilation to the host culture is associated with increased service usage, with the ability to speak English playing a central role (Fassaert, Hesselink, & Verhoeff, 2009). Research has demonstrated that British South Asians demonstrating higher levels of acculturation are likely to be bi-lingual or multilingual with a higher proficiency in English (Robinson, 2009; Ghuman, 2003). With this in mind it is likely that these individuals will experience better interactions with services.

When making sense of disability, South Asian families have been shown to locate the cause of disability in traditional explanations, such as a belief in ‘Karma’, ‘God’s will’, possession by spirits or consequences of an ‘evil eye’ (Katbamna et al., 2001). However, a recent study revealed new ideas about South Asian conceptualisations of disability, suggesting that South

Asian families hold multiple beliefs about disability which involve theological as well as medical beliefs (Croot et al., 2008). This may be indicative of an effect of acculturation as the sample used consisted of sixteen Pakistani husband and wife couples, with at least one of the partners being born in the UK, which may have resulted in these different views about disability. Another study exploring religious identities amongst second generation South Asians supports this hypothesis, suggesting that religion plays a more fundamental role in the way first generations live their lives than second generations, with the exception of second generation Muslims, suggesting that acculturation leads to a decline in the significance of religion (Robinson, 2009). Such differences may cause tensions between generations and may contribute to difficulties in the caregiving process and the way in which people make sense of disability. It is likely that acculturation or familiarity with western health practices can bring ethnic minority communities to gradually subscribe to western values and practices, which is ultimately likely to influence their caregiving experiences.

Aims of the thesis

Although much has been written about South Asian carers caring for children with intellectual disabilities, little is currently known about parents caring for a child with broader intellectual/developmental disabilities. In particular little is known about how culture (in particular acculturation) shapes South Asian carers' experiences of caring. Much of the existing research has looked at South Asian carers' interactions with services and the role of religion in shaping their interpretations of disability. This research has demonstrated that services do not meet the needs of South Asian carers for a wide variety of reasons, as mentioned above. However, relatively little effort has been made to explore the cultural context of caregiving in this group. Culture provides a framework for making sense of

experience. It is therefore crucial for services to understand the cultural frames of service users and carers, in order to deliver appropriate, effective and meaningful support.

Research has been conducted with other groups to explore the impact of culture on caregiving. For example, McCallion et al. (1997) organised a series of focus groups for carers of people with intellectual disabilities from the African, Chinese, Haitian, Hispanic/Latino, Korean and Native American communities. Differences were found in a number of themes including how disability is perceived, who are the family, who provides care, how the family makes decisions, what family members expect of each other, friends and community, cultural values and willingness to accept service providers.

Other studies have looked at cultural perspectives relevant to caring for family members with mental health problems. For example, Penny, Newton, & Larkin (2009) explored South Asian families' and carers' understandings of psychosis, Whittaker (2005) explored Somali women's concepts of psychological wellbeing, and Kokanovic, Peterson, & Klimdis (2006) examined general uptake of services across a range of minority communities. Thus, while there is a body of theory and research which can clearly inform the study of cultural context in relation to understandings of psychological and developmental problems, there are currently no clear descriptions of South Asian families' understandings of children with intellectual/developmental disabilities. There is also a shortage of literature on carers' experiences and understandings of children with developmental disorders, more generally. Clinically and theoretically, this is a gap in the literature which can most usefully be addressed by a carefully situated qualitative study, with a phenomenological focus on understanding carers' perspectives. With this in mind the current study aimed to explore how

culture (in particular acculturation) impacts the way in which South Asian parents make sense of and experience disability. The study focused on parents caring for children with intellectual/developmental disabilities which encompassed a range of disabilities ranging from moderate to severe intellectual disabilities and autism. Additionally, the study aimed to provide a detailed insight into the challenges posed to service providers working cross culturally in learning disability services, an area which has received little attention. The primary objectives of the research were:

1. To explore the role of culture in shaping the caregiving experiences of South Asian parents caring for a child with intellectual/developmental disabilities using groups discussions and interactions (Study 1, Chapter 3).
2. To build on the findings from the previous group discussions by using one to one interviews and in doing so provide detailed accounts of how culture, in particular processes such as acculturation (exposure to two cultures) shape the experiences of South Asian families caring for a child with intellectual/development disabilities in the UK (Study 2, Chapter 4).
3. To provide a cross cultural focus and explore the cultural meaning making of a group of Indian parents of children with intellectual/developmental disabilities in Delhi, India. In order to provide insight into the origins and preferred understandings of British South Asian parents living in the UK and explore how cultural values and beliefs are maintained, coexist or are transformed with exposure to British culture (Study 3, Chapter 5).

4. From the perspectives of service providers working cross culturally in learning disability services in the UK, to describe the experiences of service provision to South Asian families in an attempt to make recommendations for the delivery of culturally competent care to this minority group (Study 4, Chapter 6).

CHAPTER 2

Methods – An introduction to Interpretative Phenomenological Analysis (IPA)

Methods

This section provides a detailed description of the methods and analysis employed to conduct the research. It describes the way in which interpretative phenomenological analysis (IPA) was used to analyse both interview and focus group data and the measures taken to meet ethical and quality standards.

A qualitative approach to studying culture

There are a number of qualitative studies exploring the experiences of South Asian parents caring for children with intellectual disabilities as outlined in Chapter 1 (Introduction).

However, very little exists about how culture shapes the experiences of parents caring for a child with broader intellectual/developmental disabilities. Qualitative approaches are ideally suited for in-depth exploration of people's experiences, especially in novel areas given their flexible data collection and data requirements. As a result, it was thought to be suited to the current research.

There are several qualitative approaches that can be used to understand human behaviour. For example, discourse analysis (Willig, 2003) focuses on exploring the role of language in describing participants' experiences. However, the current research aimed to go beyond providing a descriptive narrative and instead aimed to explore how people make sense of their experiences. Grounded theory (Charmaz, 1995) allows an exploration of the complexity of human experience and has a focus on generating theory from participant data. However, the focus on theory generation does not account for individual participants' experiences which are the main focus of the current research. Grounded theory also aims to use a disparate sample to

produce a universal theory, which is in contrast to the aims of the current study that used a homogenous sample to explore similarities as well as differences, with no attempt to generate a universal theory.

IPA focuses on understanding and meaning making. Culture provides a framework for meaning making and therefore forms an important part of IPA research. Therefore IPA includes an interest in cultural competence (Smith, Flowers, & Larkin, 2009) which concentrates on becoming familiar with a culture in order to better understand a participant's frame of reference. The focus of the current research was to report in detail understanding and meaning making from within a South Asian cultural context, without making generalisations about all South Asian groups. Instead, the research aimed to use a series of small studies to provide a detailed set of accounts from which more nuanced claims could be made.

Interpretative Phenomenological Analysis (IPA)

Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009) is an approach to qualitative, experiential and psychological research which has been informed by concepts and debates from three key areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography (Smith et al., 2009). IPA's commitment to each of these areas is consistent with the explicit aims of the current research which is to explore how South Asian parents make sense of and experience caring for a child with intellectual/developmental disabilities in the UK. The following section will provide a brief overview of the main theoretical ideas which have influenced IPA.

Phenomenology

Phenomenology has an epistemological focus on how people make sense of their own experiences. The underlying principle to phenomenological enquiry is that experience should be explored in the way that it occurs and in its own terms. The phenomenological emphasis of IPA is particularly important given that people's experiences are deeply personal whilst at the same time constrained and influenced by societal constructions of "what should be".

With regards to IPA, phenomenology is thought to have two important phases which are transcendental phenomenology and hermeneutic/existential phenomenology. Transcendental phenomenology was introduced by Husserl who argued that we should "go back to the things themselves" and in doing so focus on description. In comparison hermeneutic/existential phenomenology recognises that when trying to get close to a person's world/experience it is impossible to do so completely. Heidegger focused on 'dasein' (being in the world) which raises the question of 'being' and interpreting the meaning of 'being'. In doing so he highlighted the importance of interpretation and employing a method of hermeneutics.

Hermeneutics

Hermeneutics is a theory of interpretation and focuses on the way in which a researcher's 'conceptual lens' (e.g. assumptions, preconceptions) shape the way in which they make sense of and interpret a person's world. The IPA researcher is said to be engaged in *double hermeneutics* in that they are attempting to make sense of the participant attempting to make sense of what is happening to them (Smith et al., 2009). A key principle of IPA analysis is the *hermeneutic circle* which focuses on the relationship between the part and the whole. For example, in order to understand the part one must understand the whole and vice versa. The

hermeneutic circle forms an important way in which the IPA analysis is conducted, in an iterative way (e.g. moving back and forth through different parts of the data). As one considers the data at various stages and through the hermeneutic circle different perspectives and understandings are opened up.

Idiography

IPA has an idiographic focus which concentrates on small sample sizes in order to provide a detailed account of human experience given the complexity of most human phenomena (Smith et al., 2009). In doing so it focuses on subjective experience and situates people within their socio-cultural contexts, by concentrating on what it is like for a person. This idiographic nature focuses on the lived experience of an individual and attends to all elements of this lived experience such as desires, wishes, belief systems and how these are manifested into behaviours and actions. Capturing the essence of what this experience “is like” is important towards understanding how South Asian parents experience care-giving and has been utilised by healthcare staff as a means of informing clinical practice (Biggerstaff & Thompson, 2008).

The advantage of IPA is that participants are viewed as experts with regards to their own experiences (in this case caring for a child with intellectual/developmental disabilities).

Therefore IPA offers an often overlooked minority group a chance to tell their own stories in their own words and in detail. By providing their own detailed stories, participants are likely to draw on cultural meanings which provide insight into the cultural context of caregiving.

IPA relies on an open approach, giving participants the freedom to explore issues that are important to them and therefore leading to rich and detailed accounts. It is a “bottom up”

approach in which participant narratives are used to formulate general themes. This is ideal because it provides flexibility for new ideas to be brought up.

Data Collection

The research used a combination of interviews (Study 2) and focus groups (Studies 1, 3 and 4). Specific details on the recruitment process, participant details and interview schedules can be found in the methods section of each study chapter.

IPA adopts an open approach to data collection which aims to explore the meanings that participants assign to their experiences. As a result, IPA relies on flexible and open ended questioning schedules. Using open ended questions and prompts should allow the researcher the flexibility to explore issues that were brought up by the participants. For example, the use of prompts in the current research helped to produce experiential level data (Palmer, Larkin, de Visser, & Fadden, 2010; Tomkins & Eatough, 2010). They allowed participants to engage with the topics in terms of *narrative* [what happened to you?], *impression* [what really struck you at the time? What do you remember most now?], *type* [what usually happens?], *imagery and metaphor* [what was it like?], *embodied emotion* [how did you feel?], *evaluation* [what should be different?] and *explanation* [why do you think it happened that way?]. As well as using prompts I also ensured that I took care to use words that were in keeping with the participants' discourses, and regularly asked for feedback and elaboration on certain points to ensure they were fully understood.

The current research utilised two main methods of data collection which were focus groups and interviews. Focus groups are ideal for exploring cultural experiences because they allow group members to share and build on each other's thoughts, ideas and beliefs and therefore can provide insight into new ideas. In the current research focus groups were ideal as they enabled me to make use of pre-existing, naturally occurring group settings (e.g. carer support groups and staff groups). This was particularly useful as it increased the likelihood of people being open. However, focus group data introduce the challenge of dealing with multiple accounts which makes it harder to infer and develop personal phenomenological accounts (Palmer et al., 2010). This is because an individual participant's experiential claims, narratives or reflections are likely to be shaped by the group dynamics such as: what is brought up by the other participants; the researcher's questions and reactions (which in turn is influenced by the group dynamics); the degree of shared experiences between participants; the nature of pre-existing relationships; the sensitivity of the questions; and the positions opened up or closed down by other members (Palmer et al., 2010).

Interviews on the other hand, enable participants to articulate details about their experiences and explore deeper understandings about their subjective meaning and experiences.

Interviews provide an "insider's view" into the participants' view of their world by giving meaning to cultural and social contexts which was of particular importance in the present research. As IPA uses open ended and flexible approaches to questioning which are guided by the participants' responses, it often leads to spontaneous responses which provide the opportunity for eliciting unexpected insights into the phenomenon under investigation. This was particularly important in the current area in order to highlight new ideas.

For each study a topic guide was prepared which are briefly outlined below. An overview of how the schedules were developed and further details of the data collecting procedures for each study can be found in the methods section of the study chapters.

Study 1: Focus groups with parents (Chapter 3)

This interview schedule was guided by the literature in the area, as well as being reviewed by a peer review group and piloted tested on a small group of South Asian mothers. Using a loose discussion schedule I aimed to give participants an opportunity to explore issues that were important to them.

Study 2: Interviews with parents (Chapter 4)

This interview schedule was guided by the findings in Study 1. Using the schedule I hoped to elicit more in-depth information from carers which built on the experiences described in Study 1 and also explored how acculturation can impact on caregiving experiences.

Study 3: Cross cultural focus groups with parents in India (Chapter 5)

This interview was the most unique in that it was the loosest schedule used. This is because the cross cultural context introduced an added complexity to the experiences that I aimed to explore and as a result I was unsure about what to expect from the focus groups. Therefore using a loose schedule allowed me to adapt the questions asked in response to the issues raised by the groups.

Study 4: Focus groups with service providers (Chapter 6)

This discussion schedule was based on previous literature in the area as well as the findings from the previous studies. The schedule covered three core areas which were direct experiences of working with South Asian families, training and recommendations.

All interviews and focus groups were transcribed verbatim. In the case of Study 1, where focus groups were conducted in Punjabi and Mirpuri, translating services were used the details of which have been outlined in the methods section of Chapter 3.

A critical feature of IPA is that the researcher takes a facilitative role with the aim of encouraging participants to talk about their experiences openly and in detail in their own time. This is particularly suitable for exploring the experiences of South Asian parents of children with intellectual/developmental disabilities as it allows for the exploration of cultural factors and how these shape caregiving experiences. When conducting the research I felt it important not to simply attribute beliefs, behaviour, values and attitudes to culture, but instead acknowledge that gender, socioeconomic factors, immigration status, racial identity, ethnic backgrounds and acculturation may influence these factors. Therefore, the current research aimed to recognise the complexity of individual and group experiences by using an open ended and loose approach to collecting data.

Data Analysis

The following section describes how IPA was used to analyse both interview and focus group data.

Analysing Interviews

There are no set rules for analysing data using IPA, however the premise behind IPA is to foster reflective engagement with participant narratives, which involves the analyst shifting between two positions: 1) listening to what the participant is saying about their experiences and 2) showing awareness of what you as an analyst are bringing to the process of listening to the participant (which increases interactive and reflexive analysis). Therefore, IPA analysis is dependent upon the participant and analyst, with the overall aim being for analysts to provide an account of the way they think the participant is thinking.

Smith et al. (2009) outline six steps which were used as a framework for analysing the interview data:

Step 1: Reading and re-reading

The first step in IPA analysis involved familiarising myself with each transcript. This involved reading and re-reading each individual transcript, which helped ensure that the participant was the focus of the analysis through active engagement with the data. During this stage I also kept a notebook to record my initial thoughts and ideas about each transcript, which again helped to ensure the participants' experiences remained the focus of the analysis and were not overshadowed by my own perceptions of the data.

Step 2: Making initial notes

This formed the lengthiest stage of the analysis and focused on exploring the semantic content and language used in each transcript (Smith et al., 2009). At this stage anything of interest within the text was noted down in the right hand column of the transcript which increased familiarity with the text and helped me to recognise the way in which participants understood

and talked about specific issues or concerns. This stage of the process was open and involved taking a note of anything that stood out in the text. The idea was to produce a detailed set of notes and comments describing the data set. In keeping with Smith et al. (2009), the guidelines of initial note taking involved making a note of the following three processes:

- *Descriptive comments:* I focused my attention on the descriptive comments of the participants which had a phenomenological focus. This included descriptions of things that mattered to participants (e.g. key objects of concern such as relationships, processes, places, events and principles) and what these meant to the participant. This involved taking a note of key words, phrases or explanations used by the participant.
- *Linguistic comments:* At the same time I also began to explore the language used and the context in which participants' concerns were placed in order to make sense of the patterns of meaning in their accounts. This involved paying attention to the use of pronouns, pauses, laughter, repetition and metaphors.
- *Conceptual comments:* I also began to conduct more of an interpretative exploration of the data by taking an interrogative approach. This stage of the analysis involved a shift away from simply identifying the explicit claims of the participant and instead focused on how participants understood what they were describing. To do this I used a process of discussion, reflection, trial and error and refinement of ideas and thoughts. When doing the conceptual coding I employed the following strategies as suggested by Smith et al. (2009):

- *Personal reflection* - This involved drawing on my personal and professional knowledge in order to identify potential meanings. I also drew on my cultural knowledge of being a second generation South Asian to shed light on how culture may have shaped the way in which people made sense of their experiences.
- *Talking to staff within the services* - This helped to set a context for the interviews and provided a clearer understanding of the issues facing South Asian carers. This enabled me to submerge myself with participants lived world.
- *Asking questions of the data* - This involved asking why certain things were said and asking my own questions of the data. Even though participants might not have had an answer, the intention was to open up possibilities of meaning.
- *Thinking about the context of the participants* – This involved thinking about what I knew about the parents’ situations (e.g. children, diagnosis, interactions with services, country of birth etc.) and what I knew about them from my prior meetings during the engagement process. This helped me to familiarise myself with the context of each participant which, enabled a more accurate analysis and in doing so increased the credibility of the results (see page 55 “sensitivity to context”).
- *Thinking about the transcript as a whole*- This involved thinking about how ideas linked in together throughout the whole transcript which, was in keeping with the hermeneutic circle.

The important thing when doing conceptual coding was to make sure that all interpretations were tied to the original text of the participants and documented. A copy of a worked extract from an interview from Study 2 (Chapter 4) can be found in Appendix D (page 255).

Step 3: Developing emergent themes

This stage involved creating short statements that captured the main essence of specific parts of the transcript and were written in the left hand column of the transcript. As a result, I concentrated on small chunks of the text but also considered the whole text. This is in keeping with the hermeneutic circle which focuses on interpreting the part in relation to the whole and the whole in relation to the part. The emerging themes reflected both the participants' original narratives but also my interpretations.

Step 4: Looking for connections between emergent themes

The next step involved exploring how the themes identified in the transcript fit together. All the themes were typed onto a Word document and once printed, cut up so that each theme was on a separate strip of paper. All the themes were then placed on a table and the themes which represented similar ideas or recurring patterns of meaning were grouped together under broader "master themes". Some themes were stand alone and were therefore placed to one side. Following this, each master theme and the corresponding emerging themes were typed into an Excel spread sheet and all the corresponding transcript extracts were inputted into the sheet.

Step 5: Analysing the next participant

The above steps were repeated for the remaining participant interview transcripts.

Step 6: Looking for patterns across participants

At this stage, for each participant, I had created an Excel spread sheet which included one sheet detailing the main master themes and the emergent themes that it was composed of. Additionally, for each master theme I compiled a table of transcript extracts which illustrated the themes, which were recorded using line and page numbers. At this stage, I printed off the main themes for each participant in a separate colour and cut them up into separate strips. I then began to look for connections across different participants. I adopted a flexible stance when looking for connections and this process meant that some themes were relabelled as connections emerged. Some emergent themes that were similar were relabelled and used as sub-themes. Following this the main themes and corresponding sub themes were recorded in an Excel spread sheet. Alongside this I compiled a table of quotes which illustrated each sub theme and included extracts from each participant. This was helpful when it came to choosing the quotes that best illustrated the themes. This formed the final stage of the analysis.

Analysing focus group data

There has been recent debate about whether the theoretical foundations or procedures used with standard IPA interview research can simply be transferred to IPA focus group data, because focus groups introduce an added complexity of dealing with interactions between group members. Smith (2004) suggests that in order to successfully implement focus group designs into IPA research, we need to recognise the challenges involved in doing so.

Recently, two papers have explored some of the challenges associated with the application of experiential analyses to group situations (Palmer et al., 2010; Tomkins & Eatough, 2010).

Both of these papers have been used as frameworks in order to guide the successful

interpretation of focus group data in Studies 1, 3 and 4 of the current research. The following section will now describe the process with which the focus group data were dealt with.

Step 1: Identifying the group's primary concerns

In keeping with the standard practices of analysing IPA interview data, I began by familiarising myself with each transcript by reading and re-reading it. I then began to identify the groups' experiential claims and concerns. This involved firstly identifying anything that was important to the groups and secondly exploring the claims made about these. Like the standard IPA approach this involved staying close to the participant's own language.

Step 2: Deeper exploration of group data

On subsequent readings and after having highlighted the main concerns of the group I became aware that the interactions between group members played an important role in shaping the way in which participants described their experiences. Being a group setting, participants passed ideas and thoughts relating to objects of concerns back and forth between each other and in doing so provided their own personal experiential perspectives on the issues through their own positional relationship to it. Positionality refers to the experiential meaning associated with a person's stance relating to a phenomenon (Palmer et al., 2010). Participants positions have been explored in more detail in the results sections of each study chapter, where relevant. Exploring participants' positionalities enabled me to develop an understanding of how the group discussions both enabled and constrained different perspectives.

On subsequent readings I also began to explore the roles and relationships described by participants and what they meant, as suggested by Palmer et al. (2010). These differed for

each group. Generally for the parents (Studies 1 and 3) this involved descriptions of their relationships with family, friends and their child, as well as interactions with services. For service providers (Study 4), their descriptions concentrated on their interactions with South Asian families. These have been explored in more detail in the results sections of each study chapter.

Finally, I also began to highlight some of the emotive language used by participants to describe their experiences, which is in keeping with a standard IPA framework (Smith et al., 2009). Particular attention was paid to the use of metaphors which featured prominently in the focus groups and I examined the ways in which language mapped onto the emerging themes.

The above information was recorded on the right hand side of the transcripts, using different coloured pens for each phase of the analysis (objects of concern, roles and relationships and language). Preliminary emerging themes were then generated and written down on the left hand side of the margin. Appendix E (page 265) gives an example of how this analysis was conducted on a focus group transcript from study 1 (Chapter 3). These themes were then entered into an Excel spread sheet.

Step 3: Identifying individual concerns within the group

At this stage of the analysis the data were dealt with at a group level. Following the creation of a table of the emerging themes for the group as a whole, I then went back to the original transcripts and began to explore individual perspectives to the group discussions. This involved combining a top down approach to explore each participant's contributions, and a bottom up approach which involved mapping to see how well individual contributions

reflected the emerging themes, as has been suggested by Tomkins & Eatough (2010). The top down approach involved highlighting the text relating to each participant in a separate colour to provide an account of the individual within the group. This helped to determine what themes did and did not represent the individual group members' positions. Next a bottom up approach was employed, which involved looking at the main group concerns and individual concerns. I did this by creating a table of group quotes (e.g. where participants interacted and responded to each other) and individual quotes (e.g. one off comments by single participants) for each emergent theme, encompassing all the possible quotes. This was used to determine whether group concerns reflected what individuals felt and what was specific to individual participants.

Step 4: Bringing the groups together

Steps 1 and 2 were carried out for each focus group transcript following which the group themes were brought together. This involved identifying commonalities between groups in order to identify master themes. I did this by printing out the themes for each group in a separate colour and cut them up into separate strips. I then began to look for connections across different groups. I adopted a flexible stance when looking for connections and this process meant that some themes were relabelled as connections emerged. Some emergent themes that were similar were relabelled and used as sub themes. Following this the master themes and corresponding sub themes were recorded in an Excel spread sheet. Alongside this, I compiled a table of quotes which illustrated each sub-theme and included extracts from each participant. This was helpful when it came to choosing the quotes that best illustrated the themes. This formed the final stage of the analysis.

Assessing the quality of the research

This section outlines how the validity and quality of the research was assessed. There has been much debate amongst qualitative researchers in trying to establish a set of criteria for assessing the quality of qualitative research and a number of guidelines have been proposed (Aguinaldo, 2004; Eakin & Mykhalovskiy, 2003; Patton, 1999; Yin, 1999). More recently Yardley (2000) has proposed a more refined set of guidelines. Yardley's guidelines have been recommended by Smith et al., (2009) for use with IPA research specifically, as they offer a broad range of criteria for assessing quality. Yardley (2000) suggests four principles for assessing the quality of qualitative research which are presented in Table 2.1 below. In the following sections I will go through each principle and illustrate how it has been upheld in the current research.

Table 2.1

Yardley's (2000) principles for assessing the quality of qualitative research

Four Principles	Description
Sensitivity to context	The degree to which the research demonstrates sensitivity to the context in which a study is undertaken.
Commitment and rigour	The commitment on the part of the researcher to engage with the participant and what they are saying. Rigour refers to the thoroughness of the study (e.g. appropriate sample size, thoroughness of the analysis).
Transparency and coherence	The clarity and detail with which each stage of the research is presented and written up.
Impact and importance	The degree to which the research introduces news ideas or interest.

Sensitivity to context

Yardley (2000) proposes that good qualitative research demonstrates sensitivity to the context in which a study is undertaken and can be achieved by considering the following: attention to the socio-cultural situation of the study, consideration of the existing literature on the topic and recognition of the challenges to obtaining material from participants. I will now explore the ways in which the current research demonstrated sensitivity to the context.

The process of choosing IPA as a method demonstrates the research's sensitivity to the context. IPA was chosen as an ideal method as it aimed to provide an in-depth exploration of the cultural context of experiencing intellectual/developmental disabilities in South Asian communities. Sensitivity to the context was also demonstrated through a review of the existing literature in the area. For example, Chapter one (Introduction) provided a detailed account of the context and rationale for the present research which was grounded in existing literature. This highlights the thoroughness with which I approached the work. Additionally, Chapter 7 (overall discussion) relates the findings of the studies to existing research which is a fundamental component of any piece of research.

Additionally, the 'reflections on challenges faced' section on page 59, outlines the challenges I faced when conducting the research, including difficulties with recruitment and efforts to minimise interactional difficulties during data collection. My attention to these difficulties demonstrates my sensitivity to the context.

Commitment and rigour

Commitment when referring to IPA studies refers to attention to the participant during data collection and analysis. To conduct a quality IPA study requires a commitment on the part of the researcher to engage with the participant and what they are saying. Rigour refers to the thoroughness of the study which can be determined by examining the adequacy of the sample selected in terms of its appropriateness to answer the research question and the comprehensiveness of the analysis. In order to ensure that the current research was conducted rigorously the process of triangulation was employed. Triangulation is a form of cross checking which often involves more than two methods in order to check results for consistency. For the current research triangulation was used in the following ways:

- The use of “*multi-perspectives*” to explore the cultural context of caregiving to children with intellectual/developmental disabilities from the point of view of parents (Chapters 3, 4 and 5) and service providers (Chapter 6) .
- The use of *more than one method to collect data* (focus groups and interviews).
- The use of *more than one person to analyse the data*. Although the bulk of the analysis was conducted by myself, the phenomenological and interpretative stages of the analysis were verified by my supervisor who has experience in IPA. Additionally, a number of pages of at least one transcript for each study were given to an independent IPA researcher (another qualitative PhD researcher) to check for consistency in coding.

Another important aspect of commitment and rigour is the use of appropriate sample sizes. The appropriateness of each sample can be established with reference to the ‘Participants’

section in each study chapter. Conrad (1990) argues that there is no definitive means of determining the appropriate number of participants to make a good quality qualitative study. Reid, Flowers, & Larkin (2005) reviewed studies using IPA and suggested that study sample sizes ranged from 1-40 with a mean sample size of 14. In fact, IPA researchers advocate the use of small sample sizes which encourage the idiographic exploration of participants' experiences (Smith et al., 2009; Smith, 2004; Smith & Eatough, 2007). Table 2.2 shows the number of participants recruited for each study in the current research. The total number of participants was 46 which fitted in well with an IPA approach.

Table 2.2
Numbers of participants and interviews/focus groups in each study

<i>Study description</i>	<i>No. of participants</i>	<i>No. of interviews/focus groups</i>
Study 1: Focus groups with Sikh and Muslim parents	9	2
Study 2: Interviews with Sikh and Muslim parents	7	7
Study 3: Focus groups with Hindu parents – A cross cultural study in India	10	3
Study 4: Focus groups with multi-ethnic service providers	20	5
Totals	46	17

Transparency and coherence

Transparency and coherence of a qualitative study can be established through clear and detailed descriptions of the research process. The current chapter details the methods I used to

collect and analyse the data and worked extracts of raw data have been presented in the appendices in order to increase the transparency of the analysis. Additionally, the methods section of each study chapter includes the following information:

- *Participants* - details of the demographic profile and recruitment process.
- *Data collection* - details of the interview/discussion schedules and context in which data was collected.
- *Translation and interpretation processes* - where appropriate.
- *Presentation of the findings* - in the results sections, illustrated and supported by data extracts as well as supplementary extracts in the appendices. (For more details please refer to the methods/results section of each study chapter).

Impact and importance

This principle refers to the impact and importance of the findings. The findings of the current research shed light into some interesting new ideas which have received little attention in the literature and have been discussed in further detail in the individual discussion sections of each study chapter as well as the overall discussion at the end of the thesis (Chapter 7).

Additionally, the impact and importance of the present work has been strengthened by the dissemination of the findings through publications and presentations which have been listed in Appendix Z (page 317).

Reflections on challenges faced

One of the biggest challenges faced during the research was trying to recruit South Asian parents. Participants were recruited from a city and town within the West Midlands, both of which had large Sikh and Muslim communities. Through consultations with services in the areas I became aware that one of the major challenges to recruitment may be language difficulties. The two frequently spoken languages amongst the two communities were Punjabi and Mirpuri. As a result making sure that information about the study was accessible was an important part of the recruitment process. Given the linguistic requirements it was decided that in Study 1 (focus groups, UK), information would be presented in the participants' first languages (Punjabi or Mirpuri). Therefore information sheets and consent forms were translated by an independent translating service. However, during the recruitment process it became apparent that participants preferred to have the information in English but at the same time requested that the researcher translate the information sheet and explain the purpose of the study and what their involvement would entail in their own language.

Both communities had been involved in a variety of academic research prior to this research. Therefore, I had naively assumed that this would be an advantage because the individuals would be familiar with the research process. However, as I began to engage with parents from within the communities I became aware that unhelpful previous experiences with researchers meant that the parents had very negative perceptions about research participation and showed a reluctance to get involved in future studies. Many of their concerns focused on the fact that they felt research was not a reciprocal process and they felt as though they had not received any tangible benefits as a result of taking part in previous projects. Consequently, my experiences of conducting research, involved having to build bridges as a researcher and

create a degree of trust amongst the parents before I was able to begin recruitment. As a result, I found that building trust and a cultural rapport with parents was critical for recruitment and participation, which has been demonstrated by other research (Barata, Gucciardi, Ahmad, & Stewart, 2006; Feldman, Radermacher, Browning, Bird, & Thomas, 2008). In the initial research design stage I had overlooked the importance of engagement and the amount of effort and time this would take up. Consequently, I found this process put a great demand on the time frame of the research.

The process of building rapport and trust with parents was easier when dealing with pre-existing support groups, as in Study 1 (focus groups, UK). This is because the premeditated group situation meant that I was able to attend group meetings and gradually introduce myself and, in return get to know parents. Although from the out-set I made it clear that my interest in the group was for 'research purposes', I believe that engaging with the group over a series of meetings enabled participants to become comfortable with my presence and ultimately made the recruitment process easier. It also meant that I was giving something tangible back to the group. Taking this time out to engage with group members also meant that the focus group setting was more comfortable and individuals were more likely to talk freely and openly about their experiences which they might not have done had I been a complete stranger. The disadvantage of using this approach is that there was a long gap between initiating contact with the groups and actually recruiting participants, which highlights the significant amount of engaging and work required prior to formal data collection and the flexibility required in order to conduct such research.

Having worked closely with pre-existing support groups in Study 1 (focus groups, UK), the transition to relying on service providers to initiate the recruitment process in Study 2 (interviews, UK) was difficult and took up much research time. Due to ethical requirements, the recruitment process of individuals for Study 2 (interviews, UK) involved having to ask service providers within a children's learning disability team (CLDT) to identify and approach participants. Consequently, it meant that I did not have the ability to build up a rapport and trust with parents as I did in Study 1 (focus groups, UK). Being reliant on staff was made harder due to their already heavy workloads which often meant that the research was regarded as secondary to their main responsibilities. As a result, service providers described difficulties in fitting recruitment into their schedules and were often only able to distribute information sheets without providing detailed explanations about the nature of the study. Although parents were able to contact me for additional information if they wished, I believe this lack of detailed description greatly influenced the recruitment process and resulted in poor recruitment. Consequently, efforts were made to approach other support groups in the area to see if I could adopt the process of recruitment employed in Study 1 (focus groups, UK), by making use of the support group settings to engage with parents on a personal level. However, identification of support groups proved difficult because they were poorly advertised and not easily 'visible' in internet searches.

As mentioned in Study 2 (interviews, UK), one support group was identified through a colleague and this helped to recruit five participants. However, the participants in Study 2 were limited to younger South Asians and recruitment of older South Asian parents proved harder. Although a number of potential participants were approached they declined, expressing concerns about the use of an audio recorder, as well as reservations about the

purpose of the research project and whether the outcomes would lead to any real significant changes to service delivery.

Another important part of conducting qualitative research in ethnic minority communities is how researchers position themselves and are perceived by the potential participants (Archer, 2002; Lee, 2008). Being from a South Asian background I was aware of the need to embrace my understanding of South Asian cultural practices and norms in order to create a positive perception amongst the parents and increase the chances of building a trusting relationship. This involved accommodating my dress and social behaviour in accordance with the social and cultural norms of the participants. However, I still felt that certain issues such as being female, younger and second generation may have affected my ability to develop a relationship with some of the older participants. In some cases, in particular during the focus group settings in Study 1 (focus groups, UK) I became aware of these differences. For example, I found it extremely hard to act as a mediator in the group settings. This was difficult because as I was younger and consequently some of the older men assumed a position of leading the group, which I felt was a reflection on the expected norm of South Asian culture. My recognition of and accommodation to these cultural expectations reflects my sensitivity to the context in which the research was conducted.

As a result of all the fore-mentioned challenges, reflection became an important tool in allowing me to improve the way in which I conducted the research. This involved using 'time lines' to chart the course of the child's disability and doing so helped create a less question focused interview style, as well as using terms/phrases that the participants used in their narratives and using prompts and rephrasing to help participants understand questions. For

example, I became aware through attending the support groups that parents did not directly refer to their child's disabilities using medical terminology, instead they preferred to refer to the difficulties in a more personable way such as "*the thing with my child*" or "*these difficulties with my child*". Consequently, I used these descriptions when asking questions about the child's difficulties.

Facing these challenges greatly shaped the design of the thesis. Originally, it was anticipated that observations would be used as a means of validating the data collected through the focus groups and interviews. I had also planned to use a photo-elicitation interviews (Harper, 2002) as a secondary measure if participants were not keen on observations. PEI uses a combination of photographs and interviews to help capture the tangible and intangible aspects of participants' lives (Harper, 2002). It was anticipated that PEI would be used in order to attain additional information about the family's daily lives. However considering the reluctance of participants to take part in interviews it was thought that such approaches would be regarded as too intrusive. Alternatively, I decided to adopt a cross-cultural focus (Study 3, Chapter 5) and explore alternative perspectives by looking at the experiences of service providers (Study 4, Chapter 6) working with ethnic communities.

Ethical considerations

Participants were recruited from a range of sources which are listed below:

- Study 1 - NHS Children's Learning Disability Team's (carers support groups)
- Study 2 - NHS Children's Learning Disability Team and a carers support group
- Study 3 – A specialist service for children with disabilities in Delhi, India

- Study 4 – NHS Learning Disability Teams; Private Organisation; Voluntary organisation

Full NHS ethical approval was granted by Research Ethics Committees to recruit participants from NHS sites (further details are provided within the methods section of each study chapter). The private and voluntary organisations accepted NHS ethical approval. I completed a separate ethical review in order to conduct the research at the specialist service in Delhi, which has been described in the methods section of Chapter 5. The following section details some of the ethical issues that were considered during the course of the study.

Participant safety

All participants were given an information sheet explaining the scope of the research and what would happen to the information that they shared as part of the study (details of which are provided in each study chapter). It was made clear to all participants that the information they provided would not impact on the care that their children currently received or may receive in the future. All participants were informed that their participation in the studies was entirely voluntary and that they could withdraw at any time. All participants were informed that an interpreter/translator would be used where necessary (e.g. if the participant did not speak a language that the researcher was able to speak).

All participants were invited to sign a consent form to demonstrate that they understood the terms of the research. Where appropriate participants were given the option of receiving translated versions of the information. However, all participants (even those for whom English was not their first language) preferred to receive English versions. In such

circumstances the information was translated verbally to ensure it was fully understood. Some participants became emotional (started crying or expressing anger) during the interviews/ focus groups due to the nature of the topics being discussed (children's intellectual/developmental disabilities). The interviewer handled such expressions of emotion with care and responsibility and I only proceeded with the consent of the participants.

Researcher Issues

There was a slight chance that I may have been called to address issues related to vulnerable adults and child protection. I had undergone training on such procedures in a previous role as a researcher in the NHS and therefore understood that in such circumstances I would be required to record the facts relating to the cause for concern and consult the head of the Children's Learning Disability team, who would then take appropriate action. However, there were no incidences which had to be reported.

Data protection and confidentiality

Data from all four phases of the study was treated in confidence. All information (electronic and paper records) was stored in a locked filing cabinet at the University of Birmingham. A password controlled system, of which the password was only known to me, was used to store all electronic data. Each participant in the study was allocated a pseudonym to ensure confidentiality of all written and electronic data. Following transcription all audio recordings were deleted from the recording device and the computer. All transcripts were kept anonymous through the use of pseudonyms. At the end of each interview/focus group participants were asked if there was anything that they had said which they would prefer not

to be quoted. This was important because despite the data remaining anonymous there was a possibility that direct quotes may have been identified by family members or other service providers.

CHAPTER 3

Study 1 - Using focus groups to explore the experiences of South Asian parents caring for children with intellectual/developmental disabilities in the UK: A pilot study

Introduction

In the UK the term South Asian usually refers to people who originate from India, Pakistan, Bangladesh and Kashmir (British Sociological Society, 2005). The prevalence of intellectual disabilities amongst South Asians aged between five and thirty-two has been shown to be three times higher than any other community in the United Kingdom (UK) (Azmi et al., 1997). Additionally, of those families caring for a member with intellectual disabilities, 19% had more than one member with an intellectual disability. This high frequency has been linked to a poor uptake of maternity services, higher genetic risk factors as well as pervasive social and material disadvantage amongst South Asian communities in the UK (Emerson & Hatton, 2004; Mir, 2001).

The experiences of South Asian families caring for a child with learning disability in the UK can be very distinct from those of white families. When interpreting disabilities, families tend to draw on a range of resources such as religion and theology (Bywaters et al., 2003). South Asian parents may hold simultaneous multiple beliefs about the cause of their child's disability (Croot et al., 2008). These may include attributing causation to the notion of karma (belief in rebirth based on the events of past lives), God's control over the disability and beliefs that the person with a disability may be possessed by spirits or been given the evil eye (Fatimilehin & Nadirshaw, 1994; Katbamna et al., 2001).

These alternative understandings of disability can alienate parents from services as they may feel judged and unable to identify with health professional views which can lead to poor service uptake (Bywaters et al., 2003; O'Hara, 2003). South Asian families may face

additional strains from within their own communities in the form of negative attitudes towards the child with disabilities (Bywaters et al., 2003; Hatton et al., 2003) which can lead to isolation (Gilbert et al., 2004). A common stereotype is that South Asian families receive support in the form of extended families, however this misconception has been challenged by Katbamna et al. (2004) who found that South Asian carers received limited support from extended families and often held sole responsibility to provide care themselves with little or no support.

British South Asians as a diverse group

Individual positions on cultural and ethnic identity tend to be complex and variable. This will ultimately influence how parents make sense of their child's intellectual disabilities and the types of resources they draw on in doing so. "Multiple interpretations are often available and provide flexibility in the understanding and interpretation of serious illness" (Good, 1997, p. 234). South Asians are not a homogenous group, sharing cultural practices and beliefs, but instead a culturally diverse and heterogeneous group made up of a number of sub-groups such as Indian-Punjabi, Indian-Gujarati, Pakistani-Mirpuri. Within each group, there is often great variation in terms of languages, religious practices, migration histories, education levels, financial status and degree of acculturation (Berry, 1997). Two such groups are Muslims and Sikhs, who together make up over 3% of the UK's population (Census, 2001).

Aims

A focus on meaning making allows the exploration of individuals own personal understandings of their experiences, such as making sense of intellectual disabilities.

Qualitative research plays a central role in allowing this exploration because it draws out the complexity and variability of individuals experiences. A major premise of qualitative research is that it holds no preconceptions of what certain experiences or concerns of individuals might be and in doing so allows the participant to explore issues that are important to them.

Therefore, the current study used qualitative methods (focus groups) and adopted a hermeneutic and phenomenological approach to understand participants' experiences and relationships to a specific phenomenon (in this case caring for a child with intellectual disabilities) from their own subjective perspectives, drawing on how they make sense of these experiences (Larkin, Watts, & Clifton, 2006; Smith et al., 2009).

Focus groups were used as they made use of group interactions to explore people's knowledge, experiences, cultural values and group norms. In doing so, it was anticipated that group discussions could be used to determine how people think and feel but also why they think and feel that way. By using open ended and flexible questions I aimed to encourage participants to explore issues important to them.

Method

Context

The research was conducted within two areas, one a small city and the other an urban district. NHS (National Health Service) Learning Disability Teams from both areas helped support the recruitment of participants. Both teams had a significant proportion of South Asian families on their caseloads. This is representative of the population of both areas. The 2001 census revealed that 15.8% of the City's population and 6.1% of the district's population were of an 'Asian' ethnic origin. In the City Sikhs made up the single largest Asian group whereas, in the district Pakistani's make up the single largest Asian population group.

Participants

Participants were recruited from two pre-existing carers support groups (Participant details can be found in Table 3.1, page 75). One group reported themselves as being Sikh and the other as being Muslim. In total nine parents were involved in the focus group discussions, including 4 fathers and 5 mothers. Efforts were made to recruit further participants and identify more support groups. However, this proved difficult and other groups or individuals did not want to get involved in the study. Therefore, it was decided that due to the small sample size this study would be treated as a 'pilot' study which would help shape the subsequent phases of the thesis. All carers were the biological parents of their children with intellectual/developmental disabilities. The children were aged between 7-19 years old and were self reported by parents as having either autism, severe intellectual disabilities or intellectual disabilities. Each child had been born in the United Kingdom. Parents were aged between 40-60 years old. The Sikh parents had been born in India and the Muslim parents in

Pakistan. Parents reported they had lived in the UK for between 12-28 years. All Sikh parents and two of the Muslim parents were caring for one child with intellectual disabilities. Three of the Muslim parents were caring for more than one child with intellectual disabilities.

Interview schedule

The interview schedule (see Appendix F, page 270) was semi structured and therefore allowed the researcher the flexibility to explore issues that were brought up by the parents. An initial draft interview schedule was designed after conducting a literature search of the area (see Chapter 1 Introduction for an overview of the literature). The initial draft of the interview schedule was reviewed by the research team, made up of academic supervisors and a range of NHS supervisors from a peer review group. The feedback from these sources was incorporated to develop a final schedule. This was pilot tested on a group of four South Asian mothers from a local play group. The interview schedule used non-direct, open ended questions in an attempt to avoid imposing specific understandings of the intellectual disabilities onto the parents. The questions aimed to provide a loose guide, which enabled participants to take the interviewer on a journey of their own personal experiences of caregiving and understandings of their child's disabilities. In doing so, the interviewer was guided by the participants and asked questions in response to what was being discussed by the groups. The interview schedule consisted of general open ended questions and prompts to explore important ideas and issues.

Ethics

Ethical approval for this phase of the study was granted by Coventry Research Ethics Committee, NHS (see Appendix G, page 271). Written consent was obtained from all participants prior to commencing with the focus groups. All data remained anonymous, using pseudonyms to preserve the participants' identities. After written transcripts were produced all recordings were destroyed.

Procedure

The researcher initially contacted the group facilitators (staff who co-ordinated the groups) to discuss whether members would be suitable to be approached to take part in the focus groups. Following the group facilitator's advice the researcher went to visit each group separately during a number of their monthly meetings in order to build up a rapport and sense of trust with group members. This was important due to the sensitive nature of the issues being discussed in the groups. The researcher provided each group with verbal details of the focus groups and what their participation would involve. Each member was given an information sheet (see Appendix H, page 273) outlining the nature of the study and a consent form (see Appendix I, page 276). All participants were asked if they would like translated copies of the information sheet and consent form, however they were happy to receive English versions. After a week the researcher contacted the group facilitators to find out if the groups were interested in taking part. As both groups were happy to take part, the researcher met each group during one of their monthly meetings to conduct the focus groups. Informed written consent was obtained from each member of the group prior to conducting the focus group. The Sikh carers' focus group was conducted in Punjabi and the Muslim carers group in

Mirpuri. All interviews were conducted by the first author who was able to speak and understand both Punjabi and Mirpuri. Focus groups lasted just over an hour.

Analysis

Both focus groups were audio-recorded, transcribed and translated into English by the first author. In order to check the accuracy of the translation, ten per cent of the focus group recordings were re-translated by an independent professional translating service and showed consistency. Transcripts from all three groups were analysed using interpretative phenomenological analysis (IPA) using guidance from Smith et al. (2009) as a framework. As the data consisted of group discussion a protocol for applying IPA analysis to group data was used as a template (Palmer et al., 2010). Please see Chapter 2 (methods) for more details of this process.

Credibility and validity of analysis

Credibility of the analysis was upheld through the use of regular supervision and cross checking of the analysis with a secondary researcher with knowledge of IPA. This involved a method of triangulation whereby a number of qualified researchers in IPA verified the findings through repeated and regular checks of both the phenomenological and the interpretative stages of the analysis (see Chapter 2, methods, for more details). Furthermore, all interpretations in the results section have been illustrated with numerous examples from the data and additional quotes can be found in Appendix J (page 277).

Table 3.1
Participant Details

	Participant Pseudonym	Relationship to Child with ID	Language Spoken	Details of child with intellectual/developmental disabilities (I/DD)		
				Gender	Age	I/DD
Sikh Carers Group	Mr Samra	Father	Punjabi	Male	17	SID
	Mr Bhambra	Father	Punjabi	Male	19	Autism and Epilepsy
	Mrs Bhuppal	Mother	Punjabi	Male	8	Autism and Epilepsy
	Mrs Virk	Mother	Punjabi	Female	18	Autism and Epilepsy
Muslim Carers Group	Mr Ahmed	Father	Mirpuri	Male	16	ID*
	Mr Rasheed	Father	Mirpuri	Male	10	SID*
	Mrs Hussain	Mother	Mirpuri	Male	7	ID
	Mrs Akhtar	Mother	Mirpuri	Female	19	SID
	Mrs Rahman	Mother	Mirpuri	Male	18	ID*

* Participants have more than one child with an ID.

ID = Intellectual Disability SID = Severe Intellectual Disability

Results

Following analysis of the transcripts four master themes emerged and are presented with their sub themes (where relevant) in Table 3.2. below which also demonstrates how many participants are represented within each theme.

Table 3.2

Master and sub themes reflecting participants' experiences of caring for children with intellectual/developmental disabilities and the number of participants who represent each theme

<i>Master theme</i>	<i>Sub theme</i>	<i>No. of Participants representing each theme</i>
Making sense of the disability	<i>"God's choice"</i>	5
	<i>A problem with epilepsy, 'bad' behaviour and speech</i>	5
	<i>Struggling to get a diagnosis</i>	8
	<i>Medical negligence as a cause</i>	5
Feeling let down by services		7
Being isolated through the stigma of local communities		9
Looking to the future	<i>Concerns for future well-being</i>	5
	<i>Wanting help vs giving up</i>	4

Master theme 1: Making sense of the disability

This theme describes how the parents understood and tried to make sense of their children's disabilities whilst drawing on a range of resources including their religious views as well as their interactions with healthcare services.

“God's Choice”

Mothers from both groups drew on religious resources in an attempt to make sense of their children's disabilities which focused on a belief that their disabilities were in the hands of God. There were differences in terms of how these religious interpretations influenced the parents' perceptions of the disability. Mothers in the Muslim group talked about the child being a test from God, which provided them with evidence of God's purpose and faith in them as parents. For example, Muslim mothers made reference to the child with the disability being a “*special*” God given gift which provided them with reaffirmation of their belief in God. For these mothers religion provided them with resilience to endure the demands of caregiving:

- Mrs Hussain:* “We have full faith in God and have accepted his will. Our other children are healthy and he has given this child to try us, whether we can look after this disabled child... this is a special person, you are a special person because God has chosen you, that you have patience that you can look after them that's why you should have this gift.”
- Mrs Rahman:* “If these types of children are in our fate, we take it as God's will and tolerate it.”

For mothers in the Sikh group, religion offered less discernable explanations and instead they accepted that the disability was in God's hands and something that they had to live with: “It's up to God why he did this.” (*Mrs Bhuppal*). For these mothers, religion offered less positive beliefs about the disability which focused on the disability being viewed as an

adversity: *“We pray to God that this type of thing doesn’t happen to anyone, not even a child of our enemy.” (Mrs Virk).*

A problem with epilepsy, ‘bad’ behaviour and speech

For parents in the Sikh group, the process of making sense of their children’s disabilities was done in relation to what they perceived as behavioural difficulties. Despite having received a diagnosis the parents identified their children’s difficulties in terms of “*bad*” or troublesome behaviour. For these parents the “*bad*” behaviours appeared to have a direct connection with their children’s epilepsy. As one Sikh parent described below, the “*bad*” behaviours acted as indicators of the onset of an epileptic seizure: *“When the fits are about to happen, two or three days before she starts talking to herself. Her behaviour gets bad. She becomes very stubborn and very angry.” (Mrs Virk)* The significance of the epilepsy was related to its unpredictability which caused disruption to the normality of their family and work lives: *“It would be time for work and then he’d start having fits. I wouldn’t go to work then and instead go to the hospital.” (Mr Bhabra)* As a result management of the epilepsy and its associated “*bad*” behaviours through medication featured prominently in the parents’ accounts.

Additionally, for mothers from both groups, their children’s disabilities represented problems with expression rather than understanding. For these mothers, difficulties with expressive speech were the main problems for their children: *“She understands, but she can’t tell, she can’t speak, she can’t talk.” (Mrs Virk)* They highlighted that their children’s disabilities made it difficult for them to develop speech which consequently hindered their ability to communicate, despite being able to understand what people were saying to them: *“My seven and a half year old son, he has developmental delay and he does not speak and understands*

everything but can say one or two things.” (Mrs Hussain) For some of the mothers their children’s ability to understand speech and conversations provided some relief that there was potential for change: *“He understands talk that, ‘you can do this and this is wrong’. He understands, watches telly, compared to before he didn’t know about telly nothing! So he’s changing.” (Mrs Bhuppal)*

Struggling to get a diagnosis

A number of parents from both groups described their struggle in trying to get a diagnosis of their children’s conditions. The parents highlighted that doctors were quick to minimise their concerns about their children’s delays as being a part of normal development:

- Mrs Rahman: “My elder son was 15 when we found out. Earlier for 15 years they told us when he grows up, he will get well. But we noticed his disability, that something wasn’t right.”*
- Mrs Akhtar: “If our children were given proper care and treatment in the beginning then it is possible that today their life might have been totally different.”*

For these parents the deterioration in their child’s health was rooted in their doctor’s inability to recognise the severity of the behavioural alterations early on. Since behavioural delays were normalised by doctors during the early phases of the disability, the psychological impact of the condition was still circumscribed. As a result, emotional reactions of the parents included anger and feelings of helplessness: *“When we see the condition of our children then we are distressed and we are furious.” (Mrs Rahman)*

Some of the parents reported receiving an earlier diagnosis of their child’s delays, however only in response to a crisis. For these parents the adaptive decline of their child’s condition reached a threshold of severity, which triggered major concern for the parents: *“She went to*

school and the teachers say she kept having fits. They got scared and then we took her to the hospital. They checked her out and kept her there and afterwards, they told us what they were.” (Mrs Virk) A striking element described by the parents who had received a diagnosis was the uncertainty that seemed to envelop their children’s difficulties. The uncertainty was in relation to not being able to comprehend the diagnosis. For example, Sikh mothers emphasised their first encounters and experiences of dealing with their child’s epileptic seizures:

- Mrs Virk: “We didn’t know what it was or wasn’t...she cried a lot, when she had a fit for the first time. We didn’t know what happened. You couldn’t tell, we’d never seen it before.”*
- Mrs Bhuppal: “You can’t tell what it is. We didn’t know either, what are fits.”*
- Mrs Virk: “And then we took her to hospital. They checked her out and kept her there. Afterwards, they told us they were fits, I said what are they? I said ‘I don’t know what they are.’ Honestly I swear, I never knew.”*
- Mrs Bhuppal: “Yes I didn’t know either, it’s not like we’d heard of it before. It was the first time we saw it.”*

Above, Mrs Virk and Mrs Bhuppal describe their feelings of bewilderment and helplessness during their first experiences of their children’s epileptic seizures. For these two mothers, their feelings of helplessness were associated with their lack of awareness and knowledge about epilepsy.

Medical negligence as a cause

Parents who experienced delays in diagnosis or whose concerns had been dismissed, perceived their child’s disabilities as resulting due to poor medical care. Some parents associated the cause of the disabilities with insufficient attention from health care staff during pregnancy. For example below, Mr Samra described his feelings of disappointment and

helplessness experienced during the birth of his child, over something which could have been prevented:

Mr Samra: "My child was starved of oxygen. The nurse was running after three ladies and my wife was in trouble, I tried to help her put oxygen on. By the bloody time my son was born he was starved of oxygen. And you know what happens to the brain when it's starved of oxygen, damage."

Additionally, a father from the Muslim group attributed his son's disabilities to the suspicious activities of a service provider which allowed him to make sense of why only two of his sons, rather than all of his sons had been affected by disabilities: *"I am completely suspicious, some man came and he did something. I am 70% sure that this is birth neglect. Two sons are ok and two are ill. Two that were born in Pakistan are ok."* (Mr Ahmed) Additionally this parent held strong inclinations towards Pakistan, believing that if his sons had been born in Pakistan they were unlikely to have had any disabilities thus, situating the cause of his sons' disabilities in the failures of Western services. As well as struggling to understand their child's disability, some of the parents also struggled to locate the potential cause. This uncertainty and an absence of other explanations meant that some parents attributed the causation to problems with medication: *"The epilepsy, I don't know if she had too much medicine or the inhalers were too much. We don't know what the problem is. We can't understand."* (Mrs Virk)

Summary of master theme 1

This theme described how parents made sense of their children's disabilities. Religion played an important role in the mothers' interpretations of the disability as being part of "God's plan". There appeared to be subtle differences across the two religious groups in terms of whether these religious appraisals led to positive or negative interpretations. In terms of

features of their children's disabilities challenging ("bad") behaviours and speech delays were identified as prominent difficulties which the parents struggled to come to terms with. Finally, both groups of parents highlighted their struggle to receive a diagnosis of their child's disabilities which was attributed to the unresponsive nature of services and having their concerns dismissed. As a result, both groups appeared to struggle to understand their child's delays and identified medical negligence as a primary cause.

Master theme 2: Feeling let down by services

This master theme is treated as a whole master theme rather than consisting of smaller sub-themes because the overarching experiences described by parents were their feelings of being let down. It focuses primarily on the perceptions of parents from the Muslim group, who reported frequently and in detail on their negative experiences with service providers.

All parents in the Muslim group described strong feelings of anger and frustration towards service providers who they felt were not doing enough to help their children. For one mother, these frustrations were about not receiving a quick enough diagnosis of her child's condition: *"My youngest is 18 years old. Till today no test are done. Doctors have done no tests and they do not know what the problem is."* (Mrs Rahman) For Muslim parents who had received a diagnosis, their frustrations were related to the perceived inappropriateness of their GPs' recommended interventions. In such cases there appeared to be a conflict between the parents' and the professional's agendas. For one Muslim parent, her particular frustration was with her doctor's ambiguity about suggested pharmacological interventions: *"Doctors say he does not have epilepsy but they have given epilepsy medication. If he does not have*

epilepsy then why give him epilepsy medication?” (Mrs Rasheed). For such parents services appeared to be mismatched in terms of providing appropriate interventions for their children’s health conditions, which further heightened parental frustrations.

In some cases parents described their negative interaction specifically with ‘Asian’ service providers, which led to feelings of disappointment in their expectations that service providers from within their own community (“*our people*”) should have been more helpful:

Mr Samra: “Our women don’t tell us, I was hoping there would be a white man, I could talk to. Our woman knew nothing. She was there to help our people but she was creating more problems.”
Mr Bhambra: “Yes that’s what they do, backstabbers.”

For Mr Samra and Mr Bhambra, their disappointment of being let down appears to be linked to their false expectations that service providers from within their own community “*our people*” would have had a propensity to be more helpful. This is reinforced with Mr Bhambra’s use of the word “*backstabbers*” to describe Asian service providers, which creates a perception of feeling let down or having had greater expectations. The parents also talked about the stigma with which disabilities were viewed within their own communities. This stigmatisation may have led to negative perceptions about Asian service providers

Parents in the Muslim group also described feeling blamed by health professionals, who they felt associated them with the source of the child’s disability, in the form of genetic causes:

Mrs Rahman: “The main thing they say to us is ‘you people do marriages in the relations.’”
Mrs Hussain: “Yes, that is the main reason they say we marry in relations but we are doing this since the beginning of the world, and even now...”

For these parents genetics did not provide a valid explanation of the cause of the disability because it did not seem to explain why all of their children had not been affected: *“I have three children and they are ok, why aren't they like this?” (Mr Ahmed)* Interestingly, parents with more than one child with an intellectual disability also refused to accept genetics as a possible cause, and instead they questioned why genetic disorders were prevalent amongst other communities who did not practice consanguineous marriages: *“Indians, Bangladeshi, Hindus these families have children that are disabled. We do have marriages in families, but they don't so why do they have disabled children?” (Mrs Rahman)*.

Summary of master theme 2

This master theme described the parents' negative perceptions of what were considered to be unhelpful services. Muslim parents in particular reported difficult interactions with the GPs in terms of getting a diagnosis and understanding the rationale for the treatments prescribed. Additionally, Muslim parents described feeling blamed by service providers who attributed their children's disabilities to genetic causes, thus suggesting the disabilities may have been inherited. Finally, both groups described negative perceptions towards service providers from the same ethnic backgrounds, from whom they had expected more support.

Master theme 3: Being isolated through the stigma of local communities

In this master theme both groups discussed the stigma with which disabilities were viewed within their own communities. As with the previous master theme it has been treated as a whole. For Sikh parents this stigma was directed towards the child themselves in the form of

misconceptions that the disability was contagious. However, for Muslim parents it was directed towards the parents by associating them with the cause.

Sikh parents appeared regretful of the “*negative*” reactions they experienced from Indian communities and extended families. The “*negative*” reactions described focused around individuals’ fears of the disability being contagious and passed onto their own children. As a consequence this led to avoidance of the child with the disability:

Mr Bhambra: “*I’m sorry to say that our people are negative, they think negative.*”
Researcher: “*So when you say negative, what kind of things do they think?*”
Mr Samra: “*That we don’t want our child to become like that, they move away.*”

Muslim parents described difficult relationships with their extended family members, who they felt had deliberate intentions to cause them stress. Muslim parents felt judged by their extended families who viewed the disability as a transgressive problem, which occurred due to the parents past misdeeds, thus situating the causation with the parents:

Mr Ahmed: “*They cause more pain, it’s just our family.*”
Mrs Hussain: “*They put more pressure on.*”
Mr Rasheed: “*Pakistani families, if they had the opportunity they’d want to add fuel to the fire.*”
Mrs Akhtar: “*No it’s just our family.*”
Mrs Hussain: “*They just add salt to the wound, that’s it.*”
Mrs Akhtar: “*It’s better if you don’t ask about that.*”
Mr Ahmed: “*They say that you have committed sins and God has given punishment for these deeds, it’s daft. We are supposed to remember it is God’s will and he will remember us in return.*”

In response to feeling judged, Muslim carers sought to provide their own alternative religious explanations and meanings of the disability. These explanations focused on positive connotations of the disability as being evidence of God’s plan for them. Stigma from within their extended families left Muslim carers feeling isolated and withdrawn away into their own immediate families (“*It’s just our family*”).

Given the negative encounters of both groups of parents, it is no surprise that the parents had developed means of dealing with the negativity. Two of the coping strategies employed included becoming an advocate for their child and trying to ‘numb out the pain’. For example, in response to the negative comments of other people towards their children, both groups of parents reported themselves or their other children advocating the inclusion and acceptance of the child with intellectual disabilities:

- Mrs Hussain:* “The number of times whenever I go anywhere, with my youngest child, to attend weddings with my disabled child, some people mind it, but I do not bother what they say. I take him along. I said ‘this is my child then what else is my purpose?’ I only leave him at home when he is not well and I have to go urgently but I take him to every place.”
- Mr Rasheed:* “When I have weddings I take them there.”
- Mrs Hussain:* “Absolutely! We have attended weddings up to London in our family and I have never left him at home. I say ‘why should I?’ If anybody is ashamed of anything, they should remain at home and not look.”
- Mr Rasheed:* “We tell everybody about our children.”

For the Muslim parents this involved promoting the inclusion of their child at social events. One Muslim carer (Mrs Hussain) described having strong feelings of a maternal obligation to care (“I said this is my child then what else is my purpose?”) and act as an advocate on behalf of her child by making people aware of her child and promoting his inclusion. Furthermore, this parent stressed the importance of making efforts to include her child in social gatherings such as family weddings and overcoming obstacles such as attitudinal barriers (negative reactions from people).

Both groups of parents described learning to live with the negative reactions of other people by numbing out the pain. For both groups it appears that this is something that they have had to learn to do over time (“I don’t really bother now” and “Previously I used to take notice”). One Sikh father described being given false hopes and expectations by a family member,

which led to feelings of rejection and led him to adopt a “*don’t bother*” attitude towards family members in the future: “*I don’t really bother now, my uncle said bring the little one to the house, I called him but he never called back.*” (Mr Bhambra)

Summary of master theme 3

This master theme described the parents’ experiences of stigma from within their own communities. There appeared to be subtle differences between the two groups in terms of the source of the stigma (contagion or punishment from God). Although the parents described their attempt to ‘numb out’ the pain caused by these negative attitudes, it often led to isolation and limited social support.

Master theme 4: Looking to the future

In this theme parents in both groups described their concerns as well as hopes for the future of their children. Both groups of parents stressed their desires to provide long term care within the family home.

Concerns for future wellbeing

Parents from the Sikh group expressed their concerns over the future care of their children. One of the main sources of worry for these parents was how their children would manage without them in the future: “*Our major worry is that once we die who will look after him?*” (Mr Samra). Concerns about future care, may have been linked to the parents’ worries about their own deteriorating health. It is interesting that despite expressing concerns about their child’s future welfare, only one of the parents had taken any practical steps to safeguard their

future care. This parent emphasised and encouraged the other parents to prepare for the future by making wills to ensure financial security for their children: *“That’s why I am saying to you all if you have not made a will, make a will.” (Mr Samra).*

Wanting help versus giving up

Parents in the Muslim group, did not express direct concerns about their child’s future, but instead stressed the need for services to deliver appropriate care and treatment to meet the health needs of their children. Muslim parents stressed the importance of seeking entitlement to their children’s rights to healthcare. They expressed wishes to see practical changes and as a result witness tangible benefits for carers and their children. For Muslim parents improving communication with doctors was very important, they stressed the importance of being heard when acting as advocates on behalf of children. This could be linked to the Muslim parents’ concerns about being dismissed by doctors as described in theme 1.

Mrs Hussain: “We want that the requirements of our children are fulfilled. We want something done about our doctors.”

Mr Rasheed: “They should do something, somebody should get benefit.”

Mr Ahmed: “We require that practical steps should be taken and not paperwork. They should take notice of our children they should give them relaxing medication.”

Mrs Hussain: “They should think about doing something about doctors that if these disabled people go to see them, they should be treated after proper examination. We cannot do more than telling the problems of our children, we can’t do anything else.”

One mother also raised concerns about what she perceived as mismatched services, who in her view unnecessarily exaggerate the needs of carers and in doing so fail to address the health needs of their children: *“We do not demand anything for us. At least they should take care of our children.” (Mrs Rahman).* This may be a reaction to taking part in the research which was focused on the caregivers’ experiences and therefore gave prominence to

the needs of caregivers. Finally, for parents with more than one member of the family with intellectual disabilities, there was a sense of ‘learned helplessness’ (Mir and Tovey, 2003), whereby numerous difficult encounters with services and feelings of being let down, left them feeling powerless and resigned to the expectations of receiving little help in the future: *“Our children are now old and since a very long time we have been telling services but everything is futile. If they don’t know by now it is useless.”(Mr Ahmed)*. The Parents in the Muslim group also reported concerns about the nature of research and their perceptions of research being non reciprocal, providing benefits for the researchers and very little for themselves or their children.

Summary of master theme 4

This master theme described the parents’ views about what the future may hold for themselves and their children. Overall they described their desire for care to be provided within the family home with little interventions from services. Additionally, parents described the need for more helpful and practical services with consideration of their individual needs. Due to previous negative interactions with services the parents appeared to have lost hope in services and their situation improving.

Discussion

This study has provided accounts of the experiences of South Asian parents caring for children with intellectual/developmental disabilities in the UK. Using group interactions it has explored the role of culture in shaping the way parents make sense of their children's disabilities and their perceptions of services. IPA was employed to gather four clusters of master themes which were: making sense of the disability, feeling let down by services, being isolated through the stigma of local communities and looking to the future. The following discussion explores the four master themes in relation to previous findings and in terms of their implications for service delivery.

Master theme 1: Making sense of the disability

Religious understandings of disability amongst South Asian families in the UK have been well documented in research (Fatimilehin & Nadirshaw, 1994; Bywaters et al., 2003; Croot et al., 2008; Mir, 2001; O'Hara, 2003). The findings of the current study support this and give insight into the subtle differences in the beliefs of different religions which can impact parents' perceptions of the disability. As described in the sub theme "*God's choice*" only the mothers made reference to religious explanations for the disability, which may be indicative that gender plays a role in the use of religious resources when making sense of disability. Mothers in the Muslim group offered more positive explanations, by viewing the disability as a "test" from God. Conversely, for mothers in the Sikh group, religious explanations offered more negative views of the disability, but religion still played an important role in their personal interpretations of the disability as being part of "God's plan". Grounding explanations of disability in religion may have given these parents a context for making sense

of and coping with the challenges of the disability and caregiving, as well as avoiding more negative emotions such as guilt or blame.

Attributing disabilities to external causes such as religious explanations is not something which is specific to South Asian cultures. Many cultures have been shown to use religion as a means of acceptance and making sense of the disabilities in a positive way. For example, one study explored the role of religion for 50 North American, European and Australian parents caring for children with special needs and found that religion provided a means of coping and grieving (Thomas et al., 2004). It is important for services not to underestimate the importance of religious beliefs for families caring for a child with intellectual disabilities, but at the same time to recognise the differences in these religious interpretations and how they may influence experiences of caregiving. Services could draw on the positive outcomes of religious beliefs such as promoting resilience and coping, by incorporating a religious facet to service provision alongside the routine medical approaches.

For parents in the Sikh group, challenging behaviour and epilepsy were identified as being problematic, as described in the sub theme *“A problem with epilepsy, ‘bad’ behaviour and speech’*. For these parents there was a direct association between the two, with the “bad” behaviours indicating the onset of an epileptic seizure. The relationship between epilepsy, intellectual disabilities and challenging behaviour is unclear, with some research reporting positive associations (Lund, 1985) and others no association (Deb & Hunter, 1991).

Challenging behaviour may be a manifestation of underlying mental health problems, which have been shown to be higher amongst children with intellectual disabilities (Emerson & Hatton, 2007). The unpredictable nature of epilepsy and the difficulty in managing the “bad”

behaviours meant that parents concentrated on management and control via medication.

Although medication may successfully manage challenging behaviour, it may not deal with the root cause of the behaviour. This highlights the need to encourage and support parents to help their children deal with the psychological aspects of the disability rather than concentrating on the somatic symptoms.

For parents from both groups, the disabilities resulted in problems with their children's expressive communication (speech) rather than receptive communication (understanding). The severity of a child's communication impairments has been shown to correlate with parental stress and adjustment, with more severe difficulties leading to harder adjustments (Hassall, Rose, & McDonald, 2005; Hoare, Harris, Jackson, & Kerley, 1998). Despite accepting their children's difficulties with expressive communication (speech), the parents' beliefs that their receptive communication (understanding) was intact may have provided them with relief and hopes for improvement in the future, thus allowing easier adjustments and less stress.

The disclosure process is important because it allows parents to accept, adapt and cope with their child's disability (Hatton et al., 2003). A positive disclosure or diagnosis process can lead to long term benefits for the whole family including early interventions, better adjustments and more support (Hatton et al., 2003). Parents in this study described in detail "*struggling to get a diagnosis*" which may have meant that they were constantly searching for a way to make sense of the disabilities. Often, minority families who do not speak the host country's language may find the disclosure process a lot harder due poorly assimilated information which could have been complicated by communication difficulties. This could be

improved through the involvement of interpreters/translators and better post disclosure support for parents. Additionally, more culturally appropriate written and audio visual information needs to be readily available so that parents are given the resources to fully understand the complexities of their child's delays and the support available to them.

Difficulties with the disclosure process meant that parents drew on alternative explanations to make sense of their child's disability. In response, parents associated the cause of their child's disability to the negligence of service providers, either at the time of the birth or as a side effect of wrongly prescribed medication as described in the sub theme "*Medical negligence as a cause*".

Master theme 2: Feeling let down by services

In the master theme "*Feeling let down by services*" parents in the Muslim group reported difficult interactions with GPs. These difficult interactions left the parents experiencing problems with the referral process to specialist services and, ultimately, diagnosis. This highlights the need to improve the ease with which parents can navigate western service systems. Positive encounters with services during the early stages of detection may increase the likelihood of parents engaging with services on a long term basis, which could lead to earlier diagnosis and interventions. In the UK, GPs are often the initial "port of call" for parents with concerns about their children. Awareness and uptake of GP services amongst South Asian's has been shown to be higher than specialist services (Katbamna et al., 2002). More in-depth training for GPs to promote the early recognition of symptoms of intellectual delays and cultural competence training could improve interactions between GPs and South Asian parents during the early stages of detection.

The risk of first cousin couples having a child with severe medical conditions is thought to be between 5-6 %, almost three times higher than non cousins (Saggar & Bittles, 2008). Muslim parents did not accept medical explanations that the disability may have been inherited. This may be associated with the parents' feelings that services were adopting 'culture blaming attitudes' (O'Hara, 2003), which view their cultural practices in a negative way. Additionally, parents felt that they were being blamed for contributing to their children's health conditions such as obesity, due to inappropriate meal choices. Research suggests that people with intellectual disabilities and those from ethnic minorities are more likely to be obese than the general population (Emerson 2009; Reinehr, Dobe, Winkel, Schaefer, & Hoffman, 2010). Sensitivity when talking about 'lifestyle' and cultural practices should be prioritised so that parents do not feel blamed or singled out.

Both groups described negative interactions and experiences with Asian service providers. This result was surprising given that both groups were facilitated by South Asian service providers, with whom the parents had built up strong relationships. Negative encounters with a small number of Asian service providers and with the South Asian community (due to stigma) may have meant that parents found it difficult to trust South Asian service providers whom they did not know well. The current study highlights the need to actively involve parents in deciding by whom services are delivered and the need for more training for service providers, in particular for those working closely with ethnic families, to promote interpersonal skills and cultural competence. It can be taken for granted that ethnic service providers will naturally be aware of cultural issues important to service users from the same ethnic group. However, variations may be present due to acculturation, language, country of birth, social background and religion.

Master theme 3: Being isolated through the stigma of local communities

The stigmatisation of disability amongst South Asian communities has also been reported in other studies, in the form of negative attitudes and expectations (Bywaters et al., 2003; Ali et al., 2001; Hatton et al., 2003). In response, parents had developed means of resisting the stigma. For example, carers described having to distance themselves and ignore the comments of extended family and local community members. This led to the isolation of the child and family. Isolation can have negative effects on the whole family, including the child with the disability and can exacerbate mental health problems, leading to poor self-esteem, depression and anxiety (Azmi et al., 1998; Butt & Mirza, 1996). Stigma arises from the socially constructed negative stereotypes associated with disabilities and is likely to be linked to a lack of information and awareness about disability (Berzins, Petch, & Atkinson, 2003). It is important to reduce stigma attached to the label of intellectual disability, so that families feel less isolated from their communities and are more likely to access much needed support.

Education is an important contributor to challenging these misconceptions and raising awareness within local communities. Much of the work done to address stigma within ethnic communities has concentrated on mental health in general, with little reference to intellectual disabilities. Anti stigma projects have been used to reduce stigma attached to mental health problems. However, it is difficult to assess the success of such projects due to poor or no outcome measures. More recently, community interventions have been shown to have some success that is, working closely with community members, clinicians and media, promoting mental health awareness in culturally appropriate methods including using translated material (Knifton et al., 2010).

Master theme 4: Looking to the future

The sub-themes “*concerns for the future*” and “*wanting help versus giving up*” both described the parents’ expectations about the future care of their children. All parents stressed the need to provide care within the family and they did not mention any plans for their child living independently, which has been demonstrated by other research (Bywaters et al., 2003). This may conflict with the principles of learning disability services in the UK which promote independence and choice as outlined in ‘person centred planning’ (Valuing People Now, 2009). Services could incorporate ideas of independence and choice within a traditional framework. This could be achieved by encouraging parents to promote independence in a more subtle way (through leisure activities, socialising and personal care) whilst still providing care within the home. Associated with this is the need to offer appropriate physical and emotional support for parents who decide to provide care on a long term basis, as the challenges of caregiving are likely to increase with increasing age. It is, however, important to note that parents may choose not to access services that are available to them. For example, the parents in the Muslim group stressed their concerns that services were often ‘mismatched’ in terms of the types of services they provided. These parents felt responsible to care for their children themselves without the need for formal services (such as respite care and carer related services).

Reflections

As described in the discussion, the results of the current study support and expand on the existing literature. A major challenge with the study was recruitment of participants which proved difficult because learning disability teams reported having limited numbers of ethnic

families on their case loads, which may be a representation of low service uptake amongst South Asian communities. Additionally, the parents identified were reluctant to participate due to fears around confidentiality. As a result the research was reliant on pre-existing parents support groups for participation, which may have biased the group interactions. The challenge with recruitment made me consider my plans for the next study. I felt that parents may be more likely to share their personal experiences without fear of confidentiality in one to one interviews. The interviews aimed to give parents the flexibility to talk about their personal experiences in detail and in doing so hoped to shed light on some of the intragroup variations identified in the current study.

Additionally, I became interested in my own stance and beliefs about the experiences described in the current study. In particular, I reflected on how far removed the carers' beliefs and ideas were from my own, specifically in relation to religion and stigma. On reflection, I believe these differences are due to my experiences of working in learning disability services and being a second generation South Asian born in the UK. As a result, I became interested in exploring what impact processes such as acculturation (exposure to two cultures) have on caregiving experiences by recruiting a large and diverse sample of participants in the next study.

CHAPTER 4

Study 2 - An in-depth exploration of how culture shapes the experiences of South Asian carers caring for children with intellectual/developmental disabilities in the UK

Introduction

The term ‘South Asian’ is a complex one. South Asians are a diverse group made up of a number of sub-groups such as Indian-Punjabi, Indian-Gujarati, Pakistani-Mirpuri and many more. Each group has their own languages, religious practices and migration histories. Within each group, there is often great variation in terms of education, financial status and social status. Individual positions on cultural and ethnic identity tend to be complex and may be influenced by multiple practices. This heterogeneity of ‘South Asians’ is likely to impact on the experiences of caring for a child with intellectual/developmental disabilities. For example, Study 1 (Chapter 3) revealed some subtle differences in the interpretations and responses between Muslim and Sikh carers.

Acculturation (exposure to two cultures) is another cause of diversity amongst British South Asian communities, however very little is known about how this process influences caregiving experiences. The idea of psychological acculturation was first introduced by Graves (1967) and refers to changes which occur when individuals from one culture come into contact with individuals from another culture. There are different models and theories of acculturation which have been outlined in Chapter 1 (Introduction). One prominent theory is Berry's (1997) acculturation framework, which defines acculturation across two dimensions, according to the degree of ‘participation’ with the mainstream culture and the degree of ‘maintenance’ of the heritage culture. The framework suggests that the degree of ‘participation’ or ‘maintenance’ can lead to four acculturation strategies:

- *Assimilation* – heritage culture rejected in favour of mainstream culture
- *Separation* – heritage culture retained and mainstream culture rejected
- *Marginalisation* – both cultures rejected
- *Integration* – both cultures are embraced

There is little research exploring how South Asians in the UK make sense of and handle their relationship with two cultures. Using Berry's (1997) acculturation framework the limited research has explored the differences in acculturation strategies and identity formation in first and second generations. For example, research has shown that first generation South Asians tend to favour 'separation' whereby they maintain their South Asian cultural heritage and reject British influence (Anwar, 1998; Shaw, 2000). Conversely, second generations are more likely to 'integrate' into British culture whilst still maintaining some degree of their ethnic identities, thus demonstrating bicultural identity (Azmi et al., 1998; Ghuman, 2003). These studies also suggest that intergenerational conflicts between adolescents and parents known as the 'culture conflict', (Berry, 2005) can increase risk factors for psychological problems.

Although acculturation has been explored in the areas outlined above, very little is known about how acculturation in South Asian communities influences caregiving experiences.

However, it is likely that acculturation adds to the diversity of South Asian groups in the UK and is likely to lead to different caregiving experiences and create differing service needs amongst its members. These assumptions are based on research exploring the impact of acculturation in other minority groups. For example, McCallion et al. (1997) used qualitative focus groups with African, Chinese, Haitian, Hispanic/Latino, and Korean Americans to explore how acculturation impacts the experiences of people caring for a person with

developmental disabilities. They found that families demonstrating higher levels of integration did not experience language barriers, had better uptake and relationships with services, and were less likely to subscribe to religious or cultural explanations of disability. Little is known about the impact of acculturation on South Asian groups caring for people with disabilities in the UK. Two studies have looked at the way in which South Asian disabled youth explore their identities. Using interviews with a range of young disabled South Asian (Muslim and Sikh) individuals, these studies demonstrated the complexity of coming to terms with multiple identities (e.g. the disability and ethnic identities) (Hussain, 2005; Hussain et al., 2002). Results demonstrated that in most cases participants held strong religious and cultural identities especially females.

Much of the remaining literature has explored the general experiences of less integrated, first generation South Asian carers demonstrating low English proficiency and preferring ‘separation’ strategies of acculturation which promote the retention of heritage, cultural values and beliefs. This research suggests that South Asian families tend to attribute disabilities to religious or supernatural causes, seek out religious or cultural treatments and hold collectivist values which promote caring within family units (Fatimilehin & Nadirshaw, 1994; Katbamna et al., 2001; Bywaters et al., 2003; Katbamna et al., 2004). For a more detailed description of the literature please see Chapter 1.

Aims of the current study

Given the insights from Study 1, the current study aimed to provide more detailed accounts of South Asian parents’ experiences, through the use of one to one qualitative interviews. Instead of focusing on shared experiences and socially generated accounts (as described in Study 1),

Study 2 aimed to provide an in-depth account of personal experiences. By giving South Asian parents an opportunity to narrate their experiences on an individual basis it was anticipated that they would be able to reflect on their subjective experiences of caregiving and in doing so, provide a potential counterpart to some of the ambiguities revealed in Study 1.

Additionally, following personal reflections after conducting the focus groups in Study 1, I began to consider my own positions on and understandings of disability as a second generation British South Asian. Specifically, I became aware of the distinctness between my personal views of disability which focused on western ideas and those of the parents in Study 1 which were more traditional. Therefore, I became interested in exploring whether processes such as acculturation impact on the caregiving experiences of British South Asian parents, which is an area of the literature that has not been explored previously. I hoped to achieve this by recruiting a culturally diverse sample of South Asian parents who would reflect different religions and differing levels of acculturation. It was anticipated that using IPA's open and flexible approach to data collection would provide insight into which aspects of the acculturation experience such as new language acquisition, bicultural influence and adoption of new values or retention of traditional values are influential in the caregiving process. By focusing on a group of South Asian parents for whom acculturation was not a presenting issue and removing the group dynamics I hoped that Study 2 would enable an exploration of caregiving from a different conceptual lens.

Method

Context

A West Midlands Children's Learning Disability Team (CLDT) was asked to identify parents to participate in the study. Regular contact was maintained with the team through emails, telephone calls and attendance at monthly team meetings. Potential participants were identified by learning disability nurses. These nurses initiated 'first contact' with parents by informing them about the study and asking them if they would be interested in taking part. Following this, I visited the potential participants alongside the nurses at their homes and provided them with an information sheet (see Appendix K, page 280) and further details of the study. Participants were asked if they were happy for me to contact them the day after this meeting to see if they would like to take part.

At this point I also contacted a second learning disability service in the West Midlands in search of additional participants. As a result of contacting this service I was given the contact details of a community support worker facilitating a support group for Muslim carers of children with developmental disabilities. Many of the parents accessing this support group were either second generation British South Asian parents or were first generation parents who were able to speak English. This may be a reflection of the fact that the support worker was also second generation and communicated in English. With the permission of the group I attended three of their fortnightly meetings in order to build a rapport with the parents. All members of the group were informed of the nature of my attendance and my interest in conducting research. Parents were asked if they were interested in taking part in the study and

given an information sheet (see Appendix K, page 280) and consent form (see Appendix L, page 282).

Written consent was obtained from all participants prior to conducting the interviews. The interviews were undertaken at the parents' convenience at a venue of their choice and lasted between an hour and an hour and a half. Four interviews were conducted in the parents' homes, two at the carers group meeting venue and one at the children's learning disability teams meeting room. All interviews were conducted in English. In some cases participants referred to specific words or phrases in either Punjabi or Urdu which I translated myself, as I am able to speak and understand both languages.

Participants¹

Eleven parents expressed an interest in taking part in the study and consequently were given information sheets and consent forms. Eight of those participants agreed to take part in the actual interviews. However, one interview lasted only ten minutes due to the participant feeling uncomfortable with the interviews being recorded. Due to IPA's reliance on data being recorded and transcribed verbatim it was not possible to take written notes. Therefore, this interview was discarded and deleted. Information from seven participants has therefore

¹ It was hoped that first generation South Asians (non-British born) would be compared with second generation South Asians (British born). However, during the recruitment process it became apparent that both first and second generations demonstrated similar levels of acculturation. With this in mind I decided that the sample would be taken as a whole group and the data analysed as a whole rather than looking for comparisons across the two groups. Efforts were made to try and recruit first generation South Asians demonstrating lower levels of acculturation (such as they did not speak English, less educated, married to a non-British born partner). However, this proved extremely difficult due to their concerns surrounding confidentiality and a reluctance to have the interviews recorded.

been reported in the results section. This is in keeping with the recommended number of participants required for an IPA study which is between 6-8 participants (Reid et al., 2005).

A detailed overview of the participant details can be found in Table 4.1. The participants were aged between 27 to 42 years old. Three were born in England, three in Pakistan and one in India. The parents born in Pakistan and India had been residing in the UK for between 10-20 years. The parents identified themselves as either Muslim or Sikh. All of the parents were bilingual, speaking either English and Punjabi or English and Urdu. In some cases they were trilingual. All participants were married to a partner born in either England, Pakistan or India.

As was self-reported by the parents, five of the children had intellectual disabilities (either moderate or severe) and two had autism (see Table 4.2, for details). These self-reports were based on the information they had received about their child's disability from service providers. All the parents involved in the study were full time caregivers to children with intellectual/developmental disabilities. All the children were born in the UK. Four of the children were girls and three were boys. The age range of the children was between 7 to 14 years old, which ensured homogeneity of the services available to parents and increased the likelihood of them sharing similar experiences in terms of caregiving. The parents described accessing a range of services including children's learning disability teams, occupational therapists and in some cases special schools. In comparison to the parents in Study 1 knowledge and uptake of services appeared to be higher in this sample of parents.

Ethics

Ethical approval for this phase of the study was granted by Coventry Research Ethics Committee, NHS (see Appendix G, page 271). Written consent was obtained from all participants prior to commencing with the interviews. All interview data remained anonymous, using pseudonyms to preserve the participants' identities. After written transcripts were produced all recordings were destroyed.

Interview schedule

The interview schedule (see Appendix M, page 283) was influenced by the literature (see Chapter 1) as well as the findings of Study 1 (Chapter 3). It was carefully considered so as to allow respondents maximum flexibility to develop their own thoughts and descriptions, with minimal input from the researcher. The interview questions explored four main areas:

- 1. Background demographic information* - participants were asked to provide information on their time since immigration, country of birth, languages written and spoken, religious identity, education and employment. These details were obtained for the parent themselves and their partners. These details acted as indicators of the level of acculturation of each participant and ensured a degree of homogeneity within the sample, so as to ensure feasibility of the IPA analysis. Using both demographic details and a qualitative exploration of the impact of culture on caregiving aimed to provide a detailed account of which aspects of acculturation, if any, were most influential in shaping the caregiving experiences of South Asian families.

2. *Recognition of the delays* – participants were asked to talk retrospectively about how they initially identified and recognised their child’s delays. Time lines (see Appendix N, page 284) were created as a frame of reference for identifying crucial stages in the initial recognition and diagnosis of the delays. The timelines provided a shift in focus away from the digital recorder and thus enabled participants to feel more comfortable in sharing their experiences. This worked very well and all participants, despite initial discomfort with the recorder, became more comfortable in sharing their experiences after constructing a time line. This led to the interview process being more naturalistic and thus took the form of a facilitated discussion.
3. *Impact of the disability*- participants were asked about what life was like for them as carers including the motivations, rewards and challenges of caregiving. The impact of the child on the family as a whole unit was also explored.
4. *Belief systems*- participants were asked why they thought their child had developed delays, how their families and friends responded and about their future aspirations for their children.
5. *Service interactions* – The focus groups in Study 1 identified service interactions as an important aspect of their caregiving experiences. Although it was not something the researcher asked about directly it was of significance for all the parents. Therefore, parents in this phase were also asked about the role of services in the diagnosis and treatment of their child’s disabilities.

All interviews were digitally recorded and subsequently transcribed verbatim.

Table 4.1

Participant details

Pseudonym	Age	Relationship to child with I/DD*	No. of children	Country of birth	Time since immigration	Religion	Languages written and spoken	Education	PARTNER DETAILS	
									Country of birth	Languages spoken
Khalida	27	Mother	3	England	n/a	Muslim	English and Urdu	GCSE's	Pakistan	Urdu
Fahmeeda	28	Mother	4	England	n/a	Muslim	English, Urdu and Mirpuri	GCSE's	Pakistan	Urdu and Mirpuri
Nazia	30	Mother	3	Pakistan	10 years	Muslim	English, Urdu and Punjabi	ESOL, UK	England	English and Punjabi
Kulbir	36	Mother	3	India	18 years	Sikh	English and Punjabi	GSCE's UK	England	English and Punjabi
Asim	38	Father	3	Pakistan	15 years	Muslim	English and Urdu	ESOL, UK	Pakistan	Urdu
Sanjit	38	Mother	3	England	n/a	Sikh	English and Punjabi	Pre-vocational course	India	English and Punjabi
Kabir	42	Father	2	Pakistan	20 years	Muslim	English and Urdu	O levels, UK	Pakistan	Urdu

*I/DD Child's intellectual/developmental disabilities, as self-reported by mothers

Table 4.2

Characteristics of the child with intellectual/developmental disabilities

Parent	Gender	Age	I/DD*	Age at which diagnosis given	Additional difficulties
Khalida	M	8	Autism	3 ½	-
Fahmeeda	F	9	Severe ID**	5	Epilepsy
Nazia	M	7	Autism	5 ½	Wears hearing aids
Kulbir	F	14	Moderate ID	6 ½	-
Asim	M	11	Severe ID	5 ½	Asthma and Eczema
Sanjit	F	13	Moderate ID	7	Epilepsy
Kabir	F	8	Severe ID	6	-

*I/DD Child's intellectual/developmental disabilities, as self-reported by mothers

**ID Intellectual disability

Analysis

All transcripts were individually analysed using interpretative phenomenological analysis (IPA) framework (Smith et al., 2009). Please refer to Chapter 2 (Methods) for a detailed description of the process.

Credibility and validity of analysis

It is essential for qualitative analysis to maintain validity and reliability in order to produce good quality results see Chapter 2 (Methods) for a more detailed description of how the

quality of the research was upheld). In order to gain an ‘insider’s view’ from the participants it was essential to develop a good rapport with each participant prior to commencing with the interviews. There was a sense of mutual trust and confidence on both sides, which was initiated by the numerous contacts prior to conducting the interviews. This meant that the interaction although pre-meditated was comfortable and both the participant and researcher felt at ease with the situation. I am also from a South Asian background, which meant that some respondents referred to cultural issues and referred to certain words or phrases in Punjabi or Urdu which they may not have done if it had been a non-Asian researcher.

Credibility of the analysis was upheld through the use of regular supervision and cross checking of the analysis with a secondary researcher with experience of using of IPA. This involved a method of triangulation whereby a number of qualified researchers in IPA verified the findings through repeated and regular checks of both the phenomenological and the interpretative stages of the analysis. Furthermore, all interpretations in the results section have been illustrated with numerous examples from the data and additional quotes can be found in Appendix O (page 285).

Results

Following analysis of the transcripts three master themes emerged and are presented with their sub themes in Table 4.3, below. This table also demonstrates how many participants are represented within each theme.

Table 4.3

Master and sub themes reflecting participants’ experiences of caring for children with intellectual/developmental disabilities and the number of participants who represent each theme

Master theme	Sub theme	Number of participants representing each theme
Living with loss, uncertainty and overwhelming responsibility	<i>An uncertain future</i>	7
	<i>Concurrent losses</i>	6
	<i>Fears about vulnerability of child</i>	5
	<i>Managing multiple responsibilities</i>	7
	<i>Struggling to cope</i>	4
Learning about disability and facing stigma	<i>“Everything was delayed”</i>	6
	<i>Struggling to understand the diagnosis</i>	5
	<i>“They just don’t understand it”</i>	5
	<i>“There’s a stigma attached to things like disability”</i>	6
	<i>“They have their own beliefs”</i>	5
Having to cope	<i>Coming to terms with life as a caregiver</i>	5
	<i>Adapting to a new culture</i>	4

Master theme 1: Living with loss, uncertainty and overwhelming responsibility

This master theme highlights the challenges associated with caring for a child with disabilities which includes the practical hands-on aspects as well as the emotional aspects. It is concerned with how parents' and families' lives are affected by the child's impairments, and how these impairments are accommodated. The five sub themes making up this master are will now be explored.

An uncertain future

When asked about their future aspirations for their children, all the parents talked about uncertainty due to the unpredictable nature of the disabilities. For Khalida, this uncertainty was related to her not being able to predict how her son might turn out in the future and consequently she lived on a “*wait and see*” basis. In an attempt to gain some clarity about what the future may hold, Khalida described doing her own research using internet resources:

Khalida: “It’s so different in every child, I can’t compare it to anyone, so I keep reading to see if I can get some sort of a hint, how it’ll be like as he’s getting older, but because it’s so different in everyone, it’s just like wait and see.”

Stress and anxiety were associated with this uncertainty because the parents did not know what to expect in the future. “*She’s getting bigger and bigger, sometimes I just keep thinking ‘what is going to happen to her?’ I lay awake at night thinking, it’s very difficult.*” (Kabir)

Many parents questioned whether their child would be able to make age-appropriate transitions into adulthood and to take on adult social roles, such as getting a job or getting married. Aspirations for marriage featured in several of the parents' accounts and were seen

as a means of providing security and stability in the future. However marriage prospects were still embedded within uncertainty and were ultimately dependent upon the progress and “change” their children could make as they ascended into adulthood:

Kulbir: “I’m thinking about the future, what she’ll do. I’m worried, she’s nearly fourteen and she can’t work. She doesn’t know anything yet. We can’t even get her married. She will have to stay with me... it depends on how much she changes.”

Some of the parents, when trying to anticipate their children’s future attainments, contemplated the prospect of their own death, which made them question how care would be provided in such a situation. No parents mentioned the use of any types of services when thinking about future care. Instead, two parents (Khalidia and Sanjit) mentioned solutions that depended on siblings providing ongoing support and care to the disabled child once they were adults. However this did not provide relief because both parents worried that the siblings may choose not to take on caregiving responsibilities. For these parents the disabled child’s independence was extremely important in order to ensure their children were not a burden on anyone in the future:

Khalida: “You’re not going to live forever ... I don’t want him to be reliant on anyone...I think it does get to a point where even your own brothers and sisters will not want to do it for you twenty four seven.”

Consequently, for these two mothers career goals and education were important aspirations because they provided a foundation for increasingly independent living: “I’d like her to get a career, that makes her happy, I know she’s not gonna be no brain surgeon [laughs] but I’d like her to do something and achieve some sort of goals for herself.” (Sanjit) Overall, there was also acceptance that their children’s capabilities would be limited.

Concurrent losses

In addition to feelings of uncertainty, the parents also reported grief over losses, both personally, and as a family. They described three main losses which were the loss of an expected child, loss of the parent's own lives and the loss of an ideal family life. Some of the mothers described a family loss associated with the discrepancy between the child they expected and the reality of having a child with disabilities. For example, in the extract below Nazia describes her husband's reaction to finding out the diagnosis of his son's disabilities, which was bound up with grief and disappointment over the loss of the son he had fantasised about:

Nazia: "When he was in hospital he was crying, he does love him, but he's like disappointed about what happened with his little boy."

Some mothers talked about having to make personal sacrifices in order to accommodate their new caregiving duties. For example, in the extract below Sanjit describes having to put her career aspirations on hold in order to meet the needs of her daughter:

Sanjit: "I still wanted to pursue the nursery nursing and I thought 'right college give me a crèche so I'll try that option'...and for the whole time I'd leave her she'd cry. Completely non-stop crying till the minute I got back, I just couldn't even you know start the course, let alone finish it."

Mothers also reported disruption to their work lives, due to the fulltime nature of the caregiving demands. Some of the mothers described the numerous barriers preventing them from getting and keeping a job. Obstacles preventing them from working included a lack of workplace understanding and inflexible working conditions, which made working practically impossible. For example, in the extract below, Kulbir contemplates the impossibility of having a job whilst still maintaining her role as a caregiver:

Kulbir: "How can I work? I can't work! Even if I did start work, they wouldn't give me days off. I couldn't say every week 'I need two days off.'"

Some parents reported a loss of their former lives as a result of the lack of freedom associated with their caregiving roles. Their caregiver responsibilities prevented them from being able to engage in activities that they were able to do in the past: *"I miss going out with my friends, it seems like I used to have a life and now it's like I haven't got a life. It's like I'm constantly at home and nothing else."* (Khalida) This extract highlights how Khalida's caregiving duties have created a discrepancy between her past and current life. It appears that the caregiving role means that for Khalida her life is defined by all the things she is unable to do, things which in her former life defined her sense of self. Those parents who reported experiencing such loss seemed to hold feelings of resentment towards their caregiving roles.

All the parents also described the impact of having a disabled child on the family unit as a whole, which resulted in the loss of a regular family life. For example, parents described negative impacts on their relationships with their other children as a result of having to pay extra attention to the disabled child. Parents also mentioned their other children feeling *"jealous"* and inferior as a result of always coming second to their disabled sibling:

Kabir: "I think he thinks that he is being ignored...because she's disabled we just give her more priority than him and sometimes I think he just gets angry about this. He gets jealous that she gets attention."

Fears about vulnerability of child

All the mothers highlighted concerns about their children's safety and perceived that their children were either a danger to themselves or in danger of being taken advantage of by others:

Khalida: "It seems like he would easily be taken advantage of, he can easily get misled, cos he doesn't understand what's happening around him and anyone could take him anywhere and he'll just go along."

Concerns about safety and vulnerability appeared to be rooted within the unpredictable, dangerous and sometimes socially inappropriate nature of their children's behaviour, both at home and in public, which exposed them to various threats: *"You can't leave him alone for five minutes, he's all over the place, he's just basically dangerous to himself cos he doesn't know exactly what he's doing."* (Nazia)

For two mothers, their children's unpredictable and dangerous behaviours limited opportunities for childcare support from family and friends. For Khalida, her son's dangerous behaviour meant that family and friends were reluctant to offer help with childcare:

Khalida: "I think everyone's too scared to help me out, because with Kabir's behaviour it's dangerous because he'll start hanging out the windows and things like that."

All the mothers associated the root cause of their children's vulnerability with their lack of understanding about safety and risk. Through comparisons to other children of similar age, the mothers pointed out that although their children physically looked their age, their mental ability meant that they were at risk of being taken advantage of and being misunderstood:

“She’s behind, she’s fourteen but she acts like she’s four or five years old. That’s the problem.” (Kulbir) Consequently, caregiving duties were consumed with the constant supervision of their children in order to minimise their exposure to dangerous situations. The constant concerns about their children’s vulnerability were anxiety provoking and meant that the mothers felt that they were unable to leave them unattended at home and unable to trust them to go out by themselves. In some cases, the mothers found themselves in conflict with their children when trying to strike a balance between their child’s desire for independence and their own need for control and protection:

Sanjit: “She wants to go to town with her friends. I can’t think of anything worse. She can’t understand children...I feel bad for her, because I want there to be more, I want her to have normal life...I just couldn’t trust her going to town with her friends, on her own [laughs] it’s too much for her at this point.”

Managing multiple responsibilities

All the parents reported the challenges associated with the non-stop demands of caregiving. For some parents the intense and continuous nature of caregiving was likened to the demands of a “*twenty four hour job*”:

Kulbir: “It’s like a job twenty four hours. I have to go to school, take her to hospital, then I have to go to the centres and then I have to go to other places.”

The mothers also reported having additional responsibilities on top of their caregiving duties. These included meeting family needs such as caring for other children, cleaning, and cooking. Juggling caregiving responsibilities in conjunction with family needs meant that many mothers employed strategies to ensure that they were able to stay on top of things, which

usually involved having to stick to tight schedules and fit things in whilst their children were at school:

Khalida: "While they're at school I've gotta rush and do all the things that I can before they get back. It's like all my shopping and paying my bills and everything. I've just gotta do while I can, so that once they've come home I can just sit at home with them."

The mothers also reported additional pressures to conform to traditional expectations of a wife's role in an Asian family, which included responsibilities to care for extended family members: *"My mother in-law wasn't well, she had a renal transplant and after that she was like on the bed all the time so I had to look after her as well."* (Nazia) and a pressure to attend various social gatherings: *"In Asian families, we have weddings, they just pop up, you have to go to people's houses as well, if there's a funeral you'll be going in and out of people's houses. So it's one of those things that I have to cope around society as well."* (Adeela)

There was evidence of a division of labour within some families with the mothers and fathers dividing caregiving responsibilities amongst themselves. In the extract below, Kabir defines his role as a father being primarily to provide financial support and liaise with services whilst his wife took on more physical aspects of caregiving: *"In the daytime things like feeding, my wife does, and the rest of the things I do myself...schools, education, money and health."* (Kabir) However, the division of labour was not always clear cut and in some cases appeared to be dependent on which parent was able to speak English and therefore liaise with services. For example, the mothers in this study appeared to carry the bulk of the caregiving responsibilities, because they were able to speak English either better than (where partners were immigrants to the UK) or as well as their partners (where partners were British born).

For example, in Adeela's case her husband being born in Pakistan and not being able to speak English meant that the burden of caregiving fell entirely on her whilst her husband provided financial support:

Adeela: "He doesn't do nothing, because he's at work...I think it's the person who's looking after the child all the time, which is mainly the mother...the father is there, but he doesn't understand the child as much as the mother does."

Struggling to cope

Four of the mothers described feeling overwhelmed by the constant demands and endless nature of caregiving, coupled with their additional household responsibilities. For one mother, the realisation that she could be caring for her son on a permanent basis and for the rest of her life made her question whether she was going to be able to cope:

Khalida: "...It is really hard, sometimes I just think 'how am I gonna cope? I can't do this for the rest of my life.'"

For some mothers, the feelings of being overwhelmed appeared to be linked to difficult behaviours of the child. For example, Kulbir describes below that her daughter's non-compliance and her own inability to discipline her put unrealistic demands on her, and made it extremely difficult for her to cope on her own:

Kulbir: "I'm fed-up, I can't keep telling her again and again. Keep saying and keep saying, 'do this, do this', do you know what I mean? I get angry."

This might be linked to a lack of support for the mothers, having to take on the burdens of caregiving alone, as well as other responsibilities (as mentioned in the sub-theme "*managing*

multiple responsibilities”) which meant that they struggled to cope with their multiple caregiving and household duties.

Interestingly, the parents reported positive perceptions of the services their children received. In comparison to parents in Study 1, the parents in the current study did not bring up services until they were asked about them directly. This may be indicative of the fact that they were better engaged and consequently more satisfied with services:

Kabir: “I don’t have any problems, medical wise, doctors, physiotherapists and others like education and school and those people that work with her, are perfect and, always helpful, they know how difficult it is.”

However some parents reported the need for more support from services in terms of managing their multiple responsibilities:

Adeela: “Someone looking from the outside won’t realise I need that help. They think you can cope. But if I turned around and said here I don’t want her, I can’t do nothing, my house is in a tip when they came and my kids weren’t dressed, my kids weren’t washed and bathed, they’d take my kids away and help support them on their own but they wouldn’t support me when I need the support in the house.”

For this parent, services appeared to under-estimate the numerous demands on caregivers, because of their tendency to concentrate on the immediate caregiving demands whilst dismissing any other responsibilities. Despite this, the parents still had very few negative things to say in relation to services and in general appeared satisfied with the level of care their children were receiving.

Summary of master theme 1

This theme described experiences of caregiving which are likely to resonate with those of caregivers in general. It described an overwhelming sense of responsibility and anxiety associated with the caregiving role. This anxiety was related to concerns about their child but also to how the parents manage and cope with the caregiving demands. Interestingly, parents had little to say about the role of services, and the general perception was that they were satisfied with the level of care their children were receiving however there appeared to be little in the form of support for the parents themselves.

Master theme 2: Learning about disability and facing stigma

This theme describes the parents initial recognition of their children's delays and their responses of shock and confusion to the diagnosis. Additionally, the theme highlights the stigmatisation associated with the diagnosis and awareness that their child was not a typical child. A common connection between the sub themes is the role of people in learning about the disability. Additionally, the parents described the distinctive interpretations of disability across British and South Asian cultures and how this bicultural influence impacts their own understandings of the disability.

“Everything was delayed”

The first step in seeking out a diagnosis was the initial recognition that the development of their child was not proceeding as the parents had expected. One mother described it as *“everything developed late”*, indicating delays in reaching normal child development

milestones. Some parents described noticing something was wrong with their child's development during the early months:

Nazia "After two or three months he didn't smile, he was a little bit lazy, he would just sit in my lap and suck his thumb all day long."

The most noted concerns were delays in speech, language and social difficulties. Several of the parents described their children as being very unresponsive. For example, in the extract below Khalida describes that her son was so unresponsive that "nothing bothered him", especially things that would evoke a reaction in a typical child such as a "wet nappy":

Khalida: "At two, he wasn't crawling, no babbling, he wasn't doing nothing, wherever you left him, he'd stay there. He wasn't interacting with anyone, even if he had a wet nappy no crying nothing, nothing bothered him."

For other parents, for whom this was their first child, recognition of the delays proved harder as they lacked experience and knowledge of what was considered to be 'typical' child development and that this lack of knowledge was related to being from an "Asian background". These parents felt that having an older child may have provided a comparison, and earlier validation of their concerns:

Adeela: "When she was younger I couldn't tell because she was my first child, being from an Asian background as well, I didn't understand, I didn't realise it is different from a normal child, to having a child with it."

Parents were the first ones to notice a problem with their child's development. However, some reported that it was other people's recognition and awareness of the delays that made them want to seek out medical help:

Adeela: “My family used to say ‘This girl doesn’t drink, this girl’s not growing, this girl’s not teething, this girl’s not sitting, this girl’s not crawling’ and I used to think ‘what’s it got to do with them? Why are they always saying that for?’ To me it just seemed there’s nothing wrong with my child. But now I’ve come to terms with the fact that there is something wrong.”

Initially, most of the parents perceived other people’s comments about their children’s delays as being critical and negative. This reaction may have been a way for the parents to avoid having to acknowledge and face the delays, in a sense providing a means of coping with their anxieties and fears through denial. However, other people’s recognition of the delays appeared to play a big role in making parents acknowledge the possibility that there was something wrong and turning their private concerns into a reality.

Struggling to understand the diagnosis

All of the parents described feelings of shock when first hearing of their children’s diagnosis. For example, Khalida describes experiencing shock and difficulty when trying to assimilate the diagnosis. For Khalida, not being able to understand the diagnosis and not being given thorough explanations, led to an underestimation of the severity of the disability, as if it were something that would pass overtime. As a means of dealing with the confusion, Khalida described doing her own research and trying to learn about the disability by seeking out information on the internet:

Khalida: “I didn’t know what it was, I was just sitting there thinking ‘I’ve heard of that’ but I didn’t know, I was like ‘ maybe he’s gonna be a bit slower, he’s just gonna have a bit of a learning difficulty and he’ll grow out of them’, they didn’t explain to me what it was.”

For many of the parents, the initial diagnosis was overwhelming, and was felt to be linked to their lack of exposure to disabilities, which felt like uncharted territory:

Kulbir: "It was really hard for me, I hadn't seen anything like this before, it's the first time in my family anyway. My son is fine and we are fine so how did she get this problem? Then the doctor explained he said 'don't worry you are lucky, she's still ok, she could've lost her arm, leg anything could have been damaged, but it affected her brain.'"

Additionally, the diagnosis made parents question the cause of the disability which led to confusion. For example, in the extract above, Kulbir describes trying to find a cause for her son's disability. In her search for an explanation, Kulbir finds relief in her doctor's recommendations to look on the positive side of things, implying that things could have been a lot worse for her son. Other parents also searched for a cause and often offered numerous possibilities, usually due to biological problems during pregnancy.

"They just don't understand it"

As mentioned previously, other people's reactions featured heavily in the parent's narratives about the initial recognition of the delays. However, the parents also described how people from within their communities ("*Asians*") lacked understanding about disabilities and therefore tended to be judgemental in their opinions and reactions. The lack of understanding was related to people's limited exposure to individuals with disabilities: "*...some people haven't got the understanding or they've never seen it so they don't understand it do they?*" (*Adeela*) and to older generations originating from outside of the UK: "*...a lot of them are from Pakistan and it just doesn't sink into them that there can be a disability like that.*" (*Khalida*)

Parents also reported that people born in Pakistan were less exposed to disabilities and therefore held misconceptions about disability. In the extract below, Kabir, a father of Pakistani origin describes how disability is unheard of in Pakistan and how the symptoms are often mistaken for biological infections:

Kabir: "In Pakistan they've never heard of this disability, I don't think these kind of children survive because they think 'because they got chest infection they died.'"

As a result of a lack of prior knowledge about disabilities, some of the parents described older relatives holding unrealistic expectations of their children in terms of their capabilities. For example Sanjit, described her mother in-law's constant focus on her daughter's limitations:

Kulbir: "Grandma was the worst, she was so critical of her saying 'why doesn't she do this?' she was getting annoyed with her all the time and getting angry... she knows there's something wrong but obviously her age and so forth, she was less understanding."

"There's a stigma attached to things like disability"

Associated with the lack of understanding was stigmatisation during social interactions with the public and members of their own communities. For two mothers (Khalida and Kulbir) the stigma was related to their concerns about other people's reactions. This type of stigmatisation was commonly experienced in public settings, where mothers felt that people were associating their children's inappropriate behaviours with bad parenting: For example Kulbir, described other people's reactions to her daughters challenging behaviour at a cinema: *"Everybody starts looking, they don't know, they think that we treat our children like this, badly."* (Kulbir) An additional aspect of the stigmatisation arose due to the fact that the disabilities were not visible to outsiders and consequently inappropriate behaviours were more

likely to be received negatively by the public. For example one parent described “*people don’t understand because he looks normal, doesn’t he?*” Embarrassment was a common manifestation of this type of stigma. As a result many of the parents restricted the number of public outings they had with their children so as to avoid negative reactions:

Khalida: “I tend to do all the stuff while he’s at school now, because it makes it a lot easier, I can’t take him out, he’s really embarrassing, sometimes he does such silly things.”

All the other parents associated their experiences of stigma primarily with the Asian community. For some of the mothers the stigma attached to disabilities came from their in-laws, who identified the mothers as bringing recessive genes into the family:

Kulbir: “They said ‘Oh she’s like this? Oh it’s a shame’ you know what Indians are like. ‘There was nothing like this in our family, what’s happened to her? It’s the first time on our family.’”

Two of the parents talked about the stigma within Asian communities being related to the negative construction of the label disability. For these parents, the word ‘disabled’ held very distinctive meanings for Asian communities. For example, Adeela described her belief that in the Asian community the word is loaded with negative connotations and refers to limited capabilities. For Adeela, the Asian community’s prejudiced views about disability were linked to a lack of understanding and awareness about the term disabled which is in keeping with the previous sub theme “*they don’t understand it*”:

Adeela: “...If an Asian person says ‘disabled’, it offends me, they don’t know what it means they just use it to describe someone who can’t do something, it’s like when they used to use the word handicapped, it’s like a word that this person can’t do nothing, that’s how it comes across to me.”

Additionally, some of the parents found that their bicultural identities made it difficult for them to conceptualise disability in a specific way. For example, in the extract below, Sanjit

described feeling caught between her Indian cultural values and her western values, both of which have conflicting and contradictory interpretations of disability:

Sanjit: "There's a stigma attached to things like disability in our Indian community you know, it's a bad thing. Indians can be very ashamed of it, like responses from family were, 'don't go around telling people that, you have to get her married at some point' that's the reaction I was getting and obviously being born here, you think more like a westerner so it didn't bother me that she had a disability, but the Indian side of me was bothered [laughs]."

Sanjit's Indian cultural background views disability as a taboo subject, resulting in people wanting to keep it hidden. For Sanjit, much of the taboo was based on people's concerns that exposure to the disability would hinder her daughter's marriage prospects in the future. Simultaneously, her exposure to a British way of life stresses the importance of the acceptance and inclusion of disabilities. As a result of these contradictory messages, Sanjit struggled to make sense of and cope with her daughter's disability within two very different cultural contexts.

"They have their own beliefs"

In keeping with the stigmatisation and the lack of understanding that they faced from within their own communities, the parents also reported being pressurised by family members to seek out traditional Indian remedies as a cure:

Kabir: "My sister-in-law's family used to have a son, he couldn't walk. They took him to Pakistan for about six or seven months and he start walking. They give us examples like this and then they say 'oh you maybe should take her then.'"

When asked their thoughts about the use of traditional Indian healing practices all the parents met the idea with initial scepticism. They described how older relatives were likely to

prescribe traditional healing practices and view western medical approaches as inferior. For example, Khalida described her relatives' beliefs in traditional practices as being associated with their negative thoughts about western approaches. When referring to "Asians", parents were talking about older generations who had originated from India or Pakistan:

Khalida: "I really do think white people think so much more positively, whereas Asians do think negatively, a lot of the time they tend to think that their own remedies will work whereas what professionals are saying 'oh that could be wrong.'"

Despite feeling pressurised to seek out traditional treatments, all the parents reported greater compliance with western medical interventions. This decision was attributed to other people's lack of understanding about the disabilities in comparison to medical professionals who were seen as somewhat 'experts'. The conflicting beliefs about best treatment options may be linked to beliefs about the cause of the disability. For example, relatives were described as making recommendations based on supernatural and religious causes (e.g. the evil eye due to jealousy): "Some people say it's jealousy, people are jealous." However, the parents themselves were more likely to locate causation in psychological or medical factors such as stress, trauma and pregnancy issues and therefore may have been more inclined to accept western medical interventions:

Khalida: "I don't see the logic and the point, I don't just get up and do anything anyone tells me, I have to see the logic in what they're saying. I tend to listen to the professionals cos I know that they're the only ones that can help my son. That's who's gonna help me, not people who aren't even qualified, they don't know what they're talking about."

Despite an overall compliance to western interventions, some parents reported the potential benefits of using traditional healing practices however, only as a secondary measure to western medical interventions rather than an outright alternative. Some parents were open to experimenting with the use of traditional therapies providing they were not too intrusive and were unlikely to conflict with western medical treatments: *“I wouldn’t give up the tablets and stop her treatment but doing prayers at a temple you know, if that has a miracle cure [laughs] you know why not?” (Sanjit)*

Summary of master theme 2

This theme described the parent’s initial recognition of their child’s delays and their struggle to understand the diagnosis. A striking feature of this theme were their descriptions of making sense of their children’s delays in relation to, two often conflicting cultural beliefs, thus illuminating how processes such as acculturation can introduce an added complexity to caregiving experiences and decision making processes.

Master theme 3: Having to cope

This theme describes the adjustments the parents made in order to cope with their new caregiving roles.

Coming to terms with life as a caregiver

All the mothers acknowledged that their caregiving responsibilities were something that they had *“no choice”* but to accept. For these mothers, assuming a caregiving role was something that they expected of themselves as mothers and was tied up with the fact that if they didn’t

provide for their children's needs, they would be left unmet. Having no alternative options or supports available to them meant that they had resigned to and accepted their roles as caregivers:

Khalida: "I'm just gonna get on with it cos, I know there's nothing else that can be done, it's like I've got no choice, I have to do it and nobody else is gonna come and do it for me."

As a means of coping some of the mothers appeared to have settled for their new lives as caregivers. In the extract below Khalida describes: *"this is my life now, I have to do it"*, which reflects that she seems to have settled for, as opposed to accepted, her caregiving responsibilities. Associated with this settling into a new life was the need to make personal sacrifices in order to meet the continuous demands of caregiving. For Khalida caregiving left her feeling trapped and overwhelmed by a responsibility to perform, regardless of her own needs. For example, she described feeling engulfed with her caregiving and household responsibilities, which was made harder because of her having to manage alone with no help:

Khalida: "This is my life now, this is what I have to do even if I'm down I've gotta get up and feed em and change em and do everything that I would do on a normal day although I'm not up to it and on days like that you do realise how hard it is and that you've still gotta do it all alone."

Other mothers adopted alternative methods of adjustment to their new lives as caregivers by using *"get on with it"* attitudes. For Adeela this involved normalising her caregiving duties by incorporating them into her daily customs, in way a trying to limit the disruption it caused to her life, by *"letting the day go by"*:

Adeela: "You get used to it and you think this is a routine and you just get on with it, just let the day go by, it becomes one of those things."

Sanjit also implemented a similar attitude to dealing with the caregiving duties, by “*getting on with it*”. However, for Sanjit this attitude was something she had adopted from her mother and therefore she described her resilience as being part of her inherent “*Indian mentality*”:
“You know like the Indian mentality...my mum was a trooper, she had problems but nobody knew about them, she just carried on you know, take a painkiller and just carry on...that’s my mentality, it’s something you do that’s how we’ve been brought up and that’s how we think.
(Sanjit) This “*Indian mentality*” meant that she had always accepted her role as a caregiver, and the resilient nature of her mother provided her with a source of strength to take on the caregiving responsibilities.

Adapting to a new culture

Non-British born parents described a two-fold struggle, firstly in adapting to their children’s disability and secondly, in adapting to a new culture. For example in the extract below, Kulbir describes her struggle in trying to understand her daughter’s delays whilst at the same time trying to adjust to a new lifestyle:

Kulbir: “I was from India so I didn’t know what happened, I didn’t know myself, I was young, when I came here I didn’t know what the lifestyle is like here.”

Non-British born parents acknowledged that not being able to communicate in English was the biggest barrier to adapting to life in the UK. Having to access services and liaise with English speaking health professionals was a great motivator for the parents in English language acquisition. For example, they reported using practice strategies, which involved utilising opportunities to speak English in real life situations, usually during interactions with

various service providers: The parents described their sense of hesitancy when first accessing services and interacting in the English language and their concerns about the accuracy of their pronunciation and being judged by people:

Nazia: "When we had lots of visitors (health professionals), it helped me quite a lot, to speak with them, I had to speak, otherwise there was nobody there to translate for me ...Two or three years I was very shy, it was just hesitation, I felt stuck and felt like my pronunciation was not good... when it's not your first language it's always different and it is very difficult."

Many of the parents felt they had no other option other than to learn to speak English themselves. For example, Nazia in the extract above described having nobody to translate on her behalf which meant that she had to become self-reliant. Additionally, some parents who did have access to translating services talked about the difficulties in terms of long waiting lists and associated feelings of guilt for taking up the translator's time:

Asim: "Earlier, for filling in disability forms for my child, I had to request different people and due to this claiming benefits became difficult... they gave appointments after 2-3 weeks. For the last 3-4 years I have been facing many difficulties, requesting help time and time again for filling in the forms and sometimes I feel guilty for giving troubles to others."

In addition to this, having little or no support networks (family/ friends) meant that the parents had to become self-reliant and proactive in getting help for themselves. For example, Kabir described that having none of his family in the UK was beneficial as it made him more independent and willing to try and learn how to cope on his own:

Kabir: "If you've got a family here you always keep getting help. At one stage I was on my own, I didn't have any help and then I thought 'I can't depend on other people, I have to live my own life'...I went to the social security office and decided whatever I can do myself I'll do it."

As a result many of the parents reported having to build up their confidence through their experiences of interacting with health professionals. One parent talked in detail about having to use a ‘trial and error’ method in order to navigate his way through the complex British service pathways: *“I fill out forms myself, sometimes they come back, but that helps in the future because I know what to do, I understand what mistakes I make and I don’t make it next time.”* (Kabir) For Kabir, making mistakes played a crucial role in improving his confidence.

Summary of master theme 3

There were two distinctive features of master theme 3. Firstly, the mothers described their personal journey in accepting and adjusting to their new roles as full time carers and having to give up important aspects of their former lives, as described in the sub-theme *“coming to terms with life as a caregiver”*. Secondly, for the non-British-born parents, their children’s disabilities heightened their need to adjust and adapt to a new way of life in the UK as outlined in the sub-theme *“adapting to a new culture”*. Overall this theme emphasises the massive adjustments made by parents in order to cope with the numerous caregiving demands.

Discussion

This study aimed to provide a detailed account of the experiences of South Asian parents caring for children with intellectual/developmental disabilities in the UK. In addition it aimed to explore the impact of acculturation, prompted by the work of Berry (1997) on caregiving experiences. Interpretative phenomenological analysis was employed to gather three clusters of master themes: Living with loss, uncertainty and overwhelming responsibility; learning about the disability; facing stigma and choosing to cope. The following discussion explores the three master themes in relation to existing literature and in terms of their implications for service delivery.

Master theme 1: Living with loss, uncertainty and overwhelming responsibility

The present findings support and extend those of previous authors in a number of ways. As expected the experiences described by parents in this study are very similar to those captured by other qualitative studies examining the caregiving experiences of families caring for individuals with disabilities and were not specific to South Asian groups. Although caregiving is considered to be a normal part of being a parent, caregiving to a child with functional and cognitive impairments introduces new challenges often associated with a greater dependency. For example, the first master theme described the psychological consequences of caregiving including anxiety about the future and vulnerability of the child, dealing with losses and struggling to cope with numerous challenges. Families with children with developmental disabilities have been shown to experience more long term and persistent stress and adverse mental health than those without a child with developmental disabilities (Baker et al., 2003; Hauser-Cram et al., 2001; Dumas et al., 1991; Emerson, 2003).

The findings of this master theme support existing research which shows that families caring for a child with intellectual/developmental disabilities are likely to experience a number of stressors throughout the child's lifespan. These include the acceptance of a diagnosis of disability, the loss associated with parental aspirations for their child, the loss for the disabled person achieving developmental milestones and comparison to non disabled people (Hastings & Beck, 2004). Additionally, families may experience stress related to the perceived or actual vulnerability of the person with disability, concerns about the future and transitions from childhood into adulthood (Hastings, 2003; Jenkins, Rose, & Lovell, 1997). The results also demonstrated that some challenges were unique to the mothers in this study. For example, the mothers, not the fathers reported, experiencing a loss in their own lives. This may be because the fathers in this study shared their caregiving responsibilities with their wives, whereas the mothers tended to carry the bulk of the caregiving on their own. As well as the stress associated with caregiving the mothers in the current study also highlighted their struggle to manage their "*multiple roles*" including being a caregiver to the child with intellectual/developmental disabilities, being a mother to other children, a wife and a daughter-in law. Research suggests that family caregivers, in particular mothers, often take on multifaceted responsibilities of long-term disability management (Eisenhower & Blacher, 2006; Tehee, Honan, & Hevey, 2009).

Interestingly, parents in this study had little to say about their interactions with services, unlike those in Study1 who demonstrated much dissatisfaction. The little they did say in relation to services was positive and highlighted the fact that they were happy with the care child was receiving. However, it is clear from the narratives that these parents struggled to cope with the overwhelming demands of caregiving, which appeared to be associated with the

lack of support available to them. According to Lazarus & Folkman (1984) promoting positive over negative emotions during stressful events can reduce adverse psychological consequences and support continued coping by replenishing resources that may have been depleted by stress. Lazarus et al. suggest that strategies such as gathering information and resources to help deal with problems, decision making and conflict resolution can help individuals deal with stressful situations in a more positive way. Thus suggesting that more support in this form may have been helpful for these parents.

Master theme 2: Learning about disability and facing stigma

Parents often seek interpretations of disability in relation to their own lives, which tend to be shaped by cultural resources (family and friends) of normative child development (Skinner & Weisner, 2007) as was described in the sub theme “*everything was delayed*”. In the present study, this allowed parents to become aware of the expectations of normative child development, thus enabling them to evaluate their own child’s progress and recognise the delays. Interestingly, the parents described getting a diagnosis and seeking medical help early on. This emphasis on early intervention and diagnosis is very distinct from those parents in Study 1 of the research (Chapter 3) who described that they were still “*struggling to get a diagnosis*” and other research which suggests that South Asian parents often have low service uptake and receive later diagnoses of disabilities (Bywaters et al., 2003; O’Hara, 2003; Hatton et al., 2010). This may be influenced by the fact that the parents in the current study demonstrated higher levels of integration with British culture. Although there is no research exploring the effects of acculturation on service usage in British South Asian communities, research in the United States has demonstrated that acculturation in ethnic minority groups (mostly Latino groups) is linked to increased service uptake, especially in individuals who are

able to speak English (Fassaert et al., 2009). Studies in the UK have also demonstrated that the ability to speak English is associated with better understanding and usage of services (Bywaters et al., 2003; Raghavan & Small, 2004; Hatton et al., 2003; Hatton et al., 2010). However, results from the current study indicate that despite being able to speak English, participants in this study still highlighted their struggle to understand and make sense of the diagnosis of disability, as was described in the sub-theme “*struggling to understand the diagnosis*”.

Being exposed to two different cultures meant that the parents in the current study had to make sense of their child’s disability in relation to two cultures as highlighted in the sub themes “*there’s a stigma attached to things like disability*” and “*they have their own beliefs*”. This involved constructing and negotiating their understandings of disability in relation to medical approaches (western views of disability) and a ‘traditional’ approach influenced by their Indian/Pakistani heritage. The values of Asian cultures are different with far greater emphasis on collective needs, interdependency and conformity as opposed to western values which promote individuality (Suzuki, Ponterotto, & Meller, 2001). According to Berry (2005), this can lead to acculturative stress, when individuals face problems as a result of intercultural contact. Research exploring acculturation in younger British South Asians demonstrates that disparities between traditional and modern attitudes in an individual as well as social role expectations from family and friends can lead to cultural conflicts (Berry, 2005; Bhugra, 2001; Gupta, Johnstone, & Gleeson, 2007). This imbalance can lead to additional stress for the younger generations who are more integrated because they have to deal with ethnocentric attitudes from within their minority communities, which are often in opposition to the host country’s attitudes. In the current study, five participants, including two who were

born outside of the UK, talked about older or first generation South Asian's in a way that assumed a distance between their cultural understandings of disability. The participants' constant reference to "*they*" when talking about these older generations suggests that they held views about disability which were very distinct from those of older South Asians. These findings suggest that younger South Asian generation caregivers are likely to be exposed to a different set of pressures which are culturally unique to them and, is likely to be a reflection of the different rates of acculturation between older and younger generations (Berry, 2005).

This master theme provides an interesting insight into the concept of culture. It demonstrates that culture is more than just a set of beliefs and behaviours that are simply passed down from generation to generation. Instead, it views culture as being more fluid and open to change.

The study highlights the importance of acknowledging the diversity of South Asian and other ethnic minority groups and the need to explore cultural and religious beliefs, age, time in country and languages spoken, in order to avoid providing care based on stereotypes.

Therefore services need to develop an understanding of each family's caregiving experiences possibly by having an open dialogue between carers and service providers. This would allow carers and service providers to collaboratively explore ways of identifying and accommodating families' specific needs and develop a better understanding of their contexts.

Master theme 3: Choosing to cope

Literature surrounding caregiver experiences has commonly demonstrated the sacrifices individuals have to make in order to take on their caregiving duties (Eisenhower & Blacher, 2006; Tehee, et al., 2009) which has been reinforced by the current study in the sub theme

“coming to terms with life as a caregiver”. The mothers in this study reported feeling like they had to give up on their own personal goals as well as feeling like they had *“no choice”* but to take on the caregiving responsibilities. This personal sacrifice highlights the enormity and relentless nature of the caregiving tasks. For many of these mothers there was a sense of having to cope rather than wanting to cope. Caregivers often placed low priority on their own health relative to that of their children with disabilities and their families. The provision of such care can prove detrimental to both the physical health and the psychological well-being of parents as mentioned earlier.

Parents born outside of the UK talked about coping both in relation to their caregiving roles but also in adapting to a new culture in the sub-theme *“adapting to a new culture”*.

Navigating complex NHS service systems is a difficult task, made harder for immigrants who often have to deal with issues surrounding residential status, eligibility to NHS treatments and language barriers (Sue & Sue, 1999). The parents described having to quickly adjust to a British lifestyle and emphasised the importance of learning to speak English using a trial and error method which involved regularly liaising with services and thereby learning through lived experience. This sub-theme provided a unique insight into the adaptation of immigrant parents and suggests that they employed an acculturation strategy of ‘integration’ (Berry, 1997). It also highlights the importance of language in accessing services as has been demonstrated by other research (Bywaters et al., 2003; Raghavan & Small, 2004; Hatton et al., 2003; Hatton et al., 2010).

Reflections

Reflecting on my personal positions on disability, I realised that the narratives of parents in the current study were more in keeping with my own understandings and beliefs about disability. They also made me reflect on the challenges of being a second generation South Asian in terms of trying to negotiate between two very distinct cultures.

It appears that this is one of the first studies in the area of caregiving amongst South Asians to explore the influence of acculturation. The study provides a snapshot of the possible impact acculturation can have on the caregiving experiences of South Asian families caring for children with developmental disabilities in the UK. A striking feature of the narratives is the resonance they have with the issues that carers in general face. For example, the current study has identified that the parents' narratives are embedded with their descriptions of experiencing multiple stressors much of which are directly related to the demands of caregiving. This is in comparison to parents in Study 1 for whom the main stressors were associated with dissatisfaction with services. This may be indicative of the impact of acculturation, in the sense that parents in the current study did not identify dissatisfaction and in fact were better engaged with services which could be linked to their higher levels of integration with British culture.

Additionally, parents in Study 1 showed a greater reliance on religion as a way of making sense of their child's disabilities. This may have provided them with more resilience and enabled them to cope with the caregiving demands which would explain the absence of descriptions of caregiving demands from the narratives. In comparison, narratives in the current study focused heavily on caregiving demands which may be a result of their emphasis

on medical ways of making sense of their child's delays and their self-reliant coping methods which focused on "getting on with it". These resources may have offered less positive interpretations and less successful coping.

At this point of the research I became interested in exploring these ambiguities in more detail. In the following study (Chapter 5) I decided to adopt a cross-cultural stance to exploring the experiences of parents caring for a child with intellectual/developmental disabilities in India. I anticipated that this would provide an opportunity to explore how South Asian culture, studied in its natural context, impacts on caregiving experiences. In doing so, it would remove the inter-cultural aspect that has been studied so far and provide a unique look at South Asian values, beliefs and behaviours.

Initially, it was anticipated that the next phase of the study would involve a more detailed ethnographic exploration of caregiving experiences using observations and photo elicitation interviews. However given the challenges faced with recruitment of participants in the current study and previous study it was decided that such a research design was out of scope. Given unlimited resources and finances it may have been possible to conduct such a design.

CHAPTER 5

Study 3 – The experiences of parents caring for a child with intellectual/developmental disabilities in India: A cross cultural perspective

Introduction

The experiences of South Asian families caring for a child with intellectual/developmental disabilities in the United Kingdom (UK) can be very distinct from those of white families and is usually associated with differing worldviews. Different cultures and societies generate their own worldviews based on shared sets of assumptions and beliefs about particular issues. Such resources enable people to make sense of and interpret their experiences. Included in one's worldview are values, beliefs, and attitudes which organise and shape perceptions, expectations, and behaviours. Cultural heritage, as reflected in values, beliefs, language, and individual identity is also part of these views (Skinner & Weisner, 2007). Culture can have a significant impact on the way in which South Asian families experience and perceive disability. For example, it can influence the way in which disability is labelled, understood and experienced within a family, which in return can influence service uptake, diagnosis and interventions accessed (Skinner & Weisner, 2007). For South Asians living in the UK, bicultural influence adds an additional complexity to these understandings and experiences. For example, the previous studies (1 and 2) suggest that processes such as acculturation can result in differences in understanding and experiences as a result of exposure to, two interacting cultures. So far the research has focused on parents of South Asian heritage situated within a UK context, which has revealed ambiguities and a diversity of perspectives and experiences of caregiving.

The current study aimed to adopt a cross-cultural perspective to explore caregiving amongst parents caring for a child with intellectual/developmental disabilities in India. In doing so, it aimed to provide a unique look at how South Asian values, beliefs and behaviours shape

experiences of caregiving. India was chosen as an appropriate context to explore these beliefs as Indians are the largest 'Asian' ethnic group in the UK, making up 2% of the total population (Census 2001, Office of National Statistics). Additionally, India has one of the more progressive disability frameworks in the developing world which tends to adopt western philosophies and principles (e.g. parent participation and advocacy) which to some degree mirrors the type of service delivery in the UK therefore making it easier to apply the findings to British South Asian communities. The following section provides a brief overview of the context of intellectual/developmental disabilities in India before laying out the aims of the study.

Intellectual/developmental disabilities: An Indian context

Intellectual disability affects approximately 2.3% of children and adolescents between 0 and 16 years of age in India (Srinath et al., 2005). However, data surrounding the incidence and prevalence of disabilities in India remains unclear and inaccurate. Epidemiology studies are challenged by difficulties with identification and assessment and therefore many individuals remain undiagnosed meaning that any statistics are likely to be an underrepresentation.

Health beliefs in India tend to be holistic incorporating physical, psychological, social and supernatural factors (Dalal, 2000). Often families hold multiple beliefs about disability based on medical and socio-cultural models of causation and treatment (Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010; Joel et al., 2003; Saravanan, 2004). This can include religious and theological beliefs about causation (e.g. beliefs in karma, sin, punishment, black magic, evil

spirits) as well as biological explanations (e.g. disease degeneration). As a result people are likely to seek treatment from a range of sources.

Responses toward disabilities in India are also influenced by cultural factors such as collectivist values in which the family is considered to be the most important social unit (Triandis, 2001). Often such family units consist of extended family members (e.g. grandparents, uncles and aunts) and operate on a hierarchical basis (e.g. the older members having greater authority and respect). Within this structure obligations and family interests greatly outweigh personal and individual interests and therefore there is a greater focus on interdependence (Stone, 2005). This cohesive family unit often provides security and care to disabled individuals throughout their lifespan. As a result families tend to play a central role in the care of disabled children and the decision making process of treatment seeking (Stone, 2005).

Indian society has been shown to hold negative attitudes towards disabled individuals often related to cultural and religious beliefs that the disability is caused by sins committed by parents (Grimaji, Zaman, Wijetunga, & Pejarasangharn, 2001). Individuals with disabilities and their families in India are likely to face multiple stigmas related to poverty, caste and disability (Chatterjee & Sheoran, 2007). Social stigma in particular often renders individuals with disabilities and their families the most excluded groups in India (The World Bank Report India, 2007). As a result families are often isolated, rejected and managing caregiving without any formal or informal support (Chatterjee & Sheoran, 2007). These negative attitudes towards people with disabilities are likely to be compounded by problems of poverty, social inequalities, illiteracy and a paucity of training facilities and resources. For example, almost

42% of India's population are living below the poverty line, meaning that many families have to prioritise making ends meet above their disabled child's needs (UNICEF India Statistics 2006-2009). For Indian families, uptake of already limited services is often dependent on geographical location and finances, with most services located in urban areas and being expensive. This often leaves many people with disabilities, especially those situated in rural areas, without access to services (Singhi, Goyal, Pershad, Singhi, & Walia, 1990).

Despite these challenges, India has one of the more progressive disability frameworks in the developing world, which has been influenced by the introduction of initiatives such as The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act (1995) and the National Policy for Persons with Disabilities (2005). These pieces of legislation are aimed at children with disabilities and mandate that all children with special needs under the age of eighteen receive free education. Much of this special education is provided in segregated settings, however an increasing amount of children, in particular those with physical disabilities are being integrated into mainstream schools (Vakil, Welton, & Khanna, 2002; Byrd, 2010). More recently sector specific policies are emerging such as the National Action Plan for Inclusive Education of Children and Youth with Disabilities (2005). This has led to the creation of more special schools and specialist services for individuals with disabilities. These recent efforts to promote and raise awareness of disabilities suggest that India is progressing in terms of its inclusion of people with disabilities.

A specialist service for children with intellectual/developmental disabilities (India, Delhi)

The current study was conducted within the context of a specialist intellectual/developmental disability service in Delhi, India. The service is a national non-profit organisation, founded in 1991 that is regarded as pioneering the autism and disability movement in India. The service is located on a 1400 square metre plot within the Jasola district of South Delhi. Jasola is an urbanised district of Delhi, within close proximity to commercial hubs. The service has good transport links (including the metro), residential areas, schools and hospitals. It has a focus on providing rehabilitation, research and training to families and professionals caring for children with intellectual/developmental disabilities in India. The team consists of management, administrative staff, educational staff, research assistants, occupational therapists, psychologists, special educators and volunteers.

Due to the shortage of such specialist services, families from all over India travel and often relocate to Delhi in order to access the resource. Families are required to pay a fee for using the service. However, this payment is often based on the parent's income and is changed in accordance with a family's financial situation. The service offers an eclectic mix of clinical and behavioural interventions which are based on western models and assessments including:

Assessments:

- *Diagnostic assessments:* Completed using diagnostic observations, interactions with the child and interviews with family members. The service uses a number of diagnostic tools including the Diagnostic and Statistical Manual of Mental Disorders (DSM 4 TR) (American Psychiatric Association, 2000), the Autism

Diagnostic Instrument (ADOS) (Lord et al., 1989) and the Autism Diagnostic Interview (ADI-R) (Lord, Rutter, & Le Couteur, 1994).

- *Functional assessments:* Using observations of the child and discussions with families in order to develop Individualised Education Plans (IEP).
- *Occupational and sensory assessments:* Assessments based on a sensory profile questionnaire, observations and feedback from parents.

Intervention programmes:

The service also offers an eclectic mix of behaviour-based interventions and structured teaching. Elements of TEACCH (Schopler, Mesibov, & Hearsey, 1995), Applied Behaviour Analysis (Cooper, Heron, & Heward, 1987; Maurice, Green, & Luce, 1996), Verbal Behaviour Analysis (Lovaas, 1977; Taylor & McDonough, 1996) and various forms of Assisted and Augmentative Communication (Reichle, York, & Sigafoos, 1991) including Picture Exchange Communication Systems (Bondy & Frost, 1994) are a part of the methods used. Two of the main interventions include:

- *Mother-child parenting programme (MCP):* A twelve week programme, teaching a group of fifteen parents to train together along with their children under the guided experience of a therapist using the behavioural methods mentioned above. This programme helps parents to understand their child and their child's disabilities. Children from 18 months onwards, who are suspected or diagnosed as having intellectual/developmental disabilities are involved in this group.
- *The open door day school:* The school tests, modifies and adapts training techniques from across the world before implementing them and rolling them out

to other special schools across India. At the time the study was conducted, the day school had enrolled approximately 60 children aged between 3-18 years old.

Additionally, the service also has specialist programmes and workshops for children with autism including job training for young adults; social skills training; handwriting classes and hobby classes. Specifically for parents, there is a parents' support group, home management programme, family counselling, as well as afternoon and weekend respite. The service also holds regular training for parents and professionals including a Diploma in Special Education (DSE). It encourages its parents to become involved in training opportunities so that they go on to teach as special educators and facilitate as volunteers.

Aims of current study

Using a combination of qualitative inquiry and a cross cultural perspective the current study aimed to explore the experiences of caregiving to a child with intellectual/developmental disabilities amongst parents at a specialist service in Delhi, India. The study aimed to provide a cross-cultural focus to provide insight into the origins and preferred understandings of British South Asian parents living in the UK. I felt this would bring to light how South Asian cultural values and beliefs are maintained, coexist or are transformed with exposure to British culture.

The study also aimed to gain first-hand experience of successful service delivery with an overall aim of identifying potential considerations when developing culturally appropriate services for South Asian communities in the UK.

Using focus groups would enable me to explore social processes and the questions of “how” and “why” in more detail and in doing so shed light on the ambiguities identified in the experiences of parents from Studies 1 and 2. I choose focus groups as they would provide an informal environment which would encourage parents to discuss their experiences, beliefs, values and social meanings attached to caregiving within groups of peers. Qualitative techniques allow researchers to develop a contextual understanding of cultural values and relationships and enable participants the flexibility to discuss a wide range of topics which can help facilitate new information. This was thought to be particularly useful in the current study, as I had little prior knowledge of the Indian context and was unsure about what to expect. Therefore, the freedom of qualitative discussions allowed me to explore things in an open non-biased way.

Using qualitative focus groups I aimed to:

- 1) Explore the experiences of Indian families caring for children with intellectual/developmental disabilities in India (within the context of a specialist service), in order to provide more insight into the context of British South Asian parents cultural beliefs and responses to disability.
- 2) As a secondary aim, I also aimed to explore how a service which is based on western principles is received by Indian families who are likely to be influenced by traditional cultural and religious understandings of disability.

Method

Participants

Participants were recruited from a specialist service for children with intellectual/developmental disabilities in Delhi, India. The mothers were aged between 33-44 years old, described themselves as Hindus, spoke two or three languages including English and were educated to at least degree level. All the mothers self-reported that their children had been diagnosed as having autism. Their children were aged between 6-17 years old.

The mothers also worked within the specialist service as either special educators or volunteers. Five of the mothers interviewed had studied a Diploma in Special Education (DSE) run by the service, which trains individuals (including parents) to qualify as special educators in special schools. The aim of this course is to prepare the trainee teacher to screen, assess, educate and teach children with autism in individual or group settings. The course uses psychological principles to develop, implement and evaluate educational programmes for people with autistic spectrum disorder (ASD). The course itself is a full time one year diploma, which consists of 8 hours of working, five days a week. The remaining five mothers were volunteers at the service. They worked primarily in classroom settings, providing support to the special educators. Additional responsibilities included facilitating the mother-child parenting programme (MCP), observing assessments and diagnostic sessions, as well as providing administrative support. In total three separate focus groups were conducted involving ten participants². Participant details can be found in Table 5.1.

² Prior to conducting the research it was anticipated that the views of these participants would be biased by their experiences at the service and ultimately would not be indicative of views held by other parents from the general population of India. Therefore, it was hoped that I would be able to locate other organisations or charities in more remote parts of India, with fewer resources to give an alternative view. However, this proved extremely difficult because issues similar to those described in Study 2 with regards to participants' concerns about being recorded were presented and complicated by language barriers. An additional constraint was the limited availability of learning disability services without whom it was almost impossible to identify children with disabilities and their families.

Ethics

A research proposal outlining the full nature of the study was submitted to the services Institutional Review Board for ethical review. Following this review ethical approval was granted to conduct the study.

Procedure

A Universitas 21 Scholarship, provided by the University of Birmingham, worth £1500 was obtained in order to expand the research to provide a cross cultural perspective on how disabilities are perceived and experienced in India.

Initially I attended a group meeting in order to provide staff, volunteers and parents with details of the study, which included a verbal explanation as well information sheets (see Appendix P, page 292) and consent forms (see Appendix Q, page 294). I then attended a second meeting a few days later to find out which individuals were interested in taking part in the study. Each participant was asked for a time that was convenient for them and using this information, participants were separated into three groups. Overall, the focus group discussions lasted between forty five minutes to an hour.

All focus groups were conducted in English, as all the participants were fluent in English. Focus groups were recorded using a digital recorder and transcribed verbatim. On some occasions the participants spoke words or certain phrases in Hindi. In such circumstances these sections of the recordings were translated by another researcher who is also able to speak Hindi.

Interview schedule

Initially, all participants were asked to complete a background questionnaire providing basic demographic information (e.g. age, gender), acculturation details (e.g. education, employment, languages spoken) and details about the disabled child (e.g. age, gender, diagnosis). Three semi structured focus groups were conducted. These begun by eliciting some general information about the current involvement of the parents at the service following which they were invited to talk as widely as possible about their experiences, feelings, attitudes and beliefs about caregiving both pre and post joining the service. An interview schedule was used to loosely structure the discussions (see Appendix R, page 295). The interview schedule was constructed and based on the questions asked in Studies 1 and 2 of research project.

Analysis

Transcripts from all three focus groups were analysed using interpretative phenomenological analysis (IPA). As the data consisted of group discussions, a protocol for applying IPA analysis to group data was used as a template (Palmer et al., 2010). Please refer to Chapter 2 (methods) for a more detailed overview of this process.

Credibility checking

Credibility of the analysis was upheld through the use of regular supervision and cross checking of the analysis with a secondary researcher with knowledge of IPA. This involved a method of triangulation whereby a number of qualified researchers with experience of using IPA verified the findings through repeated and regular checks of both the phenomenological

and the interpretative stages of the analysis. Please refer to Chapter 2 (methods) for a more detailed overview of how the quality of the analysis was upheld. All interpretations in the results section have been illustrated with numerous examples from the data and additional quotes can be found in Appendix S (page 296).

Table 5.1

Participant details

Pseudonym	Age (yrs)	Education	Employment	Religion	Languages Spoken and Written	Time at service	Details of child		
							Age	I/DD ³	Gender
Bhuvi	36	BSc	Volunteer	Hindu	English, Hindi, Punjabi	1 ½ yrs	6	Autism	M
Deepa	37	BSc	Volunteer	Hindu	Hindi, English	6 mths	10	Autism	M
Krishna	39	BSc; MSc	Volunteer	Hindu	English, Hindi, Gujarati	5 yrs	12	Autism	M
Sandya	40	BSc	Volunteer	Hindu	Hindi, English, Nepali	6 mths	12	Autism	M
Aanchal	44	BSc	Volunteer	Hindu	English, Hindi, Tamil	2 yrs	12	Autism	F
Smitha	33	BEng, DSE (ASD)	Special Educator	Hindu	Hindi, English, Punjabi	5 yrs	13	Autism	F
Jaya	34	Bed, MSc, DSE (ASD)	Special Educator	Hindu	Hindi, English	3 yrs	8	Autism	M
Geeta	36	MBA, DSE (ASD) ⁴	Special Educator	Hindu	Hindi, English	2 ½ yrs	11	Autism	M
Lekha	38	BSc, DSE (ASD)	Special Educator	Hindu	English, Hindi, Bengali	2 ½ yrs	17	Autism	M
Pooja	39	BA, DSE (ASD)	Special Educator	Hindu	Hindi, English	9 yrs	13	Autism	M

³ I/DD Child's intellectual/developmental disabilities, as self reported by mothers

⁴DSE (ASD) Diploma in Special Education (Autistic Spectrum Disorder)

Results

Following analysis of the transcripts two master themes emerged and are presented with their sub-themes in Table 5.2 below. This table also demonstrates how many participants and groups are represented within each theme.

Table 5.2

The master themes and sub themes which emerged from the analysis and there representation amongst participants and within groups

<i>Master theme</i>	<i>Sub theme</i>	<i>Representation of each sub-theme</i>	
		<i>Number of participants</i>	<i>Number of groups</i>
Making a decision to get help	<i>Struggling to make sense of the differences</i>	8	3
	<i>Making a commitment to get help</i>	5	3
Seeing disabilities from a new perspective	<i>Accepting the child and the disability</i>	6	3
	<i>Regaining control as a parent</i>	4	2
	<i>Seeing a change</i>	6	3
	<i>Being a part of something</i>	6	2
	<i>“It's a completely different world outside”</i>	6	3

Master theme 1: Making a decision to get help

This theme describes the mothers initial recognition of their children’s delays and the difficult process of deciding what to do next. Consultations with extended family members who

offered more traditional interpretations of disability featured heavily in the accounts of the mothers across these two sub-themes.

Struggling to make sense of the differences

This sub-theme describes how the mothers came to recognise their children's difficulties and the resultant struggle in trying to make sense of these difficulties prior to receiving a diagnosis or accessing support services. One mother (Geeta) described how the initial recognition of the delays resulted from her realisation that her child was behaving "differently". Viewing her child as "different from us" allowed this mother to identify her child's behaviour as deviating from the social expectations and norms of behaviour:

Geeta: "For me when my child was one year old I knew something was different. He is different from us. And I was thinking 'why is he acting like this?' I could not understand and everyone said that he will speak, his speech is delayed, but I was thinking 'no it's not only speech delay it's something different.'"

This initial recognition was very distressing and led to considerable confusion and despair due to her inability to understand why her child behaved in that way. Not being able to understand was described as the most difficult aspect during pre-diagnosis by several mothers. This is highlighted in the extract above where Geeta remembers questioning herself about her child's delays in order to try and make sense of them. For this mother, other people's assumptions and reassurances about the problem being delayed speech further added to the confusion, as these beliefs conflicted with the mother's personal beliefs that the difficulties extended beyond delayed speech.

Prior to accessing the specialist service in Delhi, the majority of the mothers reported living within extended families, consisting of their in-laws within single households. As a result, the role of extended family members in the initial recognition and interpretations of the delays featured heavily in the mothers' accounts, as demonstrated in the extract below:

Lekha: "Everybody wants to give a diagnosis, they come up with a different diagnosis like 'there's nothing wrong, it's only a speech thing or something, go and show it to this person.'"

Jaya: "And let's not forget the temples and the babas⁵ and homeopathy, alternative therapies, 'go to this baba, or go to this temple and he'll be fine.'"

In particular it was apparent that the mothers themselves were more likely to seek out western bio-medical explanations of their children's disabilities, in comparison to the more relaxed parenting styles of the older generations who viewed the disability as a temporary speech delay requiring traditional Indian remedies such as prayers and homeopathy, as evident in the group discussion above.

Making a commitment to get help

For many of the mothers deciding to get help from the specialist service in Delhi, meant having to make an often life changing commitment to put the needs of their child above everything else. As a result, many of the mothers consulted a variety of specialists and travelled long distances in the hope of getting appropriate help and support for their child:

⁵ Baba's – When asked for elaboration on what participants meant by the term "baba" they suggested that it referred to a spiritual teacher or healer.

Krishna: "This centre has helped us very much, because nothing like this was available in the areas we were living. So we moved to Delhi just for the sake of the child. So that he will get a place where he can go and he can get the therapy."

There did appear to be an important role for the extended family as a whole in coming to terms with the disability. For example, the mothers described their in-laws persistence in being involved in the decision making process and their subscription to traditional beliefs about autism despite it contradicting their own personal beliefs. As a result the mothers described feeling pressurised to confirm to their in-laws expectations of a traditional Indian wife:

Geeta: "In my case my in-laws are still forcing me to take my son to some temple. Still! They're still forcing me. Whenever I call, they'll say 'you are not following what we are saying to you.'"

Jaya: "Just go for your satisfaction. Get them off your back."

Lekha: "Even my mother does the same. 'Go to this baba', even though they see no change."

However, mothers in this study reinforced the need to put their child's needs above all other relationships and make difficult decisions such as migrating and breaking away from extended families in order to seek out much needed support:

Lekha: "I used to stay with my in-laws and when I said that I wanted to shift to Delhi permanently of course, there were issues like 'how are you going to cope when you stay alone with two kids?' and they (in-laws) were like 'it's not very safe, you don't have any relatives here' and all that. So there were issues, definitely, with them. They still want me to go back. They keep calling."

It appears that for these mothers decision making about their children was done in conjugal units (consisting of the mother and father) and often in contradiction to the advice and concerns of family members who in an extended family unit may be considered as authority

figures. Migration appeared to have created a modified extended family, consisting of individual nuclear families living apart rather than together as a traditional joint family.

Summary of master theme 1

Master theme 1 described the parents' initial process of making sense of their child's delays. Family members appeared to play an important role in this process and often conversations with family members acted as a platform for mothers to explore and better understand their own concerns. Even though many of the mothers described having their concerns dismissed by family members this process seemed to be important in reinforcing their beliefs that the delays were serious. Additionally, the mothers described having to make sense of their children's disabilities and decide on the best course of action in relation to two conflicting views of disability, which were the traditional views of their family and their own personal views.

Master theme 2: Seeing disabilities from a new perspective

When describing their experiences mothers were extremely keen to focus on their new perspectives of disability and the positive impact that the specialist service had on their lives. As a result, this master theme describes the changes induced by the mothers getting involved with service provision. The changes were in relation to positive outcomes both personally and for their child.

Accepting the child and the disability

The key component of dealing with their child's autism was acceptance of the diagnosis and also the child themselves. Acceptance of the child and their delays provided mothers with a realistic outlook of the disability and enabled them to adjust and cope. A motivating factor in promoting this acceptance was the mothers' beliefs that by viewing the autism and their children in a positive way, they would influence society to take on similar perspectives, an approach advocated by the service: *"When we start accepting our children the whole of society accepts them. It is a very important thing, in my personal experience."* (Aanchal)

However, mothers recognised that acceptance was not an easy process. As Smitha describes below, for some parents, an inability to come to terms with the loss of their expected child and the reality of having a child with disabilities compounded their ability to accept the situation:

Smitha: "Sometimes acceptance is difficult. People think 'this is not my child', they think 'my child should not have this.' If you accept your child fifty per cent of the problem is dealt with."

Acceptance appeared to be directly related to receiving a diagnosis. For example, when given the diagnosis of autism mothers felt relieved of their uncertainty and confusion surrounding their child's delays and felt they had something tangible to make sense of. The diagnosis appeared to offer mothers an understanding of their child's delays and opened up opportunities to seek help. As a result, the diagnosis was accepted and embraced as providing a means of coping and making their child's disabilities appear more manageable through identification:

Pooja: "For me it was complete relief, because we had been hunting for a diagnosis for nearly two years and when I finally got the diagnosis it was almost like 'thank God! Now I know what's wrong and now maybe I can do something about it.'"

Additionally, as Deepa describes below receiving the diagnosis initiated a grieving process which had to be overcome in order for parents to come out on the other end better informed and ready to cope with their child's difficulties:

Deepa: "When you hear the diagnosis you have to give yourself strength. You will be shattered, you will be devastated by the diagnosis. But then you will have to face that and only then will you be able to move on. So it's a big journey I think, a one way on-going journey throughout life."

Dealing with the grief and coming out at the other end played an important role in accepting the disability and in the creation of more positive attitudes. However, there was also recognition of the emotional distress and the enormity associated with acceptance and the disability. For example, it is referred to as a "big" and "on-going" journey. This is interesting as often life is framed as one big journey, but here the disability and the process of acceptance is seen as a journey in itself.

Regaining control as a parent

Mothers acknowledged the role of the service in providing them with the competencies and skills to enable them to manage their children's challenging behaviours and thus enabling them to feel like they had regained control. For example, Smitha described her increased confidence and as a result her ability to implement successful parenting strategies, which in

the past she struggled to do: *“I really came to know what I have to do to my daughter. That is the main thing we got from here and now we are confident.” (Smitha)*

A contributing factor in helping parents to regain control was the improvement in their interactions with their children, through promoted communication and understanding:

Krishna: “We understand Manish, my son now and he has started recognising me as a as a person who can understand him, who can be a voice for him, that was something which gave me real strength to move on.”

In a way the parenting skills provided coping resources and many of the parents reported feeling more *“confident”* in their parenting roles. For example, as Krishna describes above, she was able to draw strength from her improved ability to understand her son which ultimately led to her feeling in control as a parent and being able to act as advocate for her son.

Seeing a change

For most mothers regaining control not only enhanced their own confidence as parents but was also successful in reducing their children’s behavioural difficulties. Many of the parents described significant changes in their children’s behaviour after coming to the service. These changes were attributed to the flexible and adaptable approach implemented by teaching staff which meant their children were understood and their needs catered for. The parents also reinforced that the service provided a safe and accepting environment for their children to develop, which was very different to their negative experiences of mainstream schooling:

Smitha: "It is worth coming here, because their (children) self-confidence definitely improves. Their teachers and others co-operate with them. That reduces the behaviour problem. If you are in other types of school you get bullying, but here that isn't a problem. Here, everyone co-operates, the teachers adjust, they go with the needs of the children."

One group of mothers attributed improvements in their children's behaviour to changes in their own attitudes and ability to manage situations, rather than an indication of changes in their children. This may be linked to the fore-mentioned sub theme "*accepting the child and disability*" whereby parents concentrated on accepting the child and their disability and on making personal adjustments in order to cater for their child's needs rather than on making the child change:

Deepa: "You see changes, we won't say that the child has changed, it's just that we have changed, that's the main thing."

Bhuvi: "We are changed. Our attitude, now we know how to handle them."

Deepa: "How to handle them and how to handle a situation. The children are the same. It's just that you know how to handle things."

Central to this concept of having to "*change*" themselves was the idea of viewing their child's disabilities in a positive way and changing their own negative perceptions of disability. This is apparent in the group discussion below, in which Bhuvi talks about her son's difficulties as "problems" and is quickly corrected by two other mothers who prefer to view things in a more positive light. This demonstrates the overall positive outlook promoted by the service:

Bhuvi: "These problems with our children are life-long. He has speech problems and he has a lot of behaviour problems."
Deepa: "OK Bhuvi! Stop calling it a problem [laughs]. Let's not say it's a problem, tell them what it really is, a disability."
Aanchal: "The main thing is that people should be told about the disability, it's not a problem, our children are not problems, right?"

Being a part of something

A re-occurring theme was the positive experiences associated with involvement with the parents support group. The group was considered to be an important source of emotional support, which is illustrated in the extract below:

Krishna: "It's less of an institution for us than a family, because we have been here for a long time. If you're having any difficulty, need any support you can come to the centre and talk to somebody, even the parents, the parents are very supportive. If I have any difficulty I can call them any time."

Mothers believed the support group offered them a reliable form of support, helping them to resolve emotional problems related to caregiving. It appears that the group provided a safe environment in which mothers could be open and honest about their difficulties. It appears that the mothers believed the experience of group support was enhanced through the creation of a sense of belonging and the group was believed to offer something beyond support. For example Krishna referred to the group as a "*big family*", highlighting the strong connections developed between the mothers. Additionally, the mothers' narratives highlight that they constantly refer to "we" rather than "I" when talking about their experiences. This reinforces that the mothers recognised themselves as a group which is likely to be influenced by the fact that they all share a common experience of caring for a child with intellectual/developmental disabilities.

In their narratives, these mothers also identified numerous personal benefits through getting involved in service delivery either as special educators or volunteers. These included increased confidence, social support, a sense of purpose and a sense of well-being. It appears that getting involved contributed to a process of personal transformation through which mothers became more confident, empowered and sociable. For many of the mothers getting involved was a response to opportunities and personal needs. For example, in the extract below it is clear that the desire to re-establish their own identity and roles aside from caregiving motivated the mothers to volunteer:

Lekha: "It has brought really a lot of confidence and kind of empowered us."

Jaya: "That's very true, absolutely."

Lekha: "I know for sure that I wouldn't have a social life like I have now, without helping here and, it helps in every way, it's not just with the child. It reflects everywhere."

Jaya: "It makes you blossom as a person, as an individual."

Pooja: "You not only come here for help, but you get involved as well, with the teaching. It makes me feel like I have something to do, my own role. Something, not just looking after my kids."

Additionally, many of the mothers talked about achieving a sense of self through getting actively involved in a voluntary teaching programme. This enabled them to re-discover their own personal goals of working and having an identity of their own, as is depicted in the metaphor *"It makes you blossom as a person, as an individual"*, which demonstrates how they embraced their individuality as a result of their involvement. Having expanded learning opportunities was another personal benefit of volunteering:

Geeta: "It interests me so much that I did some extra courses. I was totally influenced by the positivity here and everything going the right way with me and my son. So it influenced me in such a way that I decided to do something for the children and learn more about autism and everything. So I did the course and then I joined as a teacher."

For example Geeta, framed her volunteerism as a way of giving something back and fulfilling her desire to learn more about autism.

"It's a completely different world outside"

All parents made a distinction between their own perceptions and attitudes towards disability and those of the general public. For example in the extract below, Deepa highlights her own positive and optimistic outlook on autism, which she identifies as being due to her links with the service. Deepa recognises that the interventions provided by the service would have enabled the mothers to have adapted in a more positive way, therefore accentuating positive views of disability. Ultimately, the parents recognised that parents who did not have access to such services were likely to have very different and most likely negative views of autism:

Deepa: "I don't want to give any negative views. Autism is lovely. Autism is fabulous. Because you are talking to people who are coming from X (name of service) that's why. You go to people who are not coming from X (name of service), it would be a different view. You talk to people who have just got their children diagnosed. I'm sure, I think it's a completely different world outside."

Additionally, many of the mothers described experiencing stigmatising attitudes from others. These attitudes were associated with people focusing on a difference, due to their children

either looking or acting differently which ultimately led people to think that they had limited capabilities:

Smitha: "It's the thought process, they think negatively. They are labelling these children, one label is they're abnormal. That is the problem here in India. He's not normal. Whatever the problem is, it is abnormal, he's not normal, so he will not do. So that awareness is missing that he is able to do things."

In the extract above, it is clear that mothers recognised that stigmatising views were often associated with their children's deviations away from the expected norms of performing and conforming in society, which ultimately meant that they were labelled as being "*abnormal or not normal*". Parents attributed stigmatising attitudes to society's lack of awareness, lack of education and understanding about autism, which acted as a barrier to acceptance and inclusion. These findings are also in keeping with those identified by parents in the Study 2 interviews.

Summary of master theme 2

In this master theme the mothers described a type of four stage process in coming to terms with and managing their child's disabilities and the positive impact the service had on their lives. These four stages included: initially accepting the diagnosis and their child; regaining control through parenting skills training; witnessing positive changes in their children and themselves and finally; reaping personal benefits as a result of their involvement with the service.

Discussion

The study explored how disability is encountered within an Indian context and consequently, provided an insight into the cultural origins of British South Asians' understandings of disability as well as the positive impact of successful service delivery. Two main themes were identified in the parents' narratives which were "*making the decision to get help*" and "*seeing disabilities in from a new perspective*". This discussion will explore these themes with reference to existing literature and examine the implications for service delivery in the UK.

Master theme 1: Making a decision to get help

Master theme 1, "*making a decision to get help*" highlighted some striking similarities between the experiences of the parents in this study and those in Study 2 (Chapter 4). Both narratives focused on parents having to construct and negotiate their understandings of disability in relation to western medical approaches and traditional approaches to disability influenced by their South Asian heritage. Both groups appeared to be undergoing a transformation of values and cultures through the exposure to information, ideas and beliefs from western societies. Industrialisation and urbanisation in urban areas of India, has led to modernisation and social change from traditional to more contemporary culture with western underpinnings (Kashyap, 2004). For parents in the current study this was reflected in the sample studied who were middle class, educated mothers, living in urban areas, who as a result were more likely to be influenced by western ideologies promoting independence, individualism and decision making within nuclear family units. In particular, the mothers in the current study were well educated up to at least degree level, which is in comparison to parents in the previous two studies who were less educated. Although it is not possible to

infer a direct relationship due to the qualitative nature of the study, education may have made the mothers in this study more likely to engage with the education programmes offered by the service. Additionally, these mothers were more socio-economically well off than those parents in the previous studies who were from working class backgrounds. As a result, in terms of finances it may have been easier for these mothers to make the decision to move away from extended families and access paid for services in Delhi. It may also be a result of a scarcity of resources in India meaning that families have no choice but to make commitments such as relocating and consequently leaving extended family homes and adopting western service principles in order to access the limited resources.

The values of South Asian cultures are different from western culture with a far greater emphasis on collective needs, interdependency and conformity as opposed to western values which promote individuality (Triandis, 2001). According to Berry (2005), this can lead to acculturative stress, when individuals face problems as a result of intercultural contact. This imbalance can lead to additional stress for parents having to deal with opposing beliefs and values about disability. This was reflected in the sub themes “*struggling to make sense of the differences*” and “*making a commitment to get help*” which showed that consultations with extended family members featured heavily in the initial accounts whilst parents were trying to make sense of and decide what to do. Often the family views focused on traditional ways of responding to disability within Indian culture, which tend to focus on collectivist values and religious conceptualisations of disability. This was in opposition to the mothers’ views which focused on western bio-medical conceptions of disability as well as taking more individualistic and child-centric approaches to decision making. As a result, a major

component of the initial process of making sense of their child's disability involved having to choose which cultural references they wanted to adopt.

Master theme 2: Seeing disabilities from a new perspective

The second master theme "*seeing disabilities from a new perspective*" described the impact of interventions and services. Some of the core principles of these were education, parent training, empowerment and a sense of belonging which will now be explored in more detail in terms of how they could be applied to service delivery in the UK.

Acceptance of the child and their autism seemed to be a crucial aspect of the parents' narratives and played an important role in allowing them to effectively cope with their child's difficulties, as was described in the sub-theme "*accepting the child and the disability*". This is in keeping with other research which shows a positive link between parental acceptance and coping (Kandel & Merrick, 2007; Taanila, Syrjäälä, Kokkonen, & Järvelin, 2002). Central to this acceptance were changes mothers described in their own personal attitudes and perceptions about their child's autism. This involved replacing negative attitudes with more positive ones which promoted the inclusion and acceptance of their child using cognitive reframing strategies. Positive coping strategies such as problem focused and perception focused strategies are associated with lower stress in parents of children with disabilities (Jones & Passey, 2004). Additionally, a study by Hassall et al. (2005) found that mothers of children with intellectual disabilities who have more social support, higher parenting self-esteem and an internal locus of control are likely to experience less stress.

Acceptance of their situation enabled mothers in the current study to successfully move forward and embrace interventions designed to help them manage. However, for these parents it is likely to be acceptance coupled with numerous resources (e.g. social support, psychological interventions) that enabled them to cope successfully with their children's difficulties. This is in keeping with stress and coping theories which suggests that the way in which stressful situations are dealt with depends highly on the availability of appropriate resources (Lazarus & Folkman, 1984).

The specialist service in the current study concentrates on interventions which promote parental involvement through parenting programmes which aim to allow parents to personalise and implement psychological interventions to meet the specific needs of their child. The efficacy of parenting programmes as interventions for families caring for children with intellectual/developmental disabilities is well documented (Cicero & Pfadt, 2002; Eikeseth, Tristram, Jahr, & Eldevik, 2002; Matson, Mahan, & LoVullo, 2009). There is currently debate in the literature as to whether existing parenting programmes are effective in addressing the needs of culturally diverse parents (Lau, 2006). The Triple P (positive parenting programme) is one such parenting group programme designed to help parents improve their child's behaviour, for children aged 4 - 14 years old (Sanders, 1999). Recently an Australian study (Morawska et al., 2011) highlighted the possibility of successfully adapting the Triple P to meet the needs of culturally diverse groups. Although most adapted programmes have shown an increase in the recruitment of culturally diverse parents (Martinez & Eddy, 2005; McCabe, Yeh, Garland, Lau, & Chavez, 2005), few studies have shown any increases in the outcomes for parents or children of culturally diverse backgrounds (Castro, Barrera, & Martinez, 2004; Kumpfer, Alvarado, Smith, & Bellamy, 2002).

As the parents highlighted, the parenting programme had a key focus on accepting the disability and giving parents the skills to manage challenging/difficult behaviours, which have been shown to be major stressors for families caring for children with intellectual/developmental disabilities (Hastings & Beck, 2004; Baker et al., 2003). This may be particularly relevant to British South Asian families who have been shown to deal with challenging behaviour with limited support as a result of being unable to accept the disability which consequently leads to a reliance on religious and supernatural explanations (Hatton et al., 2010; White, 2009). One of the key challenges to implementing education and training through parenting programmes to ethnic populations is to ensure that the information is culturally appropriate and accessible. For example, it is important to consider language needs as well as the fact that South Asian parents may have distinct parenting strategies which may not necessarily fit into the Eurocentric models of parenting (Gorman, 1998). The beauty of parenting programmes is that they enable parents to create their own tailor-made packages of care. In doing so, they can effectively shape the programme to specifically meet their child's and family's needs. This way of working would fit in well with recent policy drivers for more personalised packages of care for people with learning disabilities and their families (Department of Health, Putting People First 2007).

Personal transformation and empowerment was evidenced in the opportunities mothers had to participate in interventions, make decisions, support one another and volunteer within the specialist service. In the UK, learning disability services tend to adopt more conventional approaches to service delivery with health professionals taking a lead in the implementation and delivery of training programmes. This study has demonstrated the effectiveness of incorporating parents into service delivery. In the UK recently there has been a shift towards

service user involvement in social care since the introduction of papers such as the Department of Health's (2006) *Our Health, Our Care, Our Say: A New Direction for Community Services and the Local Government and the Public Involvement in Health Act* (2007). Such initiatives promote the need for local authorities to inform, consult and involve service users in the running of services. However, policy makers and practitioners rarely attempt to engage ethnic service users. It appears that more needs to be done in order to appropriately allow ethnic service users to become actively involved in service design and delivery. This would require tackling barriers to service involvement including fear, lack of trust and language barriers (Begum, 2006). Additionally, working alongside other mothers with children with intellectual/developmental disabilities appeared to provide mothers in the current study with a forum for containing their anxieties in a positive, safe and non-stigmatising environment where their difficulties were understood and made manageable. This could be one way of providing emotional and social support to South Asian families who may be isolated and face stigma from within their own communities, as was described by parents in Study 1 (Chapter 3).

Reflections

This study provides a snapshot of how intellectual/developmental disabilities are experienced in India and how services are delivered. The key message is that culture plays an important role in shaping the experiences and influencing how mothers make sense of their children's disabilities. Similar to Study 2 (Chapter 4), bicultural influence appeared to introduce an added complexity to the way in which mothers made sense of their experiences in relation to two conflicting cultural views. The mothers in this study described a process of having to

choose one cultural approach over the other when making the decision to access support from the service. These mothers choose to adopt more western and medical views of disability and consequently demonstrated less-adherence to traditional understandings and responses again, in keeping with the results from Study 2. These mothers also appeared to have a choice in seeking out resources/services because they were well educated and socio-economically well off which meant that they were in a position to seek out and pay for appropriate support. Additionally, these socio-economic factors may explain the differences in experiences described when compared to parents in Studies 1 and 2.

The bicultural influence described by mothers was something that I had not expected to arise when embarking on the study. Instead I assumed that the experiences of these parents would be typically traditional. This reinforces the value of qualitative approaches in allowing new ideas/findings to arise which may have been overlooked. However, it is important to recognise that the experiences described by the mothers in the current study are unlikely to be representative of the majority population, which is something that the parents themselves identified in the sub theme "*it's a completely different world outside*". The sample reflected highly westernised Indian mothers who were well educated and middle class, and as a result their experiences are likely to be very different from poorer families or those living in rural connotations. Mothers in the current study were also Hindu, which is in comparison to those in Studies 1 and 2 who were Sikh and Muslim. Although it is not possible to confirm, religion may have led to come subtle differences in caregiving experiences across the three studies.

Secondly, the study demonstrates how culturally relevant services and resources can help parents to cope positively. It was apparent that accessing services enabled mothers in this study to adopt problem focused coping strategies, which focused on taking practical steps to help them manage their children's disabilities and in doing so reduce their stress. This is in contrast to Studies 1 and 2 where parents appeared to be coping less well and with limited support. Therefore, the study has highlighted a potential model for service delivery which leads to positive outcomes for both children and parents. However, one of the obvious challenges to incorporating the same design to service delivery in the UK is the major differences in the way organisations are structured and funded. The service in the current study relied heavily on donations and volunteers as forming a major part of their service delivery. Consequently, parental motivation and commitment is vital in order for interventions like the mother-child programme to function effectively. In such circumstances it is important to look at the social context in order to determine whether such parental commitments would be feasible for the parents.

At this stage of the research it became clear that culture played a significant role in the way parents make sense of their caregiving experiences and children's disabilities. However, the impact of culture appeared to vary and was dependant on processes such acculturation. Additionally, access to relevant services and support appeared to influence the coping strategies employed and available to parents. Following these interim conclusions I became interested in studying alternative views on these ideas, by exploring the experiences of service providers working with South Asian families caring for children with intellectual/developmental disabilities in the UK. I felt this would enable me to further explore some of the ambiguities and contradictions present across the three previous studies.

In particular I aimed to explore “why” there were differences in satisfaction with services across the groups, “how” culture and acculturation impacts the way in which services are delivered and identify “what” the barriers and challenges are for service providers working cross culturally.

CHAPTER 6

Study 4 - The challenges to working cross culturally in learning disability services in the UK:

A phenomenological exploration of staff experiences

Introduction

The prevalence of learning disabilities amongst South Asian communities is thought to be almost three times higher than any other communities in the UK (Emerson et al., 1997). A number of reasons have been postulated for this including social and material disadvantage, as well as a possible genetic risk factor (Bittles, 2001; Morton, et al., 2002). Despite this high prevalence the uptake of learning disability services remains low amongst South Asian communities (O'Hara, 2003; Bywaters et al., 2003). Research has highlighted a number of reasons for this including services being culturally inappropriate, a fear and lack of awareness amongst South Asian groups, discriminatory attitudes amongst service providers, as well as language and communication barriers (Hatton et al., 1998; Nadirshaw, 1997; Azmi et al., 1997; Hatton et al., 2010).

There is a growing body of research exploring the views and experiences of ethnic minority families when trying to access learning disability services. However, a literature search (see Chapter 1, Introduction) revealed that very little is known about service providers working within learning disability services and the challenges that working cross culturally can pose. Much of the literature in the area examines the views and experiences of generic healthcare staff caring for ethnic minority patients and explores their experiences of providing culturally competent care (Katbamna et al., 2002; Hawthorne et al., 2003; Summers & Jones, 2004; Owens & Randhawa, 2004; Vydellingum, 2006; Richardson et al., 2006; Jackson, 2007).

Only three studies appear to have looked specifically at cross cultural working in community learning disability services all of which employed case study designs (Summers & Jones, 2004; Hepper, 1999; Hassiotis, 1996). The studies revealed the challenges that different

cultural perspectives can pose in terms of creating tensions between family responses to disability and professional concerns, as well as language barriers in working therapeutically with clients. The studies provide some insight into the issues presented to learning disability teams working with ethnic minority groups. However, they tend to focus on referrals to female clinical psychologists or psychiatrists and therefore do not accurately reflect the make-up of learning disability services which often involve multi-disciplinary teams consisting of nurses, occupational therapists, speech and language therapists, physiotherapists, psychiatrists, both male and female and from different ethnic backgrounds. Being case study designs the studies are limited in their application and generalisation. Additionally, the studies appear to pay little attention to the context in which the individuals with disabilities are situated including little attention to working with the family which research has shown, can often play a central role in the lives and care of South Asian individuals with disabilities (Katbamna et al., 2004).

Other studies have explored the experiences of staff working in primary health care and palliative settings using qualitative focus groups (Hawthorne et al., 2003; Jackson, 2007; Richardson et al., 2006; Owens & Randhawa, 2004). The general findings revealed difficulties with communication and language, inadequate interpreting services, feelings of frustration and helplessness and difficulties applying cultural competence training to everyday practice.

The need to provide culturally sensitive services to ethnic minorities has been recognised as a key component in reducing ethnic health disparities (Bhopal, 2009). In the NHS and public health care services there has been investment in study days, short courses and longer cultural

competence training programmes (Papadopoulos et al., 2004). However, they are often diverse in terms of their context, duration and understanding of cultural competence.

Empirical studies have developed and evaluated culturally sensitive training programmes, instruments and interventions for healthcare professionals (Papadopoulos et al., 2004; Chevannes, 2002). Most of these studies propose principles for effective cultural competence training which concentrate on challenging ethnocentric beliefs, practices and prejudices amongst staff, rather than simply providing factual information.

Recent learning disability policy drivers have recognised the need to develop culturally sensitive support services for ethnic minority groups (Mir, 2001; Hatton et al., 2003).

Documents such as the National Carers Strategy (Department of Health 1999), Learning Difficulties and Ethnicity: A Framework for Action (2004) and Valuing People (Department of Health 2001; 2009) make recommendations for improving services for South Asian families. Despite these changes, mainstream services tend to be ill-equipped to provide appropriate services to ethnic families who define and address disability differently from the majority population (Ahmad & Atkin, 1996; Nazroo, 1997; Shah, 1995). For example, the second national survey of learning disability partnership boards (Hatton, 2007) revealed that services still fail to consider black and ethnic minority communities when planning and implementing disability services.

Aims

The current study has been informed by the previous stages of the research which demonstrated the role of culture in shaping the experiences of South Asian families caring for children with intellectual/developmental disabilities. In particular they have revealed how

culture and processes such as acculturation can shape the way parents make sense of disabilities, their perceptions and interactions with services and coping strategies employed. For example, one finding which was consistent across the three studies showed that those parents who were more acculturated (Studies 2 and 3) showed better engagement and satisfaction with services than those that were less acculturated (Study 1). In order to explore these ambiguities in more detail the current study sought to explore the experiences of service providers working with South Asian families in the context of learning disability services in the UK. In doing so I hoped to understand ‘how’ and ‘why’ acculturation leads to differences in satisfaction and engagement with services. Additionally, I aimed to explore the degree of congruence between the parents and service providers’ narratives, in order to determine if they were matched in terms of their priorities.

The study also aimed to further expand on the limited research into the area of cross cultural working in learning disability teams. I aimed to elucidate the ways in which health professionals address the challenges of working with ethnic communities in a culturally competent manner. Using a phenomenological approach I aimed to explore staffs’ experiences, beliefs and feelings about working cross culturally and how these can lead to challenges within practice. Ultimately, the study makes recommendations for improving policy and practice for service delivery to ethnic minority groups.

Method

Context

Staff were recruited from two NHS organisations, a private organisation and a voluntary organisation. Recruiting from these sites offered access to multidisciplinary teams providing a range of peripatetic/domiciliary support services to assist individuals with learning disabilities to live in community settings. At the time of recruitment the NHS community services provided support to people with learning disabilities through Primary Care Teams. The private organisation was distinct from the NHS and consisted of a range of professionals working in residential services for people with learning disabilities as well as providing support and consultancy services to community support teams in the NHS. The voluntary service received a social services grant and had the primary purpose of providing support to people with intellectual/developmental disabilities and their carers from ethnic minority communities. The services from which participants were recruited offered one or more of the following:

- Support and services in the home
- Rehabilitation, information and advice to parents and carers of disabled children and adults
- Education
- Social care
- Psychological and behavioural interventions
- Short break services
- Leisure and recreational activities

This represents the wide range of services that are available for disabled children and their families.

Participants

In total 20 service providers attended one of five focus groups. The research aimed to recruit staff from various ethnic groups and genders to give an insight into a range of different perspectives. The participants consisted of 14 women and 6 men representing a spread of ages and professions. Further details of the participants can be found in Table 6.1. The participants had been working in learning disability services for a varying amount of time ranging from less than a year to over 20 years. Of the 20 staff, 14 identified themselves as White British, Scottish or European, 3 as British Indians, 2 as British Pakistanis and 1 as African Caribbean. During the initial recruitment process it became apparent that staff from ethnic groups were under-represented in the services recruited to the study and therefore purposive sampling strategy was employed to actively seek out staff from ethnic groups. This was done through a 'word of mouth' approach by asking team managers to identify members of staff from ethnic minority communities whom they thought would be willing to take part. Staff were recruited from services supporting a high proportion of South Asian families.

Table 6.1
Participant details

Category	Number of staff (n=20)
<i>Gender</i>	
Male	6
Female	14
<i>Occupation</i>	
Clinical Psychologist	4
Learning Disability Nurse	8
Occupational Therapist	3
Psychiatrist	2
Social Worker	1
Support Worker	1
Play Therapist	1
<i>Ethnicity</i>	
White British or European	14
British Indian	3
British Pakistani	2
African Caribbean	1
<i>Length of time working in learning disability services</i>	
Less than 1 year	3
1-10 yrs	5
11-20 yrs	5
More than 20 years	7

Ethics

NHS ethical approval was obtained prior to conducting the research from the Black Country Research Ethics Committee (see Appendix X, page 307). As the study involved exploring a new group of participants (service providers instead of parents) a whole new application was required. Approval was also obtained from the research and development departments at the two NHS sites. The other two sites (private and voluntary) agreed to proceed with the research after NHS approval was granted. Written consent was obtained from all participants prior to commencing with the focus groups. All data remained pass word protected and anonymous, using pseudonyms to preserve the participants' identity. After written transcripts were produced all recordings were destroyed.

Procedure

Permission was obtained from the managers of the teams prior to commencing with recruitment. Team leaders from all services were asked to circulate details of the study including the information sheet (see Appendix T, page 301) and consent form (see Appendix U, page 304) to members of staff who may have been interested in taking part. I also attended team meetings to provide staff with further details of the study and give them the opportunity to ask questions. This was followed up by email correspondence with those members of staff who were willing to take part, in order to arrange a convenient time and place to hold the focus group.

Interview procedure

Participants were interviewed for up to 1 hour and ten minutes. An interview schedule was used to loosely structure the discussions (see Appendix V, page 305). The interview schedule was constructed and based on the questions asked in the previous studies. The interview format comprised of a list of open ended questions and prompts which were based on the following topics:

- Direct experiences of working with South Asian families
 - The nature of the problems experienced
 - Specific issues when providing culturally competent care
- Training
 - Education and training received
 - Coping with a range of needs (cultural/ religious)
- Recommendations
 - Changes to working practices
 - Additional support/ resources

The interviews took the form of group discussions which enabled me to develop a rapport with participants. As interviewer I took care to use words that were in keeping with the participants' discourses and regularly asked for feedback and elaboration on certain points to ensure they were fully understood. All focus group discussions were audio-taped and transcribed verbatim. Qualitative data were collected via five semi-structured focus groups. Focus groups were conducted in a range of settings (one in a private residential home and four at health centres). Focus groups began by eliciting some basic demographic information

about the service providers (e.g. age, gender, time of employment and qualifications) (see Appendix W, page 306).

Analysis

Transcripts from all focus groups were analysed using interpretative phenomenological analysis (IPA) which was employed in the analysis of data from all the studies, using Smith et al. (2009) as a framework. As the data consisted of group discussions a protocol for applying IPA analysis to group data was used as a template (Palmer et al., 2010). Please refer to Chapter 2 (methods) for a more detailed overview of this process.

Credibility and validity of analysis

Credibility of the analysis was upheld through the use of regular supervision and cross checking of the analysis with a secondary researcher with experience of using of IPA. This involved a method of triangulation whereby a number of qualified researchers in IPA verified the findings through repeated and regular checks of both the phenomenological and the interpretative stages of the analysis. Please see Chapter 2, Methods (analysing the quality of the research) for more details. All interpretations in the Results section have been illustrated with numerous examples from the data and additional quotes can be found in appendix Y (page 310).

Results

Following analysis of the transcripts two master themes emerged and are presented with their sub-themes in Table 6.2 below, which also demonstrates how many participants are represented within each theme.

Table 6.2

Master and sub themes reflecting service providers' experiences of working with South Asian families and their representation amongst participants

Master theme	Sub theme	Number of participants representing each theme
Language as a primary barrier	<i>Challenges faced when using interpreters</i>	18
	<i>Using informal interpreting methods</i>	7
Striving to engage	<i>Frustration at barriers</i>	12
	<i>Struggling with engagement and progress</i>	15
	<i>Managing diversity</i>	8
	<i>Making it work</i>	7
	<i>Looking for a way forward</i>	13

Each master theme and its corresponding sub-themes will now be described in detail and illustrated with participant extracts.

Master theme 1: Language as a primary barrier

This master theme discusses issues with language and communication difficulties as key challenges to service delivery. Participants talked about the difficulties including challenges

and losses through the use of interpreters and translators as well as their experiences of using more informal means of communicating with non-English speaking parents.

Challenges faced when using interpreters

When talking about the challenges to delivering culturally competent services to South Asian families participants repeatedly referred to difficulties with communication and language barriers. As one participant highlighted *“I think language and communication is always a big issue”* (Joanne, G1) Interpreters were frequently utilised as a means of overcoming language barriers. However, there was overall consensus that the use of interpreters posed serious problems. Some of these problems were highlighted specifically by South Asian participants whilst they reflected on their own experiences of being bilingual. For example, one participant identified the failure of interpreting services to recognise the distinctiveness between different South Asian languages and complications arising due to interpreters claiming to be multilingual and therefore proficient in more than one language:

Imran, G5: “Some of these interpreters say they're Punjabi speaking but can also understand Urdu, a bit of Hindi and something else as well, but then actually the only language they can properly speak is a particular dialect of Punjabi.”

Another South Asian participant, who was a clinical psychologist, described her personal struggle in trying to translate psychological ideas and concepts from one language into another. Some participants recognised that interpreters' lack of familiarity with health related concepts had a major impact on how accurately they were able to convert messages into both languages:

Sukhdeep, G5: "I think from my perspective, just from the language side, using psychological terms is quite difficult, I do speak Punjabi, so I realise how hard it is when you come to do that, I can struggle at times to cross over."

As well as recognising the difficulty in translating concepts across two distinct cultures, the participants also reported concerns that their messages were being altered during translations which left many feeling like they were unable to accurately convey their messages. This is demonstrated in the extract below in which one participant uses the metaphor "*Chinese whispers*" to describe how translation leads to the accumulation of errors in the retelling of messages back and forth, so that the translated messages differ significantly from the original one. Ultimately for this participant this raised concerns because she felt that both parties (professionals and parents) had an inadequate understanding of each others concerns which led to confusion:

Rachel, G1: "It's a bit like Chinese whispers isn't it? The more people the message goes through the more it gets changed...interpreters might receive a message in one way and pass it out to us in a different way, so that can cause confusion as well."

Additionally, service providers using psychological approaches reflected on how the use of interpreters can alter the nature of the therapeutic relationship. Working in a triad was seen as introducing a greater potential for misinterpretations and a lack of emotional sensitivity during consultations. For example, in the extract below one participant described his concerns that the empathetic and emotive qualities of his dialogue with clients were lost during interpretations and affected the therapeutic relationship:

Imran, G5: "Sometimes the questions you ask are personal and obviously you do that subtly and delicately, but the way the interpreters ask... in such a crude way and you can see the person, who's come to the appointment cringing and feeling very uncomfortable, so it's a poor experience."

The use of an interpreter was also considered to introduce added judgements and biases into the consultation process. For example, some participants described that interpreters are likely to present their own personal attitudes and in some cases volunteered their own opinions regarding clients' personal circumstances:

Sharon, G1: "I supervised a trainee once who was working with an interpreter...she said the interpreter felt that she was quite knowledgeable on a particular aspect and actually started giving advice (group gasps)."

Often, such incidents left participants feeling powerless and out of control in being unable to assess the quality of the interpretation: *"I think interpreters can be a bit of a problem can't they? Because you're not in control of the process are you? You're never quite sure what the quality of the interpretation is."*(Tom, G3) As a result of the fore-mentioned difficulties, participants described having to look out for cues during consultations as indications of poor quality interpretations, which involved monitoring differences in the duration of talk between the original and interpreted information and, looking out for nonverbal cues, in the client, such as confusion or uncertainty.

Using informal interpreting methods

As an alternative to using interpreters, participants talked about using family members or friends or calling on bilingual colleagues. Generally siblings were the preferred means of non-professional communication with non-English speaking parents, as they were seen to provide an insight into the family, had a shared understanding of the difficulties and were likely to be fluent in English. One of the drawbacks to the use of siblings was that they were sometimes perceived as having their own agendas during consultations:

Ben, G3: “Sometimes you can ask family members to translate, there’s a good side and a bad side to that, you often feel that you get very good communication and you feel you get an understanding of the situation from the family members but at the same time...it’s likely to be someone from a younger generation, translating for a parent or older relative and has its own agenda really doesn’t it.”

In other circumstances service providers called on other bilingual colleagues working in the same service to act as interpreters. Using bilingual professionals is, in fact, a common alternative to using interpreters, however often led to practical drawbacks in terms of their bilingual colleagues giving up their time and having prior commitments:

Penny, G2: “If you’re working with a family that you think might need interpreting services, there’s a tendency amongst a lot of us to think ‘there’s a South Asian worker, we’ll get in touch with them’, so that kind of bypasses the interpreting services.”

Laura, G2: “But they’ve got full time jobs and they’ve gotta do those jobs. They shouldn’t be just interpreting for us, so they’re not always available.”

Many of the bilingual staff stated that if they had the language skills they would prefer to conduct family visits in the parent’s first language themselves. For bilingual staff the ability to communicate directly with families was seen as leading to better quality interactions:

Zara, G5: “Because I can speak both languages it’s sometimes easier for families to sort of have a conversation with me than one of the other staff nurses, you get a lot more out of them as well.”

Being bilingual did not simply alleviate communication barriers. All of the South Asian service providers in this study showed a degree of multilingualism, in that they were able to understand (but not necessarily speak) more than one South Asian language. Such individuals talked about taking an adaptive and creative approach to overcoming communication barriers by using a combination of the parents’ first language and English. For Sukhdeep this involved asking her questions in English but receiving an answer in Urdu. However, this was only

possible if the parents felt they could get by on their limited understanding of English and often service providers only took such action if it was suggested by the parents themselves initially:

Sukhdeep, G5: "I had to reach a compromise, I was seeing an Urdu speaking man and he spoke to me in Urdu but I said to him 'I'm going to have to ask you my questions in English' because he could understand me, just like I could understand exactly what he was saying. I couldn't ask all my questions in a sophisticated enough way in Urdu, but that worked, he was quite happy with that. I mean obviously I tried not to use complicated terms. I think he actually gave that to me as a suggestion, saying that 'you can speak English.'"

This sub theme highlights the participants' responsive approach to overcoming communication barriers and building interactive and meaningful relationships with families. The fact that the participants were able to reflect on the limitations of using informal interpreting services demonstrates their awareness and understanding of the issues involved in working cross culturally.

Summary of master theme 1

This master theme has outlined the linguistic challenges posed for service providers working cross culturally. The theme depicts the efforts made by service providers to overcome language barriers and provides insight into the major issues associated with working with interpreting services.

Master theme 2: Striving to engage

The second theme reflects a five stage process in which participants described their *'frustrations with barriers'* and struggle with initial engagement. This led to a process of reflection and attempts at trying to overcome these barriers in the form of *'accepting difference'*, *'making it work'* and *'looking for a way forward'*.

Frustration at barriers

A main challenge to the delivery of care was trying to work within family contexts, as the family unit was seen as an important part of the caregiving process for South Asian families. The family unit was seen as a successful coping strategy and cultural source of support. However, it was evident that there were tensions between the values of western services and the cultural values of South Asian families, particularly in terms of their implications for engagement:

Ben, G3: "I feel as though I'm going to have more of a battle to persuade people to accept services, the families might feel that they want to deal with the problem themselves, which is admirable but it isn't always the best thing"

Some service providers offered an understanding of the possible underlying cultural issues which could be contributing to parents desires to provide care within the family. However, on the whole staff seemed to be ambiguous as to why certain carers felt obliged to provide care within family units. For example, some service providers talked about cultural expectations and a lack of awareness:

Rachel, G1: "People might try to contain it within their own environment and there might be shame in trying to get help from someone else, they might not know that we're out here, there are all sorts of things that aren't definite just to South Asian families, it could be anyone, it's hard to know."

South Asian families were thought to cope with difficult and challenging behaviour within the family with little help from any formal services. As a result, service providers talked about this reluctance to seek help resulting in families delaying contact with services until situations reached crisis point and could no longer be contained within the family: *"The two families that I've worked with, they didn't gain input from services until it was at crisis point and then it was like 'we really need help now.'"* (Rachel, G1) Containing caregiving within the family environment meant that often service users felt unaware of the needs of South Asian families and as a result were rendered helpless in terms of the support they provided: *"... because they don't let you in, you don't know what's going on a lot of the time do you really? So if you don't know you can't do anything."* (Tom, G3)

Specifically, South Asian service providers talked about the unrealistic expectations associated with sharing the same background as families. For example, Imran below describes his experiences of working with South Asian families who believe that South Asian service providers are better able to understand their issues and the cultural context of their situation. For Imran there were expectations amongst families that service providers from the same background would share a mutual understanding of their cultural interpretations of their child's difficulties and therefore be better able to respond appropriately to their needs. The extract describes the difficulty service providers' face in dealing with these unrealistic expectations, as well as trying to work with families whose views conflict with their own:

Imran, G5: “When I see a family from a South Asian background, because you’re more culturally acceptable to them and you speak a similar language they think that you will understand them and sort their problems out better than everybody else. So they put you in this narrative that they’re misunderstood and haven’t been helped but, you are going to rescue them from all of this, which is very awkward. Often with people with learning disabilities it’s about a cure and you know everyone else who’s seen them they’ve just given them some advice, which is actually sound advice about behavioural guidelines about what to do and what not to do which is perfect, but they haven’t actually cured the person.”

Many of the service providers had succumbed to the fact that there was only so much they could do when delivering interventions to certain families. In some cases service providers accepted that they were restricted in terms of the help that they could offer which was often advice and opinion based. However, the success of the interventions was ultimately dependent upon families compliance and engagement with what was being offered: “...you can only give your opinion and your advice and then it’s down the family and the children whether they want to sort of take that on board and go with it.” (Joanne, G1)

Struggling with engagement and progress

Four groups highlighted a major challenge when working with South Asian families which was dealing with parental denial of the disability which made it difficult to engage with families and introduce successful interventions. Denial was regarded as a defence against stigma that is often attached to children with intellectual disabilities amongst South Asian communities. In these cases families were seen as actively seeking out professionals and alternative treatments such as healers in search of a diagnosis that negated the disability. For example, in the extract below a participant describes how in his experience families “run” to

find alternative interventions, highlighting an urgency which may be linked to the idea of intervening before it gets worse. Service providers talked about the “*massive*” challenge of working with families in denial and emphasised the importance of acceptance in getting parents to move forward. As described in the extract from group 5 below, this involved a slow process of “*reminding*” parents that the disability is life-long, whilst being respectful and not forcing them to abandon denial but instead allowing them to absorb information in their own time:

Imran: “They won’t accept it’s a long term condition which needs long term management...with disabilities the stigma around it is so much...you always have this run for cures, obviously they run to doctors but they also run to lots of faith healers.”

Sukhdeep: “It’s hard because sometimes when that denial is that strong they hold onto that idea.”

Zara: “I had to explain to the family I worked with what the disability is about and how it is gonna affect the family and I think deep down they knew it but it’s just they needed someone to sort of remind them and tell them.”

Imran: “I’m impressed that you’ve seen that all the way through. I’ve had much less success I have to say.”

Zara: “But that was just the one family.”

Imran: “Yeh but it’s a massive amount of work.”

Others experienced less successful engagement with families. For example, one participant described that differences in cultural responses to dealing with disability caused tensions that in some cases proved too difficult to overcome and consequently such work “*came to an end naturally*”. In such circumstances participants were left feeling unsatisfied because they had to give in to the differences. This extract highlights the struggle of trying to respect families’ beliefs whilst at the same time trying to provide help and support in keeping with service principles:

Penny, G2: "I think sometimes the work comes to an end naturally. Kind of agreeing to differ...it wouldn't help us to be confrontational all the time, but some situations would leave us feeling a bit unsatisfied at the end of the day"

It also became evident that the underlying philosophies of learning disability services could sometimes cause dilemmas for staff in everyday practice when working with South Asian families. Principles such as individuality and choice were seen to conflict with the beliefs and values of South Asian communities. For example, in the extract below one group who had experience of working in adult services explored the issues surrounding the proposed marriage of person with intellectual disabilities:

Tom, G3: "I saw a young man and the response of the family was to get him married to someone in Pakistan and to bring over his wife to look after him in the future and that was quite a different response to the way we would normally work. I think they then saw the services as being quite oppositional because we were sort of tasked with the notion of asking was he able to consent to marriage? The services get embroiled with immigration and the legal system and then you become almost tainted ...that you're blocking the way that they want to care and in many ways it seems quite logical to me what they're trying to do."

The groups concerns centred around ascertaining whether this was a family decision and whether the person themselves was able to make an informed choice and consent to marriage. Often dealing with such taboo subjects involved working outside the scope of their traditional job role and delving into legal issues surrounding the capacity to consent. Marriage was perceived as an important concept in South Asian culture and staff generally appeared to have an appreciation for the logic and rationale behind such cultural ways of responding to disability, such as providing stability of care in the future. What was clear was that participants highlighted the importance of putting the client's needs first. Often in such circumstances staff felt that they were perceived as being resistant or "*oppositional*" to

cultural responses to disability. This ultimately had negative impacts on their relationships and engagement with families.

Although the issue of marriage is something that is specific to adult services, it highlights how cultural differences and responses can cause challenges for learning disability teams. As a result, service providers feared that being viewed as “*oppositional*” could lead to mistrust and apprehensions about using services in the future. They also acknowledged that South Asian families may experience a degree of “*loss of control*” associated with feeling powerless over the decisions made about their child’s care: “*There is a massive loss of control, you know professionals step in and do things in the individuals best interests.*” (Sukhdeep, G5) This loss of control was thought to be exaggerated in South Asian communities due to additional barriers such as a fear of the unknown and language barriers.

Managing diversity

Participants’ accounts of providing culturally competent care involved a significant amount of questioning, with regards to sameness and difference amongst South Asian communities and how these two ideas fit into their work practices. For example, the staff acknowledged that assumptions and preconceptions which viewed South Asians as a homogeneous group (sameness) were important in their initial thoughts: “*Workers might have a bit of an assumption that cultural issues might be quite important perhaps thinking about religion or values, they might think about things differently to other families that I’ve worked.*” (Sharon, G1)

Simultaneously, participants talked about the heterogeneous (difference) nature of South Asian communities, which goes beyond the preconceptions and assumptions of what is believed to be typical of 'South Asian' culture. As one participant described viewing South Asians as a collective group consequently overlooked intra-group variations in religious or cultural practices, thus highlighting the need for staff to challenge their assumptions:

Jane, G3: "Sometimes we focus too much on culture and not thinking about individuals because you can have preconceived ideas about cultures and religions can't ya and not everybody's going to believe all those things or practice those things. So I think you've just gotta go in and see people as individuals."

Participants reflected on the diversity and individuality of South Asian families and made attempts to try and avoid making generalisations about them. Additionally, there was consensus amongst most groups that some of the challenges they faced, were not unique to South Asian families and instead of being labelled as culturally specific they reinforced that they had witnessed similar responses from families within the dominant culture. This felt like an attempt to avoid making generalisations about South Asian families:

Joanne, G1: "I've found similar issues in families that I've worked with who aren't from a South Asian background as well so I don't know if perhaps it is specific to South Asian culture."

The complexity of managing diversity was further highlighted in the extract below which demonstrates how factors such as acculturation can complicate ideas about sameness and difference. Acculturation refers to the adjustments and changes experienced by immigrants in response to their contact with new host countries (Berry 1997). The extract from group 3 below highlights the dangers of how fixed ideas about sameness and difference can oversimplify the experiences of South Asian families and reiterates the importance of challenging personal assumptions:

- Tom :* “Some things are retained in second generations, we talked about a client who wants to be married, his brother was obviously a very well educated man and acting partially as interpreter, he was clearly quite conservative in his attitude and the two generations (father and son), had the same goal which was to get the brother married off. So in some ways while the well educated brother was different he was also very much the same.”
- Ben:* “But that’s about the cultural beliefs isn’t it? It’s suggestive that the Asian community does have very, very strong cultural beliefs and that sort of statement wouldn’t surprise me that somebody that’s been born in this country and exposed to that still has those strong cultural links.”
- Tom:* “But you might think that somebody who’d been born in the country and been around a long time might be trying to persuade his dad to say ‘well we do it differently here’, you know what I mean?”
- Jane:* “I think that’s quite difficult though isn’t it? To say to your dad ‘let’s change everything that we believe in.’”
- Paul:* “With first and second generations, the more generations that pass it would be easier, because there’s a dilution of that culture isn’t there in many ways?”

An interesting element of this extract is how the participants passed thoughts back and forth between each other, allowing them to build on each others ideas, which enabled them to structure their thoughts and understandings about the unfamiliar topic of acculturation. What resonates throughout the extract above is the use of questioning in order to seek reassurance and elaboration from the rest of the group, which again illuminates the ambiguity and uncertainty around this issue of sameness and difference. In fact questioning was a mode of inquiry used by all of the groups in an attempt to resolve ambiguity or uncertainty within their narratives.

Making it work

All participants described having worked with families from a range of social and ethnic backgrounds and having dealt with a complexity of needs, which was made harder by the lack of resources available to them. As a result they talked about having to adopt resilient and

flexible approaches to providing culturally competent care: *“One thing about this profession (clinical psychologist) is you do keep going, you know that you’re going to come across barriers... but, you do strive to find different ways of doing things.”*(Amrit, G4)

For example, the excerpt below reveals difficulties of working with families adopting cultural interpretations and responses to disability which are very distinct from western notions:

Brigid (G1): “I went into a family and it was quite bizarre cos I wasn’t sure what was going on and they didn’t understand the child’s disability and they had their own doctor that they bought into the family to assess the child...so that got a bit bizarre and there were a lot of ceremonies that happened to cure the child, but I just kind of got used to it, that’s how they were.”

The participants use of the word *“bizarre”* highlights that viewing disability using a western cultural lens, meant that other cultures are seen as unusual or not fitting in with the normal ways of working. Participants were accepting of alternative cultural beliefs and highlighted that in general they worked holistically alongside families’ cultural beliefs and responses.

Working holistically also involved adopting a ‘family centred’ approach. For example, some participants talked about locating the power and authority within family units in order to improve service delivery: *“I think maybe you have to navigate around to see where the power and the authority is in the family.”*(Tom, G3) Additionally, other participants

identified siblings as an important means of identifying the needs of the child with

disabilities. For example, in the extract below one participant describes working collaboratively with a client’s brother in an attempt to form relationships and grasp a better understanding of the client’s needs. This collaboration seemed to work extremely well

because siblings are likely to share similar experiences in terms of their bicultural upbringing

which gives them an appreciation of the issues and conflicts for the child with disability, which the parents may struggle to identify with:

Amrit, G4: "I've found that with male clients in particular I work with their brothers because they're closer to their own generation and I actually explain to them what's going on and trying to improve the bond between the two brothers. I find that's sometimes an easier way to develop the relationships in the family through siblings rather than the parents."

Participants also acknowledged the role of larger communities in shaping the experiences of South Asian families and in the creation of stigmatising attitudes and consequently isolation of families caring for children with disabilities. One participant described having to conduct intensive confidence building with families, in order to establish relationships and counteract their negative perceptions about the disability by encouraging the exploration of more positive outlooks which focus on the child rather than the disability:

Anju, G4: "I remember some parents felt so isolated they wouldn't even come out of their house. If they were negative I had to talk about certain positives about the child, making them aware that they're still a child, they do everything like a regular child the only thing is they're slightly different."

Specifically, South Asian participants described unique experiences of working with families with whom they shared the same cultural background, in the form of cultural expectations. As illustrated in the extract below two South Asian participants discuss their experiences of working within professional boundaries whilst still trying to engage in a culturally sensitive manner. It highlights that what is considered to be appropriate engagement with clients will differ across cultures and to some degree may require adaptation and exceptions to standard practices. This extract highlights the complexity of working with South Asian families and

reinforces that sharing a cultural background does not simply remove challenges to engagement:

Imran, G5: “In people from South Asian backgrounds, it’s much more culturally normal to ask ‘which area of South Asia are you from? Are you married?’ I ought to say ‘I’m here to talk about you not me’ but it would go down so badly, that you end up disclosing a little bit.”

Sukhdeep, G5: “That’s all part of engagement. I think it feels appropriate to give a little bit, just building that relationship... I think being from a South Asian background you kind of feel it’s not a problem. I think it’d be more of a problem if I didn’t, it’d be rude.”

Looking for a way forward

Most of the participants highlighted the fact that the barriers to engagement went beyond language and often regardless of background service providers were faced with the same challenges to service delivery: *“Having more staff from the same background ...does help in terms of building relationships and understanding but in this specific area they’re still up against the same argument.”*(Jacky, G2) What became apparent through the non-South Asian participants accounts were their concerns and worries about whether they were delivering interventions in a culturally appropriate manner and fears about their lack of awareness of cultural issues which lead to concerns about getting it wrong and potentially causing offence:

Sharon, G1: “It is hard because you kind of wanna be respectful but you think ‘oh my gosh! I’m totally naïve about this’ [group agreement] and you don’t wanna get it wrong and say the wrong thing.”

Most of the non-South Asian respondents revealed a reliance on internet search engines as a primary resource for culture specific information. For example, in the extract below one participant describes using the internet and adopting a *“trial and error”* method involving

consultations with families to gain feedback about whether their style of service delivery was meeting families' needs. Additionally, although most of the participants mentioned the need for training programmes on cultural diversity, they highlighted that cultural identities were not fixed and consequently suggested that training programmes may be limited as they tend to view South Asians as collective groups:

Laura, G2: "My first thought would be to look it up on the internet. I think there's an element of trial and error, you might go back to the family and ask if it's right and invite the family to tell you about their culture. Explaining technical things in relation to the cultural issues, sometimes that's more useful than an equality and diversity course, it's far more practical, plus every family is different and these courses don't cover for that do they?"

Other suggestions included trying to increase service uptake amongst South Asian communities. Much of these suggestions involved the use of community strategies which aimed at raising awareness of learning disabilities and facilitating prevention through the promotion of earlier intervention. Both groups with South Asian participants talked about forming partnerships with local communities and community organisations in order to effectively deliver such incentives. Discussions involved raising awareness about mental health issues, mental health services and how to access them by increasing 'mental health literacy' within South Asian communities. One group stressed the importance of working with faith organisations within South Asian communities and reflected on examples of where such partnerships had been successful, such as diabetes promotion at local Mosques: *"You can't get to the mosque without tripping over twenty stalls of people telling you to stop smoking. We could do that for mental health as well. I think that would prevent things getting to such a severe crisis."* (Imran, G5) By collaborating with local communities and faith organisations there was a sense of building trust and cohesion between the community and

services, which appeared to be a crucial element in improving service uptake and breaking down misconceptions and fears within the community about accessing services.

Summary of master theme 2

This master theme has outlined the process of engagement when working cross culturally.

The theme described the major challenges and barriers presented by differences in cultural interpretations and responses to disability. Additionally, this theme describes the efforts made by participants in trying to adopt a holistic approach to working with South Asian families which considers the child with disabilities and the context in which they are situated.

Participants' narratives highlighted the willingness and effort they put in to working with South Asian families as well as their ability to understand, appreciate and accept cultural difference in an attempt to provide culturally competent care despite facing limited resources and inadequate training.

Discussion

The study provided an in-depth insight into the experiences of service providers working cross culturally in health and social care services. Although the study focused on the experiences of service providers within learning disability services, some of challenges identified are likely to be transferable to other service domains. For example, master theme one "*language as a primary barrier*" identified communication and language as a primary barrier to effective service delivery to South Asian families. These findings are in keeping with research which has identified language as a common barrier to effective engagement with health and social care services in the UK (Katbamna et al., 2001; Owens & Randhawa, 2004; Richardson et al., 2006; Jackson, 2007). Language barriers can lead to reduced service uptake and awareness, dissatisfaction with services and a reduced understanding of disability (Hatton et al., 2010; Bywaters et al., 2003). What is interesting is that the previous studies with parents did not highlight language as a major issue.

Quality interpretations have been shown to promote improved congruence in beliefs and expectations about treatment, as well as ensuring diagnostic accuracy and quality of care (Farooq, Fear, & Oyebode, 1997; Pugh & Vetere, 2009). However, interpretation is complex requiring interpreters to translate information immediately with little time to consider emotional components or issues with translation (Tribe & Raval, 2003). Often for service providers the use of interpreters introduces a new way of working in a triad, which requires adaptation and flexibility. Training has been shown to effectively increase service providers satisfaction with interpretations (Gerrish, Chau, Sobowale, & Birks, 2005; Karliner, Perez-Stable, & Gildengorin, 2004). Simple techniques such as briefing sessions with interpreters and health professionals prior to consultations have been shown to foster collaborative and

effective consultations (Tribe, 2007). Currently health and social care services have no regulated training or requirements for interpreters, which means that there is no means of assessing how accurately they can interpret information (Tribe & Raval, 2003).

Research has identified that a common challenge to providing culturally competent services is working with families holding cultural values and health beliefs which are very different from western notions and which may conflict with service principles (Summers & Jones, 2004; Hepper, 1999; Hassiotis, 1996). As outlined in the sub-theme “struggling with engagement and progress” often service providers talked about their struggle to understand these cultural differences and felt these differences made it harder for them to reach out to and support families. A key component of this “cultural difference” was the service providers’ perceptions that South Asian families prefer to provide care within their families and as a result the challenges associated with working in family contexts as outlined in the sub-theme “*frustrations at barriers*”. This notion of South Asians “caring within the family” has been challenged by recent research, which has highlighted it is an out dated and stereotypical view (Katbamna et al., 2004). Additionally, this is not in keeping with the parental narratives from Studies 1 (Chapter 3) and 2 (Chapter 4) which highlighted that they received little support from family or friends due to stigma and isolation.

Nonetheless, almost all the participants recognised the importance of family care when working with South Asian communities. Interestingly, the service users (individuals with learning disabilities) were absent from the participants’ narratives, which appears to go against the principles of learning disability services which promote “person centred planning” to which listening and responding to the service users’ needs is central. This raises questions

about the cultural transferability of principles such as “person centred planning” to contexts in which the family as a whole plays an integral role in the caregiving process.

Participants in the current study felt ill-equipped to explore and respond to families’ cultural needs for fear of causing offence and “getting it wrong”. These concerns are in keeping with other research which has demonstrated that service providers feel ill-equipped to deal with the needs of patients from culturally diverse backgrounds and tend to rely on generalisations and stereotypes to inform the way they work (Hassiotis, 1996; Owens & Randhawa, 2004; Jackson, 2007). There appeared to be uncertainty in the way participants felt they should respond to cultural difference, which centred around whether to use a homogenous or heterogeneous approach to providing culturally competent care. A strategy of treating everyone the same tends to undermine the significance of cultural differences and how they influence the delivery of care, and the reality of minority ethnic people’s lives. This appears to be a clear challenge in developing culturally sensitive services.

The study highlights the need to move beyond a reliance on expectations and assumptions and instead conduct further assessments in order to fully understand the context in which individuals and families are situated. Participants talked about having to cope with the challenges of cross cultural working on their own, learning from experience and relying on internet resources. Health and social care services need to cultivate more culturally aware services where cultural competence is seen as a part of practice. This could be achieved by incorporating ‘cultural assessments’ into care pathways, aimed at identifying the specific cultural needs of individuals and families. This could take the form of a simple checklist identifying areas to explore, such as levels of acculturation, cultural and religious values and

beliefs, as well as the role of the family in caregiving. Alternatively, it could involve more reflective multi-disciplinary team working, which could allow service providers to make formulations in teams and ask questions related to culture, as asking questions and sharing information does not require any specific expertise. In fact, one of the things that stood out about this study was the thought and effort that participants put into trying to achieve culturally competent services, as outlined in the sub themes “*accepting difference*” “*making it work*” and “*looking for a way forward*”. The group format appeared to motivate discussions, reflection and self-appraisal to evaluate working practices in relation to ethnic minorities. The group discussion seemed to shift from problem-focused talk, which focused on identifying the challenges when working with South Asian families to solution focused talk, which focused on exploring ways of working to overcome these challenges often involving adaptability, trust and patience. This insight could help inform future service development. By using more ‘experiential’ approaches to dealing with cultural issues and providing culturally sensitive care, staff could learn through direct experience and reflection.

A fundamental aspect of delivering culturally competent care is working in teams that are representative of the ethnic mix of the community they serve and as a result may be more able to identify specific needs. This may involve the inclusion of South Asian representatives in consultation forums and strategic planning to give a voice to ethnic minority communities. Recently the UK has focused on service user involvement in health and social care since the introduction of papers such as the Department of Health’s (2006) “Our Health, Our Care, Our Say: A New Direction for Community Services and the Local Government” and the “Public Involvement in Health Act” (2007). Such incentives promote the need for local authorities to inform, consult with and involve service users regarding the running of services. However,

attempts to engage service users from ethnic minority communities have been limited (Begum, 2006). It appears that more needs to be done in order to appropriately allow minority ethnic service users to fully participate in service design and delivery so that they do not experience a “loss of control” or dissatisfaction with services. This would require tackling barriers to service involvement including fear, lack of trust, language barriers and misconceptions amongst service providers that participation amongst ethnic communities is not a priority (Begum, 2006). As illustrated in the sub theme *“looking for a way forward”* working collaboratively with local communities including religious institutions could be a way to improve engagement with ethnic communities. This approach has also been recommended by the Department of Health’s (2004) “Celebrating Our Cultures” document which aims to promote mental health amongst black and minority ethnic communities in England by setting out a framework for delivering local interventions and addressing the needs of black and minority ethnic communities.

Reflections

This study has provided an alternative view to parental perspectives by exploring service providers’ experiences of working cross culturally with South Asian communities. In doing so it has shed light into some of the findings from previous studies as well as introducing some new ideas. In particular, the study has highlighted how cultural difference can create major challenges for service providers. For example, in keeping with the previous studies it has shown how culture can influence interpretations and responses to disability. Service providers’ narratives identified challenges posed when working with South Asian families who are less acculturated and for whom their personal beliefs about disability appear to go

against service principles. Such cultural differences appeared to introduce added complexity to the way in which staff work with South Asian families. This idea of difference is in keeping with the previous three studies which showed that factors such as acculturation and religion can lead to differences in experiences of disability. Despite these challenges service providers appeared to be working hard to provide culturally competent care in the face of numerous challenges, which highlights that more is needed to support them to do this. This study could only begin to explore the complex array of issues facing service providers working with South Asian families. Although the study did sample a reasonably broad range of services and staff, I appreciate that the experiences described in this study are likely to include issues that are specific to staff working in learning disability services and may also be affected by the training received. Therefore it is suggested that the findings be used as a guide to inform service delivery. It is possible that extending the study to other cultures and different staff groups may provide more insight into the experiences of service providers and help to authenticate the results.

The composition of the group discussions may have introduced the potential for ‘conflicts of interest’ since most of the group members knew each other well and their responses may have been influenced by the hierarchical nature of learning disability services, with psychiatrists often taking a lead role in service delivery. As a result some participants may have been reluctant to express their opinions in front of their peers or team leaders. Additionally, some participants may have been reluctant to share their views in fear that they may be construed as discriminatory or racist.

CHAPTER 7

Overall Discussion

Overall discussion

The thesis has highlighted some interesting areas which have received little attention in the existing literature. In particular it has demonstrated how individuals' preferred cultural stances have significant bearings on their experiences of caregiving. Uniquely, the thesis has shed light on how bicultural British South Asian parents experience and make sense of disabilities in relation to two distinct cultural frameworks (British and South Asian). It has also identified some important considerations for improving service delivery in the UK. The following section discusses the main findings of the thesis in relation to the following areas:

- How do South Asian parents make sense of their children's disabilities?
- What are the main caregiving experiences highlighted?
- What are the main implications for theoretical developments?
- What are the implications for service delivery?
- What are the recommendations for future research?

How do South Asian parents make sense of their children's disabilities?

All parents described the process of making sense of their child's delays as a journey which involved initially recognising the delays, receiving a diagnosis and trying to understand the diagnosis. The experiences of struggle and worry were prevalent in the narratives across all three studies of parents. Initially, all the parents described noticing social, emotional, and cognitive delays in their child's development. This is in keeping with literature which suggests that the most commonly noted delays are in speech and language, social responses,

medical problems, nonspecific difficulties (e.g. sleeping, eating, attention) and delays in reaching developmental milestones (De Giacomo & Fombonne, 1998; Siperstein & Volkmar, 2004). When trying to make sense of their children's delays parents have been shown to draw on cultural models and discourses of disability from a range of sources such as services, family and support groups (Skinner & Weisner, 2007). Cultural models are assumptions, values and beliefs that are shared by members of a society that can greatly influence behaviours and understandings about events (Skinner & Weisner, 2007). These cultural models act as frameworks to enable parents to make sense of their children's disabilities. For parents interviewed for this thesis, this involved drawing on expectations of normative child development, discussions with family and friends and a process of questioning and reflection. Using different means of trying to assess the severity of the delays was important to all the parents because most of them described they "*had never seen anything like it before*". This suggests it was their lack of awareness of intellectual/developmental disabilities which made it harder to recognise the initial delays. Once the delays were recognised parents searched for ways of making sense of them in relation to their own lives (Skinner & Weisner, 2007). In doing so, they pieced together different sources of information to produce their own understandings of the delays.

For parents in Study 1 (Chapter 3, focus groups, UK) and particularly those in Study 2 (Chapter 4, interviews, UK), this process of making sense of the disability was more complicated due to their bicultural influence which meant that they made sense of their children's disabilities in relation to two very distinct cultures (British and South Asian). As a result of their bicultural influence they found themselves trying to manage the complexity of dual reference points for understanding the disability. This is an area of caregiving which has

received very little attention. In fact, it appears that only one study has specifically explored how acculturation impacts the experiences of ethnic minority communities caring for a person with developmental disabilities, in the United States. For example, McCallion et al. (1997) used qualitative focus groups with African, Chinese, Haitian, Hispanic/Latino, and Korean Americans to explore the issues of caring for a person with developmental disabilities. They found that families demonstrating higher levels of integration with US culture demonstrated fewer language barriers, had better service uptake and relationships with services and were less likely to subscribe to religious or cultural explanations or responses to disability. This in keeping with the results from Study 2 (interviews, UK) which showed that younger British South Asian parents, who were generationally removed from their heritage country, showed less adherence to the traditional beliefs of their family and instead favoured western medical conceptualisations. Interestingly, even younger South Asian parents who had immigrated to the UK, focused on the benefits of being in the UK and having access to medical services and, consequently they demonstrated less-adherence to their traditional beliefs. For these younger generations there appeared to be a need to “fit in” with the British way of life so that they could support their children and ultimately access services, as was described in the sub theme *“adapting to a new culture”*.

What is particularly interesting and something that was unexpected was that the sample of parents from India (Study 3, Chapter 5) also held a preference for western discourses of disability and who consequently resisted traditional interpretations of disability. What these results demonstrate is a sense of the parents having to ‘choose’ a preferred cultural approach when making sense of their children’s delays. Often this ‘choice’ caused tension between younger parents and older South Asian family members who offered more traditional

understandings of disability which focused on religious interpretations and responses. These intergenerational conflicts have been referred to as the ‘culture conflict’ and acculturative stress (Anand & Cochrane, 2005; Berry, 2005). ‘Culture conflict’ and acculturative stress refers to the stress caused for individuals facing problems resulting from intercultural contact. When making sense of their children’s disabilities, parents from Studies 2 (interviews, UK) and 3 (focus groups, India Delhi) who demonstrated bicultural influence, described a conflict between their own personal views and those of their parents and older generations. As a result these parents’ narratives suggest that they felt older generations were not integrated enough and held misconceptions about disability which they labelled as “a lack of understanding”.

Researchers have only recently begun to explore how this double identity is managed by bicultural individuals (Robinson, 2009; Anwar, 1998). Berry (1997) proposed a framework consisting of four distinct acculturation strategies employed by ethnic minorities to manage their cultural identities which include assimilation, integration (or biculturalism), marginalisation, and separation. Assimilated and separated individuals identify with only one culture (the mainstream or ethnic culture, respectively), marginalised individuals identify with neither culture and integrated (bicultural) individuals identify with both the mainstream and ethnic cultures. However, Study 2 (interviews, UK) demonstrated that in fact there is variation in how ‘integrated’ people experience and manage dual cultural identities. In Study 2 bicultural individuals viewed their cultural identities as oppositional and contradictory in the way they made sense of disability. Although the parents identified with both cultures they highlighted the discrepancies between the mainstream culture and their heritage culture as highlighted in the sub-themes “*they just don’t understand it*”, “*there’s a stigma attached to things like disability*” and “*they have their own beliefs*”. As a result, these parents saw their

two cultures as dissociated and described a process of having to choose one over the other, which in their case was mainstream (British) culture. This dissociation of cultures has been demonstrated by other studies of bicultural identity (Phinney & Devich-Navarro, 1997; Vivero & Jenkins, 1999). This highlights the significant impact acculturation or bicultural identity can have on the caregiving experiences of South Asian families.

Interestingly, parents in Study 1 (focus groups, UK) also showed acculturative influences when making sense of their children's delays. Like the parents in Study 2 (interviews, UK), these parents also utilised medical services during the initial phase of recognising their children's delays and getting a diagnosis. However, parents in Study 1 described their dissatisfaction with services related to their struggle in getting a diagnosis and having their concerns dismissed by general practitioners as described in the subtheme "*feeling let down by services*". As a result of this dissatisfaction with the unresponsiveness of services, the parents sought out alternative interpretations of their child's condition which enabled them to "fill in the gaps" and resolve ambiguities with medical information. Consequently, these parents re-embraced their traditional interpretations of disability which centred around religious understandings of their children's disabilities. Holding multiple interpretations of disability has been demonstrated by previous research which suggests that parents may draw on numerous resources when making sense of their children's delays and in the face of ambiguity, parents will look to alternative sources of information that make more sense to them (Bywaters et al., 2003; Croot et al., 2008; Hatton et al., 1998). This suggests that interpretations are not fixed but are open to change and in fact parents exposed to two different cultures may draw upon both cultures when trying to make sense of disability.

As well as exploring parental perspectives the thesis also provides a unique detailed account of the experiences of service providers working cross culturally in learning disability services (Study 4, Chapter 6), an area which has not been studied in such detail previously. Service providers reported having to deal with a lack of acceptance of the disabilities when working with South Asian families, as was described in the subtheme “*struggling with engagement and progress*”. Acceptance was also highlighted as an important part of allowing Indian parents in Study 3 (Chapter 5) to make sense of their children’s disabilities and cope. Both service providers (Study 4, Chapter 6) and parents in India (Study 3, Chapter 5) acknowledged the enormity of accepting disability by referring to it as a “*big journey*” and service providers as a “*huge*” amount of work. For parents at the specialist service in India, this process was made easier because they received and understood the diagnosis given to them and probably because they were able to access a range of resources.

When parents receive a diagnosis of disability they are thought to progress through a series of stages including denial (Bicknell, 1983; Fortier & Wanlass, 1984) and for some this may result in them looking for alternative explanations. Dissatisfaction with the way in which the diagnosis is received can result in parental denial of the disability (Graungaard & Skov, 2007; Sloper & Turner, 1993). Parents in Study 1 (focus groups, UK) described a struggle to receive and understand the diagnosis of their children’s delays, which meant that they relied heavily on alternative religious explanations of disability. However, holding religious explanations did not lead to a denial of the diagnosis. Instead, for parents in Study 1 (focus groups, UK) religion was used as a means of overcoming their struggle to understand the diagnosis and dealing with their feelings of being let down by services. It is possible that these

alternative/religious explanations of the disability may have been construed as a lack of acceptance by service providers.

What are the main caregiving experiences described?

A key focus of the parents' narratives involved their descriptions of dealing with multiple stressors, either related directly or indirectly to their caregiving responsibilities. Stressors were identified by all three groups and included dealing with behavioural difficulties of the child, struggling to receive and/or understand the diagnosis, managing multiple responsibilities, dealing with family issues and dealing with losses. Some of these stressors however, had a more cultural focus and included stigma from the local community and facing generational conflicts. There is a body of research which suggests that parents of children with intellectual/developmental disabilities are likely to experience significantly more stress than parents of typically developing children (Baker et al., 2003; Hauser-Cram et al., 2001; Dumas et al., 1991; Emerson, 2003). Some research suggests that carer psychological distress is elevated in South Asian communities (Hatton et al., 1998; Chamba et al., 1999; Emerson et al., 2004). These studies suggest that lower socio-economic status amongst ethnic minority communities tends to lead to poorer psychological outcomes for these families.

Models of parenting stress have been proposed to understand how parents caring for children with intellectual/developmental disabilities adapt to stressors through the use of coping strategies. A recent review paper (Hill & Rose, 2010) identified a number of parenting models which have been applied to intellectual/developmental disabilities, which include the Double ABCX Model (McCubbin & Patterson, 1983); the Transactional Model of Stress and Coping

(Lazarus & Folkman, 1984); a Two Factor Model of Psychological Well-Being (Lawton, et al., 1991) and the Model of Parent-Child Interactive Stress (Mash & Johnston, 1990). One commonly applied model across all intellectual/developmental disabilities domains is Lazarus and Folkman's (1984) Transactional Model of Stress and coping. This model suggests that the way in which a situation is appraised and the resources available to a family, will determine how stressful an event is and how well they cope. The model assumes that coping is composed of both behaviours and emotions which help to manage the negative emotions. Some of the most commonly used coping strategies include problem-focused coping, emotion-focused coping, social support, religious coping, and cognitive reframing. Some coping strategies have been shown to lead to better psychological outcomes than others. For example parents adopting escape avoidance strategies have been shown to report more stress and poorer mental health than parents using positive reframing strategies (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings, Kovshoff, Brown, Ward, & Degli, 2005).

The notion of coping is important in the caregiving process due to the numerous physical and emotional demands placed on carers. It is important to identify the types of coping strategies used by caregivers and their success in alleviating stress so that future and ongoing services can be tailored to meet their needs. The following section will explore how parents in the current research coped with their caregiving responsibilities and the influence of culture on coping. We know little about how South Asian parents in the UK cope with the stressors of caregiving. However, we know that religion plays a prominent feature in their understanding (Fatimilehin & Nadirshaw, 1994; Katbamna et al., 2001; Katbamna et al., 2004; Bywaters et al., 2003) which has been shown to be a coping strategy (Durà-Vilà et al., 2010). Coping

strategies will vary from individual to individual and are likely to differ for individuals demonstrating different levels of acculturation.

Parents in Study 1 (focus groups, UK) demonstrated a strong retention of their heritage cultural values and consequently, they used religion as a means of appraising and coping with their children's intellectual/developmental disabilities and their caregiving responsibilities. Additionally, culture was seen not only to impact on the parents' attributions about a cause, but also shaped other people's attitudes towards the disability. Consequently, religion led to both positive appraisals for the parents (e.g. God's will, test from God) and negative appraisals from family and friends (e.g. punishment from God). This is in keeping with literature into the area which has demonstrated that religion plays a central role in South Asian carers understandings of disability and in the creation of stigmatising attitudes (Dobson et al., 2001; Fatimilehin & Nadirshaw, 1994; Katbamna et al., 2004). Framing experiences in religious ways has been shown to provide parents with a means of making sense of their experiences, but can also aid the grief process and can lead to acceptance and coping (Thomas et al., 2004; Hatton et al., 2003; Durà-Vilà et al., 2010). The parents in Study 1 also used avoidance coping strategies such as ignoring negative comments in an attempt to deal with the stigma they faced from local communities. Both religion and avoidance can be regarded as emotion focused coping strategies. The fact that these parents relied on emotion focused strategies is likely to be a reflection of the limited resources available to them. For example, these parents reported receiving little support from services and family/friends and consequently reported feeling isolated.

In comparison parents from Study 2 (interviews, UK) showed signs of acculturative differences in their appraisals of the disability and the way in which they coped. Interestingly, the parents in Study 2 (interviews, UK) used problem focused strategies during the initial process of recognising and getting a diagnosis of the disabilities which focused on seeking out medical help. However, these parents reported using emotion focused strategies to manage the emotional stresses and strains of caregiving which, involved “*getting on with it*”. This is interesting because it was these parents’ narratives that demonstrated the highest caregiver burden in the form on multiple stressors such as, behavioural difficulties of the child, dealing with losses, managing household responsibilities, dealing with stigma and acculturative stress. Overall, these parents seemed to be coping least well, which is reflected in the fact that they had the least positive narratives when describing their experiences. Despite the fact that they were accessing services, they felt unable to manage the considerable challenges they faced on a daily basis. The use of emotion focused strategies such as “*get on with it*” tend to provide temporary relief but do not effectively help make the caregiving burden more manageable. This highlights that the parents clearly need more help in managing their children’s challenging behaviour.

Parents in Study 3 (focus groups, Delhi) provided the most positive descriptions of their caregiving duties. Their narratives highlighted the use of problem focused coping strategies from the offset. For example, they appeared to have adopted problem focused strategies during the initial recognition of the delays which concentrated on getting access to specialist services that they needed, as described in subtheme “*making a commitment to get help*”. The ability of these parents to adopt problem focused strategies and services may have been influenced by the fact that they were well educated (to at least degree level or more) and came

from socio-economically well off backgrounds. This may have made it easier (in particular financially) for them to break away from their extended families and seek out relevant interventions. This is in comparison to the parents in Study 1 (focus groups, UK) and 2 (interviews, UK) who were less educated and from working class backgrounds. This leads to questions about the influence of context of caregiving responses.

Additionally, acceptance played a crucial role in allowing parents in Study 3 (focus groups, Delhi) to come to terms with their children's difficulties and ultimately to cope. These parents described a three stage process of coping which involved firstly "*accepting the child and the disability*", secondly, "*regaining control as a parent*" and thirdly "*seeing a change*". These parents seemed to have made the best adjustments to caregiving which may be due to the fact that they received an array of support from the specialist service in Delhi. This appeared to provided them with the skills and confidence to manage their children's behavioural difficulties. This included problem focused strategies which involved drawing on medical and psychological principles (e.g. Applied Behavioural Analysis, TEEACH) which guided their treatment and management of their child's disabilities. However, they also utilised social resources (e.g. support groups) as well as positive reframing which focused on the acceptance and inclusion of their children into mainstream society. This suggests that coping strategies may be greatly influenced by the types of resources that are available to parents, which is in keeping with stress and coping theory (Lazarus & Folkman, 1984).

In comparison parents from Studies 1 (focus groups, UK) and 2 (interviews, UK) appeared to be coping on their own with very little support from family or friends. The mothers described being responsible for the bulk of the caregiving responsibilities and felt isolated due to the

stigma of local communities which is in keeping with literature (Chamba et al., 1999; Fazil et al., 2002; Katbamna et al., 2004). However, these results are not consistent with the service providers' narratives in Study 4 (Chapter 6). Instead, their perceptions were that caregiving within a 'family context' was a prominent feature of caregiving for South Asian families as described in sub theme "*frustrations at barriers*". This may have been an assumption of the service providers, which has been highlighted by research exploring the experiences of staff working cross culturally (Hassiotis, 1996; Owens & Randhawa, 2004; Jackson, 2007). However, it might be that the service providers had mistaken the fact that South Asian families coping on their own, using emotion focused coping strategies, as being indicative of the fact that they prefer to cope within family contexts. This is important because misconceptions can lead to the needs of parents being underestimated and their ability to cope overestimated.

What are the main implications for theoretical developments?

When considered as a whole the results from the thesis introduce some new ideas in terms theoretical developments about caregiving. They suggest that parents across the three studies moved back and forth between incompatible cultural positions when making sense of their child's disability. This idea introduces a new dimension to Berry's (1997) model which moves beyond viewing the stages of acculturation as linear and identifying people as belonging to a certain group. Instead, the results of the thesis show that parents negotiated and reproduced cultural stances on disability in relation to their context which included interactions with other people and services and in relation to their own understandings of disability.

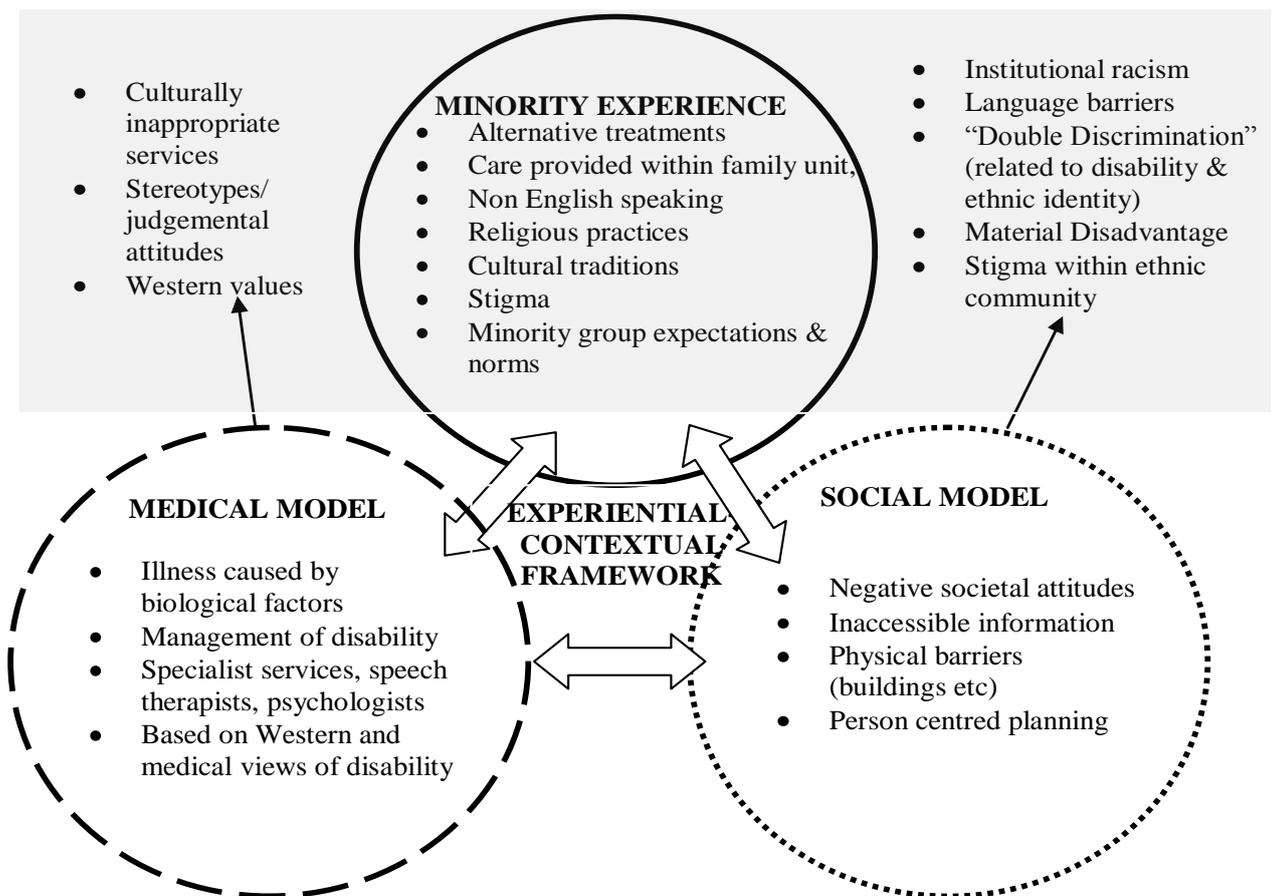
The thesis has also provided insight into the resources and coping styles used by South Asian parents of children with intellectual/developmental disabilities, an area which has received little attention. The thesis views Lazarus & Folkman (1984) stress and coping model from a cross cultural perspective. For example, the thesis suggests that South Asian parents' experiences are embedded in socio-economic and cultural contexts both of which appeared to be influencing coping. In the current research the socio-economic context included aspects such as education, ability to speak English and affluence. Socioeconomic disadvantage appeared to be linked to a greater level of unmet needs (due to limited resources) and as a result less positive coping amongst parents. For example parents in Study 1 (focus groups, UK) and 2 (interviews, UK) were socio-economically more disadvantaged (working class, less educated) than the Indian parents in Study 3 (middle class, well educated) and their narratives highlighted more dissatisfaction with services (Study 1) and greater caregiver related stress (Study 2). These results seem to suggest that socio-economic advantage may give parents more opportunities and choice for seeking out alternative interventions and treatments, as was the case for parents in Study 3 (focus groups, Delhi) and consequently may lead to more positive and problem focused coping.

The research demonstrates the need to consider the interaction between culture, belief and context in order to understand the experiences of South Asian families. These experiences can be viewed in terms of a newly proposed experiential-contextual framework (Heer et al., 2012). The experiential-contextual framework (Figure 7.1) integrates three models of disability (minority, medical and social) and examines the role they play in creating a context for shaping the experiences of South Asian families caring for children with disabilities in the UK. The framework examines how context (contextual) can relate to people's experiences

(experiential) of caregiving to children with disabilities. In doing so it provides a more holistic view of understanding the complexity of experiencing disability in multicultural societies.

Figure 7.1

An experiential-contextual framework of disability*



***Adapted from:** Heer, K., Rose, J. & Larkin, M. (2012): Understanding the experiences and needs of South Asian families caring for a child with learning disabilities in the United Kingdom: An experiential–contextual framework. *Disability & Society*. doi:10.1080/09687599.2012.699276

The model suggests that South Asian families will ultimately be influenced by their minority community contexts and the way in which their own community recognises and responds to learning disabilities (Skinner & Weisner, 2007). This is encompassed as the “minority experience”. They will also be influenced by social factors such as poverty, class and discrimination which are covered in the social model. Finally, the families will also be influenced by their interactions with healthcare systems, which predominantly operate under a medical model. This framework demonstrates a large overlap between three models of disability (medical, social and minority) in terms of their influence in shaping the experiences of South Asian families. The experiential-contextual framework provides a basis for services and practitioners to better understand ethnic families within a wider socio-cultural context. It provides a means of assessing what factors may be important for service providers to consider when working cross culturally. Thus, it avoids making assumptions and stereotypes based on cultural or religious identity alone.

What are the implications for service delivery?

Literature suggests that South Asian families caring for an individual with intellectual/developmental disabilities report negative interactions with services (Azmi et al., 1997; Chamba et al., 1999; Hatton et al., 2010). This is in keeping with the results from Study 1 (focus groups, UK), in which parents described “*feeling let down by services*”. Similarly, service providers in Study 4, in particular South Asian service providers, described their struggle to deal with the unrealistic expectations South Asian families had of them.

However, it is important to stress that parents in Studies 2 (interviews, UK) and 3 (focus groups, Delhi) reported less dissatisfaction with services which suggests that acculturation and adopting western interpretations of disability may lead to more successful interactions with services. As a whole, the findings of the studies in the thesis highlight some key challenges to providing culturally competent care to South Asian communities, which included:

- Poor communication between service providers and South Asian parents demonstrating lower levels of acculturation.
- Language discordance between service providers and service users
- Service providers feeling ill-equipped to deal with cultural diversity
- Parents struggle to understand and in some cases receive a diagnosis
- Preference amongst South Asian parents to cope with the challenges of caregiving on their own, and often as a result of no acceptable support
- Conflicts between parental understandings and responses to disability and, service principles

As was demonstrated in Study 4 (Chapter 6), service providers appeared to be working hard to provide culturally competent care within their limitations as outlined in the sub-themes “*making it work*” and “*looking for a way forward*”. An important aspect of the service providers’ narratives were their attempts to understand cultural differences between themselves and South Asian families. These differences were described as nuanced and complex. It is clear from the studies with parents that there is much diversity in how South Asian groups understand and cope with the experiences of caring for a child with

intellectual/developmental disabilities. This highlights the importance for services to understand how these factors interact with health and social care services and either prevent or enable people from getting help. Service implications will now be considered in terms of three broad areas:

Identifying different cultural needs

Cultural diversity was one of the factors highlighted in the current thesis and the need for services to move beyond a reliance on expectations and assumptions of working with ethnic minorities. In order to do so, services need to gather information from a range of sources in order to understand the context in which individuals and families are situated to explore their positions in terms of cultural preference. This could be achieved by incorporating cultural assessments into care pathways. This could take the form of verbal or written assessments which aim to explore individual positions on factors such as religious beliefs, languages spoken, role of family and acculturation which has been discussed in detail in the discussion section of Study 4, Chapter 6. It may also help to do an assessment of the resources available to parents in order to identify how effectively they are likely to cope and introduce new resources if they are limited.

Working with cultural difference

Service providers showed a good appreciation of the way in which cultural factors shaped the health beliefs and behaviours of South Asian families. However, they felt ill-equipped to deal with these cultural differences due to limited resources and inadequate training. Therefore, a

key implication for services is to equip service providers with the tools and skills to manage these factors. This could be achieved by integrating 'cultural competence' training into normal practice rather than viewing it as a stand alone aspect which usually involves service providers attending a short cultural diversity course. By incorporating cultural competence into professional development for example, it could become an on-going process of development and enable service providers to keep up to date with the changing cultural needs of ethnic minority groups. This would make sense given that the thesis has highlighted that cultural identity is not fixed and instead, is constantly changing as cultures are being integrated and exposed to new ideas and beliefs from other cultures. Therefore, it makes sense that services keep up to date with these changes. As well as implementing cultural competence into practice, it is also important to have means of evaluating the efficacy of such incentives, for example through the use of service provider and user feedback.

The results have highlighted that culture plays a role in shaping the understandings and experiences of South Asian families, especially their understandings of disability and their adaptations. The research demonstrates that older South Asian parents (Study 1, focus groups, UK) who demonstrated less integration into British culture tend to adopt traditional cultural approaches, with religion playing a central role in the way in which they conceptualise disability. Therefore, bicultural individuals demonstrating more integrative strategies may show a preference for western approaches. It is important for services to understand how these cultural differences interact with health and social care services. This is important because research demonstrates that parental beliefs surrounding the aetiology of disabilities greatly influence whether they choose to engage with treatment and interventions (O'Hara, 2003).

This highlights the need for services to consider the cultural orientation of ethnic communities in order to implement and deliver culturally appropriate interventions.

Services could utilise a multi-dimensional approach encompassing both the medical and traditional understandings. In doing so, service providers would need to adopt flexible approaches which encourage the exploration and sharing of cultural views of learning disabilities in a non-judgemental manner, so that families feel understood. Services could draw on the therapeutic qualities of religious explanations in allowing parents to better cope and deal with the challenges of caregiving. Doing this could promote more collaborative relationships and ultimately lead to better engagement. Study 4 demonstrated that although service providers recognised the religious and cultural interpretations of South Asian families, they did not feel they possessed the right skills to deal with these factors in a sensitive enough way. Therefore, such an approach would require training to provide professionals with the cultural competencies to make them confident in exploring these alternative views in a sensitive manner. An obvious method would be through formal teaching and training. However, alternative techniques such as reflective practice may be more appropriate and lead to more helpful insights in particular for staff working closely with families in their homes. This could be in the form of group supervision during which staff collectively reflect on case studies and share examples of effective ways of working collaboratively with families from ethnic backgrounds, thus utilising an “experiential” model of learning (as has been described in the discussion section of Study 4, Chapter 6).

An interesting part of the service providers (Study 4) narratives were their reflections on working with culturally diverse communities and thinking about new ways of working, as described in the sub-themes *“looking for a way forward”*. One of the key ideas identified was

to create stronger links with the community in order to improve engagement with hard to reach ethnic communities, currently underrepresented in services. This seems very relevant considering that many learning disability services in the NHS are community based services. Yet it appears that these services are disengaged from some local communities that require their support, such as South Asian groups. Therefore, it appears that community services need to expand their relationships with community groups (e.g. religious institutions) so that they can effectively deliver culturally competent, community orientated services. Creating an environment which embraces and celebrates diversity (e.g. celebrating cultural/religious holidays) could help to break down misconceptions and miscommunication between services and South Asian communities. This approach has also been recommended by the Department of Health's (2004) *Celebrating Our Cultures* document which, aims to promote mental health amongst with black and minority ethnic communities in England by setting out a framework for delivering local interventions and, addressing the needs of black and minority ethnic communities. This would be one way of breaking down the barriers which lead to families "*feeling let down*" by enabling services to build bridges and reconnect with communities. It may also be a means of reaching out to individuals demonstrating lower levels of integration into mainstream society. It could also enable families to access much needed support rather than coping on their own and thus avoid leaving situations to reach crisis point before getting help from services. This concept of engagement has been identified as an important part of working with South Asian communities by the service providers in Study 4 but also something which the research process and recruitment has highlighted.

Overcoming Language barriers

As the service providers in Study 4 suggested, one of the major challenges to working with South Asian families was dealing with language and communication difficulties, as described in the master theme “*language as a primary barrier*”. Surprisingly, parents in Study 1, for whom English was not their first language did not report any difficulties with language barriers. This is likely to be due to the fact that these parents reported having interactions with service providers from the same ethnic backgrounds (as they described in the sub-theme “*feeling let down by services*”) and therefore, language was unlikely to have posed a major problem. This demonstrates that efforts will have been made by services to culturally match service providers to ensure linguistic demands were met.

However, parents in Study 1 (focus groups, UK) described a preference for white service providers, highlighting the importance of exploring individual preferences of service users and not just assuming people would prefer support from someone of the same background. Additionally, the fact that parents in Study 1 did not mention language barriers, may be linked to the fact that these parents would have been engaged with services for a long period, as is suggested by the children’s ages which ranged from 7-19 years old. Therefore it may be that extended exposure to services meant that these parents found ways of overcoming potential language barriers (e.g. through the use of interpreters, family members or ethnically matched service providers) and therefore they were not such an issue. However, for service providers, working with interpreters or family members as interpreters, poses an on-going challenge which may explain the differences this study found.

South Asians in the UK speak a wide range of languages. However, there is no data identifying the number of people speaking a particular language. Language has been identified as a barrier to service uptake and delivery of specialist disability services (Bywaters et al., 2003; Raghavan, 2009). Currently the NHS has no regulated training or requirements for interpreters, which means that there is no means of assessing the accuracy of information exchange between service users, service providers and interpreters (Tribe & Raval, 2003). Only the legal system in the UK has official requirements of interpreters which specify that they must have some formal qualifications to indicate that they are able to interpret at an acceptable standard (The Law Society). This usually means that they are required to have passed the diploma in public service interpreting (DPSI). Similar prerequisites could be utilised by health and social care services, especially as the diploma already exists and includes an option of training to ‘interpret within the context of health and local government’. Additionally, the diploma offers mental health add-ons which aim to train interpreters to deal effectively with the challenges of interpreting in mental health contexts, with a particular emphasis on working with healthcare professionals and accurately conveying sensitive information between professionals and patients. As well as requirements of interpreters, it may be beneficial for service providers to have access to training courses which enable them to obtain the skills necessary to work in a triad. Finally, something which was not highlighted by the participants but which could be important is to ensure that written information is also accessible to South Asian communities in their preferred language, so that parents have access to the information they need.

The Government have recently stressed a push towards encouraging people from ethnic minority communities to learn English thereby giving them the resources to help themselves

move out of a cycle of marginalisation and deprivation (The Smith Institute, 2011). This is in keeping with what was mentioned earlier in relation to more positive coping being linked to socio-economic advantage and higher acculturation in the current research. It is likely that this will lead to cuts in the amount of funding available for interpreters and translators, which could have a negative effect on older generations who are less acculturated.

Recommendations for future research

The following section makes recommendations for future research based on the findings of the thesis.

Given that the thesis identified how culture shapes caregiving experiences. It would be interesting to explore how the process of acculturation shapes caregiving experiences using a quantitative design. This would expand on the current qualitative research and enable more solid conclusions to be drawn from larger samples and data sets. For example, a potential study could use acculturation scales which measure the following:

- Engagement in culturally specific behaviours, such as music, diet, and media
- Proficiency in, use of, and preference for the English language
- Knowledge of culture specific history and current events
- A sense of cultural identity
- Adoption of and belief in culture specific values

Using such acculturation measures alongside psychological assessments of coping and distress (such as the Shortened Ways of Coping, Revised, Questionnaire (SWC-R), Hatton & Emerson, 1995); and the General Health Questionnaire (GHQ), which has been validated for use with Indian samples in the UK (Jacob, Bhugra, & Mann, 1997), would enable an exploration of the way in which families cope with caregiving to a child with intellectual/developmental disabilities. In this way using Lazarus and Folkman's (1984) model as a framework would enable an exploration of the appraisals and resources parents draw on in order to cope with the demands of caregiving. Alongside the measures of acculturation this would help to identify if there is a causal link between culture and coping styles employed as well as identifying which appraisals lead to more positive coping.

The current research has demonstrated the positive impact services such as the one in Delhi can have through the use of eclectic behavioural interventions. However, the efficacy of such interventions in learning disability services and across cultures in the United Kingdom is less well developed. Therefore, one recommendation would be to employ such strategies in the UK. Preferably, this would employ a randomised control trial (RCT) design if funding and resources were unlimited or a smaller scale follow-up study. This would allow an exploration of whether such interventions are effective in reducing stress in parents caring for children with intellectual/developmental disabilities over a long period of time.

The current research involved a religiously diverse sample of parents including those from Muslim, Sikh and Hindu backgrounds. These religious differences may have led to some differences found across the groups in terms the way in which they made sense of and coped with their children's disabilities. However, due to the small sample

size and qualitative nature of the research it is not possible to infer any definite conclusions about the role of religion. Therefore, another recommendation would be for future research to try and tease out the role religion might play in shaping care giving experiences by recruiting a large and religiously diverse sample across which comparisons can be made.

Additionally, it might be interesting to explore the views of parents who have just entered services and therefore have younger children. These parents may have very different experiences of caregiving and hold different perspectives of service providers. Additionally, they may be able to give a different view of how language barriers affect their interactions with services. This could potentially be conducted as a longitudinal study following the same parents at entry level and at various follow-ups (e.g. five year intervals). However, given the struggles to recruitment faced in the current study, both recruitment and retention of participants would need serious consideration in such a large scale study.

One way of overcoming challenges to recruitment might be to incentivise participation in the research. This may be achieved by using monetary incentives. The issue of monetary payments for participants is a controversial area in terms of whether it is ethically correct to pay participants. Overall, studies suggest that payment is likely to increase willingness to take part in research (Bentley, 2004; Singer & Kulka, 2002). For example, a review of 292 randomised control trials found that monetary incentives doubled participant response rates (Edwards et al., 2002). Other researchers have stressed the ethical concerns the use of payments introduces in terms of informed consent and the likelihood of participants feeling coerced to take part regardless of risks involved (Russell, Moralejo, & Burgess, 2000).

Bentley (2004) suggests that payments can impact the integrity of research as participants may behave differently (introduce bias) as a result of receiving payment. Head (2009) suggests that when used in qualitative research, payments should have a fair return. Additionally, she stresses the need to make participants aware that payments are for attendance and participation and withdrawal is still voluntary. Other studies have found that participants stressed the need for more recognition of their time and effort in the research process rather than payment of fees (Russell, et al., 2000). This suggests that more participatory research such as action research may be a better approach to engaging participants.

Dissemination of the results

Appendix Z (page 317) outlines how the results of the research have been disseminated through publications and presentations.

Summary

This thesis explored the cultural context of caregiving amongst South Asian parents caring for children with intellectual/developmental disabilities in the United Kingdom, an area which has received little attention in the existing literature, as reflected in chapter 1 (introduction). The current study therefore set out to fill this gap. This was achieved by conducting a series of interviews and focus group discussions with parents and service providers in order to provide a detailed insight into the needs of South Asian families. This identified how cultural identity can shape the understandings and adaptations of British South Asian families caring for a

child with intellectual/developmental disabilities, and the implications this has for service delivery.

Study 1 (Chapter 3), set out to explore the experiences of a group of British South Asian parents caring for children with intellectual/developmental disabilities. The findings corroborated existing literature by highlighting the importance of religion and culture in the interpretations of, and responses to, disability. This study identified high levels of dissatisfaction often expressed with regard to ‘unresponsive’ services.

Study 2 (Chapter 4) expanded on some of the issues highlighted by parents in the previous study, through the use of in-depth interviews with parents. This provided a unique insight into how culture shapes the understandings and the adaptations of South Asian carers.

Acculturation and the parents struggle to manage two conflicting cultures were identified as influencing the caregiving experiences of South Asian parents. This further adds to the complexity of South Asian experiences of caregiving and, suggests that more acculturated British South Asians are likely to face a unique set of pressures, something which has received little attention in the area.

Study 3 (Chapter 5) was a cross cultural study exploring the perceptions of a group of mothers caring for children with intellectual/developmental disabilities at a specialist service in India. The results demonstrated a similarity to those of parents in study 2, again reinforcing the role of cultural identity in determining the way in which families make sense of and respond to disabilities.

Finally Study 4 (Chapter 6) explored the experiences of service providers working with South Asian families in the UK. In doing so it elucidated the ways in which service providers address the challenges of working with ethnic communities in a culturally competent manner. The results highlighted some similarities between the influence of culture and religion on the interpretations and responses of South Asian families and the enormous impact on families caring for a child with disabilities.

Ultimately the research has generated important knowledge using participants' lived experiences to enhance understanding of South Asian carers' experiences of caring for a child with intellectual/developmental disabilities in the UK.

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APPENDICES

Appendix A: Checklist for critically appraising quantitative articles (links to chapter 1)*

Area of critical appraisal	Criteria	Research paper										
		Chilaka et al. 2001	Durá-Vilà et al. 2009	Emerson et al. 1997	Emerson et al. 2004	Emerson 2007	Hatton et al. 1998	hatton et al. 2003	Hatton & Emerson 2009	McGrother et al 2002	Morton et al. 2001	
Truth value	Extraneous variables	<i>Extraneous variables identified</i>	✓	✗	✓	✓	✓	✓	✓	✓	✓	✗
		<i>Extraneous variables controlled in analysis</i>	✗	✗	✗	✓	✗	✗	✗	✗	✗	✗
	Ethics	<i>Informed consent stated</i>	✗	✗	✗	✗	✗	✗	✓	✓	✗	✗
		<i>Ethical review undertaken</i>	✗	✓	✗	✗	✗	✗	✓	✓	✗	✗
Applicability	Rationale	<i>Statement of purpose</i>	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
		<i>Objective stated</i>	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Design	<i>Description of setting under which data collected</i>	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
		<i>Design stated explicitly</i>	✓	✓	✗	✗	✓	✓	✓	✓	✓	✗
	Sample	<i>Participant recruitment described</i>	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
		<i>Study population defined</i>	✗	✓	✓	✓	✓	✓	✓	✗	✓	✗
		<i>Source of subjects stated</i>	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
	Missing data	<i>Statement about non-respondents</i>	✓	✗	✗	✗	✓	✗	✓	✗	✗	✗
		<i>Missing data addressed</i>	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
		<i>Power calculation to assess adequacy of sample size</i>	✗	✗	✗	✗	✗	✗	✗	✗	✗	✗
	Statistical analysis	<i>Satistical procedures described</i>	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
		<i>p values stated</i>	✓	✓	✗	✓	✓	✓	✓	✓	✓	✗
		<i>confidence intervals given for main results</i>	✓	✓	✗	✓	✗	✗	✓	✓	✓	✗
		<i>Data collecting procedures described (e.g. Instruments)</i>	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
TOTAL		12	11	9	12	12	11	15	13	12	7	
RATING		Silver	Silver	Silver	Silver	Silver	Silver	Gold	Gold	Silver	Silver	

* Based on the following article: Sale, E.M. and Brazil, K., 2004. A strategy to identify critical appraisal criteria for primary mixed-method studies. *Quality and Quantity*, 38, pp.351-365.

Appendix B: Checklist for critically appraising qualitative articles (links to chapter 1)*

Area of critical appraisal	Criteria	Research paper							
		Azmi et al. 1997	Hatton et al. 2010	Hensel et al. 2005	Hepper 1999	Katbamna et al. 2002	Mir & Tovey 2003	Raghavan & Waseem 2007	Summer & Jones 2004
Sensitivity to context	<i>Description of study context/setting</i>	✓	✗	✓	✗	✓	✗	✓	✓
	<i>Statement of purpose & rationale for using qualitative methods</i>	✓	✓	✓	✓	✓	✓	✗	✓
	<i>Consideration of existing literature on the topic</i>	✓	✓	✓	✓	✓	✓	✓	✓
	<i>Recognition of challenges to recruitment</i>	✗	✗	✗	✗	✗	✗	✗	✗
Commitment & rigour	<i>Use of triangulation (multi perspectives; more than one method; more than one person to analyse data)</i>	✓	✓	✗	✗	✓	✓	✗	✗
	<i>Appropriateness of sample size</i>	✓	✓	✓	✓	✓	✓	✓	✓
Transparency & coherence	<i>Use of quotations</i>	✓	✓	✓	✗	✓	✓	✗	✗
	<i>Description of participants</i>	✓	✓	✓	✓	✓	✓	✓	✓
	<i>Description of recruitment process</i>	✓	✓	✓	✗	✓	✗	✓	✗
	<i>Details of data collection</i>	✓	✓	✓	✗	✓	✓	✓	✗
	<i>Audiotaping/transcription details</i>	✓	✓	✗	✗	✓	✓	✗	✗
	<i>Data analysis described</i>	✓	✓	✗	✗	✗	✓	✗	✗
Ethical considerations	<i>Informed consent stated</i>	✗	✗	✗	✗	✗	✗	✓	✗
	<i>Ethical review undertaken</i>	✗	✓	✗	✗	✓	✗	✓	✗
Impact & importance	<i>Research introduces new ideas/findings</i>	✓	✓	✓	✓	✓	✓	✓	✓
TOTAL		12	12	9	5	12	10	9	6
RATING		Gold	Gold	Silver	Bronze	Gold	Silver	Silver	Silver

*Based on the following article: Sale, E.M. and Brazil, K., 2004. A strategy to identify critical appraisal criteria for primary mixed-method studies. *Quality and Quantity*, 38, pp.351-365; Yardley, L., 2000. "Dilemmas in qualitative health research." *Psychology and Health*, 15, pp.215-228.

Appendix C (page 1 of 9): Summary table of the core articles identified in the literature search (links to chapter 1)

Article and Author	Aims	Sample	Method of data collection	Method of data analysis	Key findings	Critical review
Listening to adolescents and adults with intellectual disabilities (ID) from South Asian communities Azmi et al. 1997	To explore the experiences of South Asian adolescents with ID in relation to important aspects of their lives	<i>n</i> = 21 South Asian adolescents and adults with ID Age = 14-44 yrs Sample = ID Ethnic groups = Pakistani, Gujarati, Bengali and Indian	Unstructured interviews, using an interview schedule based on previous research.	Content analysis	<ul style="list-style-type: none"> • Strong and positive ethnic and racial identities • Reported satisfaction with home and family circumstances • Reports of experiencing racism and stigma • Experiences of double discrimination due to race and disability • Limited social activities due to discrimination 	GOLD
Knowledge of Down syndrome in pregnant women from different ethnic groups Chilaka et al. 2001	To explore the awareness and understanding of Down syndrome in a cohort of women receiving antenatal care	<i>n</i> = 245 women Age = 17-41yrs Sample = Down syndrome Ethnic groups = Asians born in the UK and Asians born outside of UK	Self-report questionnaire consisting of three areas: demographic information; knowledge of Down syndrome; perceptions of information received. Translated where necessary.	Chi squared analysis of significance	<ul style="list-style-type: none"> • Quality of spoken English affected knowledge • Sources of information included GPs; midwives; hospital; friends; magazines • Christians had better knowledge than other religions • In Asian group Hindus had better knowledge than Sikh and Muslim groups 	SILVER
Ethnic variation in service utilisation among children with intellectual disability Durá-Vilá et al. 2009	To examine whether ethnicity or culture influences service utilisation amongst families of children with intellectual disabilities	<i>n</i> = 242 children Age = 7-17 yrs Sample = mild and moderate ID Ethnic groups = not specified in methods	Survey of teacher reported ethnicity and service usage. Using teacher reported survey collecting demographic details, information regarding diagnosis and ethnicity.	Regression analysis	<ul style="list-style-type: none"> • Higher usage of community based social services and respite among black communities • Lowest service usage among South Asian communities – possible reasons included more family support and parental belief systems 	SILVER

Appendix C (page 2 of 9): Summary table of the core articles identified in the literature review (links to chapter 1)

Article and Author	Aims	Sample	Method of data collection	Method of data analysis	Key findings	Critical review
<p>Is there an increased prevalence of severe learning disability (LD) among British Asians?</p> <p>Emerson et al. 1997</p>	<p>To explore the prevalence of severe learning disability among Asian communities in the UK</p>	<p><i>n = 221 people with LD</i></p> <p><i>Age = 0-45yrs</i></p> <p><i>Sample = LD</i></p> <p><i>Ethnic groups = Asian (originating from Indian sub-continent) and non Asian</i></p>	<p>Study comprised of two parts: Part 1 – Asian people with LD identified through multiple sources, including making contact with a range of services. Part 2- Asian and non Asian people with LD identified through a pre-existing case register.</p>	<p>Use of population figures from Census to calculate prevalence rates</p>	<ul style="list-style-type: none"> Increased prevalence of severe learning disabilities among Asian community among people aged 5-34 yrs old 	<p>SILVER</p>
<p>Levels of psychological distress experienced by family carers of children and adolescents with intellectual disabilities in an urban conurbation</p> <p>Emerson et al. 2004</p>	<p>To identify factors associated with the level of psychological distress reported by family carers of children with intellectual disability living in an urban conurbation</p>	<p><i>n = 1319 children</i></p> <p><i>Age = 5-16 yrs</i></p> <p><i>Sample = moderate/severe or complex learning difficulty</i></p> <p><i>Ethnic origin = South Asian (primarily Pakistani) or non-South Asian (primarily White)</i></p>	<p>Postal questionnaires sent to carers (where English was the first language) or structured interviews (where English was not the first language)</p> <p>Questionnaire comprised of demographic profile; Adaptive Behaviour Scale-School Version); Developmental Behaviour Checklist and GHQ-12.</p>	<p>Postcodes & index of multiple deprivation used to determine deprivation.</p> <p>Non-parametric bivariate analysis and binary logistic regression.</p>	<ul style="list-style-type: none"> 47% of carers scored above the threshold for psychological distress on the GHQ and this was linked to emotional and behavioural needs of child, ethnicity and severity of child's delay in communication Strong association between South Asian ethnic identity and carer psychological distress 	<p>SILVER</p>

Appendix C (page 3 of 9): Summary table of the core articles identified in the literature review (links to chapter 1)

Article and Author	Aims	Sample	Method of data collection	Method of data analysis	Key findings	Critical review
The association between area-level indicators of social deprivation and the emotional and behavioural needs of black and South Asian children with intellectual disabilities in a deprived urban environment Emerson et al. (2007)	To explore the impact of social context on the emotional and behavioural needs of children with intellectual disability from black and South Asian backgrounds.	<i>n</i> = 386 South Asian & 118 black children with ID <i>Age</i> = 5-19 yrs <i>Sample</i> = ID <i>Ethnic groups</i> = Pakistani, Indian, Bangladeshi, Kashmiri, Sikh, Gujarati, Caribbean and African	<i>Cross-sectional survey</i> of teacher reported emotional and behavioural needs (using background questionnaire; Adaptive Behaviour Scale AAMR; Nisonger Child Behaviour Rating Form N-CBRF; postcodes and index of multiple deprivation).	<i>Multivariate methods</i> (binary logistic regression) to look for associations and mann-whitney U to look for differences between groups.	<ul style="list-style-type: none"> Higher rates of emotional & behavioural needs among black children For black children increased deprivation led to increased need & for South Asian children increased deprivation was associated with decreased need 	SILVER
Informal carers of adolescents and adults with learning difficulties from South Asian communities: Family circumstances, service support and carer stress Hatton et al. 1998	Explore South Asian carers perceptions of family circumstances, service support and levels of stress	<i>n</i> =54 carers from South Asian backgrounds <i>Age</i> = 22-68 <i>Sample</i> = Learning Difficulties <i>Ethnic groups</i> = Pakistani, Bangladeshi, Indian & East African	<i>Structured Interviews</i> (including Disability Assessment Schedule; Client Service Receipt Inventory and Malaise Inventory)	Descriptive statistics & multiple regression	<ul style="list-style-type: none"> Greater material disadvantage amongst South Asians Lack of awareness of specialist services, despite high need for such support Difficulties with language barriers and neglect of cultural and religious needs led to dissatisfaction with services 	SILVER

Appendix C (page 4 of 9): Summary table of the core articles identified in the literature review (links to chapter 1)

Article and Author	Aims	Sample	Method of data collection	Method of data analysis	Key findings	Critical review
<p>The disclosure process and its impact on South Asian families with a child with severe intellectual disabilities (SID)</p> <p>Hatton et al. 2003</p>	<p>To explore the disclosure experiences of South Asian families caring for a child with SID</p>	<p><i>n</i> = 162 carers</p> <p>Age = not specified</p> <p>Sample = SID</p> <p>Ethnic group = Pakistani, Bangladeshi, Indian and East African</p>	<p>Mixed methods (26 semi-structured interviews and 136 structured quantitative interviews)</p>	<p>Quantitative statistics and thematic analysis</p>	<ul style="list-style-type: none"> Poor disclosure experiences reported due to language barriers and lack of post disclosure support 	<p>GOLD</p>
<p>Does socioeconomic position moderate the impact of child behaviour problems on maternal health in South Asian families with a child with intellectual disabilities?</p> <p>Hatton and Emerson 2009</p>	<p>To determine whether socioeconomic position moderates the relationships between child behaviour problems and mental health in South Asian families caring for a child with ID</p>	<p><i>n</i> = 123 South Asian mothers</p> <p>Age = 22-63 yrs</p> <p>Diagnosis = ID</p> <p>Ethnic groups = Muslim, Hindu and Sikh mothers</p>	<p>Cross sectional survey design (using a range of assessments such as caregiver information questionnaire; Malaise Inventory; Clinical Interview Schedule)</p>	<p>Univariate analysis (Pearson's correlations, t-tests)</p>	<ul style="list-style-type: none"> No association between socioeconomic position and child behaviour problems and parental health Associations found between child behavioural problems and parental anxiety, depression and self-reported health, which was moderated by socioeconomic position 	<p>GOLD</p>

Appendix C (page 5 of 9): Summary table of the core articles identified in the literature review (links to chapter 1)

Article and Author	Aims	Sample	Method of data collection	Method of data analysis	Key findings	Critical review
Majority and minority ethnic family carers of adults with intellectual disabilities: perceptions of challenging behaviour and family impact Hatton et al. 2010	To explore majority and minority ethnic family members perceptions of challenging behaviour	<i>n</i> = 14 families <i>Age</i> = 33-70 yrs <i>Diagnosis</i> = ID <i>Ethnic group</i> = Muslims, Hindu and Christians	<i>Semi-structured interviews</i>	<i>Interpretative phenomenological analysis</i>	<ul style="list-style-type: none"> • 4 main themes identified • All families reported difficulties associated with the behaviour of the person with intellectual disabilities • Minority ethnic families experienced reduced human capital (related to a limited understanding of ID & inability to speak English) as well as reduced support from services and social groups • Combined these factors resulted in reduced well-being and family functioning 	GOLD
Impact of policy shifts on South Asian carers in the United Kingdom Hensel et al. 2005	To explore how new service policies in the UK impact the lives of people with ID from South Asian backgrounds.	<i>n</i> = 19 families <i>Age</i> = 30-75 <i>Diagnosis</i> = ID <i>Ethnic group</i> = Indian, Pakistani, Bangladeshi and British Asian	<i>Semi-structured interviews</i>	<i>Thematic analysis</i>	<ul style="list-style-type: none"> • Families experienced disadvantage, poor health and low service uptake • Little evidence that policies had impacted the lives of families • Culture of caring and protecting person with ID within family context often conflicted with service principles 	SILVER

Appendix C (page 6 of 9): Summary table of the core articles identified in the literature review (links to chapter 1)

Article and Author	Aims	Sample	Method of data collection	Method of data analysis	Key findings	Critical review
<p>“A woman’s heaven is at her husband’s feet?” The dilemmas for a community learning disability team by the arranged marriage of a Bangladeshi client with intellectual disability</p> <p>Hepper 1999</p>	<p>To explore the social and cultural factors influencing decision making in ethnic minority groups and the challenges this presents to learning disability services</p>	<p><i>n = 1 case study</i></p> <p><i>Age = 27 yrs</i></p> <p><i>Sample = ID</i></p> <p><i>Ethnic group = Bangladeshi</i></p>	<p><i>Case study</i></p>	<p>Detailed description from a single case report</p>	<ul style="list-style-type: none"> • Dilemmas posed for services included bridging cultural differences • Insight into the cultural and social factors that can influence decision making 	<p>BRONZE</p>
<p>Supporting South Asian carers and those they care for: the role of the primary health care team</p> <p>Katbamna et al. 2002</p>	<p>To explore the role of primary health care teams in supporting carers from British South Asian communities</p>	<p><i>N = 105 carers</i></p> <p><i>Age = 20 + yrs</i></p> <p><i>Sample = multiple and complex disabilities</i></p> <p><i>Ethnic groups = Pakistani, Gujarati, Bangladeshi and Punjabi</i></p>	<p>Focus groups & interviews</p>	<p>Framework approach</p>	<ul style="list-style-type: none"> • Failure to recognise carers needs • Lack of information on services & provision • Dissatisfaction with GP consultations • Language & communication barriers 	<p>GOLD</p>

Appendix C (page 7 of 9): Summary table of the core articles identified in the literature review (links to chapter 1)

Article and Author	Aims	Sample	Method of data collection	Method of data analysis	Key findings	Critical review
Prevalence, morbidity and service need among South Asian and white adults with intellectual disability is Leicestershire McGrother et al. 2002	To compare prevalence rates of intellectual disability, psychological morbidity and service usage among South Asian and white adults in Leicestershire, UK	<i>n</i> = 2256 people with ID, 206 South Asian and 2334 white carers <i>Age (of people with ID) = 20 + yrs</i> <i>Sample = ID</i> Ethnic group =South Asian (no specific ethnicities or religions identified)	<i>Cross-sectional study</i> comprised of two parts. Part 1 – analysis of prevalence based on data from all South Asian and white adults known to the Leicestershire learning disabilities register in 1991. Part 2- structured interviews using the disability assessment schedule.	<i>Logistic regression analysis and chi squared</i>	<ul style="list-style-type: none"> • Similar prevalence rates between South Asian and white adults with ID • Similar psychological morbidity between South Asian and White adults with ID • Lower usage of psychiatric services, residential care and respite care amongst South Asians 	SILVER
Asian carers' experiences of medical and social care: the case of cerebral palsy Mir & Tovey 2003	To explore the experiences of South Asian carers caring for an individual with cerebral palsy	<i>n</i> = 20 carers <i>Age = not specified</i> <i>Sample = cerebral palsy</i> <i>Ethnic groups = Pakistani & Indian (Muslim, Sikh & Hindu)</i>	Semi-structured interviews	Framework approach	<ul style="list-style-type: none"> • Parental views of causation differed from medical explanations • Lack of material & emotional support can lead to negative constructions of cerebral palsy • Religion provided a means of support and enabled carers to deal with uncertainty 	SILVER

Appendix C (page 8 of 9): Summary table of the core articles identified in the literature review (links to chapter 1)

Article and Author	Aims	Sample	Method of data collection	Method of data analysis	Key findings	Critical review
Disability in children from different ethnic populations Morton et al. 2001	To explore the prevalence of neuro-disability in children in Southern Derbyshire	<i>n</i> = 1454 children <i>Age</i> = up to 19 yrs <i>Sample</i> = SID <i>Ethnic groups</i> = Indian, Pakistani, black Africans, Chinese and Bengali	<i>Quantitative</i> : Child development centre records used to obtain data regarding the incidence of different disabilities in different ethnic groups. Number of children with different disabling conditions recorded as well a measure of the level of disability.	Qualitative analysis used to determine prevalence of particular types of disability in certain ethnic groups	<ul style="list-style-type: none"> • Higher incidence of severe learning disorder, severe hearing loss, severe visual problems, autism and cerebral palsy amongst Pakistani children • Genetic related disability found to be ten times more common in Pakistani communities- linked to consanguineous marriage practices 	SILVER
Cultural diversity and intellectual disability Raghavan et al. 2004	Review paper exploring cultural diversity and intellectual disability	n/a	Review of research papers published from January 2001 to March 2004.	n/a	<ul style="list-style-type: none"> • High prevalence of ID in ethnic communities • Experience of stigma, isolation & racism • Lack of cultural sensitivity in service delivery and negative attitudes of service providers 	n/a

Appendix C (page 9 of 9): Summary table of the core articles identified in the literature review (links to chapter 1)

Article and Author	Aims	Sample	Method of data collection	Method of data analysis	Key findings	Critical review
Services for young people with learning disabilities and mental health needs from South Asian communities Raghavan & Waseem 2007	To explore the beliefs and perceptions of family carers from Pakistani and Bangladeshi communities about the problems and issues in accessing appropriate services	<i>n</i> = 35 young people with LD <i>Age</i> = 14-25 <i>Sample</i> = Mild, moderate and severe LD <i>Ethnic origin</i> = Bangladeshi and Pakistani	Qualitative, semi-structured interviews	Not specified – themes generated	<ul style="list-style-type: none"> • Higher usage of mainstream & GP services • Low uptake of specialist services for behavioural/mental problems • Barriers to accessing services included lack of knowledge and awareness of services, language barriers and lack of culturally appropriate services. 	SILVER
Socio-cultural studies of families of children with intellectual disabilities Skinner & Weisner 2007	To review socio-cultural studies of families of children with ID in terms of methodological, conceptual and theoretical contributions	n/a	Literature review (details of literature search not provided)	n/a	<ul style="list-style-type: none"> • The advantage of using sociocultural studies to explore a more experiential and holistic view of families beliefs and adaptations 	n/a
Cross-cultural working in community learning disability services: clinical issues, dilemma and tensions Summers & Jones 2004	To determine the issues raised for community learning disability teams when providing culturally sensitive services	<i>n</i> = 3 case studies <i>Age</i> = not specified <i>Sample</i> = moderate LD <i>Ethnic groups</i> = Pakistani	Case studies	Description & exploration of issues arising from cases studies	<ul style="list-style-type: none"> • Issues with regards to power differentials between professionals and families (related to gender & culture) • Conflicts present between service values & cultural values/beliefs 	SILVER

Appendix D (page 1 of 10): Worked Interview Transcript (links to chapter 2)

Participant 5: Kulbir

Duration: 47 mins

Child: Serena

1 I: Ok so first can you tell me a little about Serena, what type of things she has and what type of behaviours she has?

2 Kulbir: Serena has a learning disability and it's really hard with her, so [pause] it's more no understanding with Serena, *struggle of looking after her*

3 so it's different with the normal and the special kids. *her lack of understanding - 'Different' as hard*

4 I: So when you say different, how? *identifying difference between normal + special kids*

5 Kulbir: Different like er, Serena is really, the normal kids more understanding, so Serena doesn't have understanding, she *'Don't know' 'don't understand' - limited to mums fears and concerns about safety of child in public or on her own!*

6 doesn't know about safety how to keep herself safe, that's the different with normal kids and the special ones. *'Different' - normal v's special child's lack of "doesn't know" fears about*

7 No road safety, she doesn't know, she doesn't know how to cross. She doesn't know what's hers, it's mine or *- mums concerns about safety the world and what's acceptable!*

8 some ones else, you know what I mean? That's the difference. *Difficulties with basic social knowledge!*

9 I: Are there any other things that are different?

10 Kulbir: Different er, like she can't go to the shop on her own. I can't leave her at home alone and things, I have to keep *- inability to do things on own*

11 her with me, all the time, keep with me, to keep an eye on her like and things like that. *- Dependence on mother - leads to dependence on mother - mum not wanting to risk leaving child alone for fear of consequences.*

12 I: Are there any differences at school?

13 Kulbir: School, the school people say she's really good at school. Behaviour really good at school, at home really *- Difference in child's behaviour at school + home*

14 opposite (I: Oh really) yeh so...she's not good at home, her behaviour problem. She's very stubborn, very *- Disruptive behaviour*
Disruptive behaviour in the home.

1

Handwritten notes on the left margin:

- STRUGGLING WITH CHILD'S LACK OF UNDERSTANDING
- COMPARISON TO OTHERS
- FEARS AROUND SAFETY
- STRUGGLING WITH CHILD'S LACK OF UNDERSTANDING
- OVER PROTECTIVE BEHAVIOURS
- STRUGGLING TO MANAGE DISRUPTIVE BEHAVIOURS IN THE HOME

Appendix D (page 2 of 10): Worked Interview Transcript (links to chapter 2)

SEEKING EXTERNAL SUPPORT WITH DISRUPTIVE BEHAVIOUR	15	stubborn at home, she don't listen, then she gets angry and loose her temper and break things, I told Sue as well	- Disruptive behaviour in the home! - Seeking external help!
	16	(LD nurse) she's dealing with the case.	Seeking external help to deal with problematic / challenging behaviour.
	17	I: Ok so you said learning disability, how did you find out that Serena has this?	
FEELING LUCKY: COULD'VE BEEN WORSE	18	Kulbir: Serena, when she was born, the hospital, like she didn't eat or drink, because she born with caesarean, I had a	
ACCEPTANCE OF LIFELONG CONDITION	19	caesarean, so they said she doesn't look well to us, and then they took all the tests and then they sent her to	- Had child tested early - early identification
	20	Birmingham hospital and they checked her there and she's got a chromosome missing, number 46 and then we	- genetic disorder - aware of details of genetic disorder
	21	found out, they said you are really lucky that she's hasn't lost her [inaudible][2.46]. It had an affect on her brain,	- acceptance of it being a lifelong condition
	22	that's why she is like this, so that's for life (I: Right so it's for life) it's for life hhm.	- acceptance of lifelong condition She has come to terms with this
GRIEF OVER THE LOSS OF NORMAL CHILD	23	I: So when you found out, how did you {feel?}	what they expected! - upset by the fact that her daughter isn't normal like her other children
	24	Kulbir: {Really upset} like my son was normal no problem with my son and my younger daughter she was normal too,	- comparing this child against others - emphasises on normal v/s 'special'
	25	and they said one out of a million children are like this. Then they took both of our blood tests, my husbands and	- genetic screening - natural causes
SEEKING GENETIC SCREENING	26	mine and they were normal, and they said it's natural with Serena. So they checked everything. When she was	
	27	born she can't hear, everything developed late. Everything late, like speaking she's only just started talking when	- Delays - mums own observations of signs of delays.
SIGNIFICANCE OF TIME: LATE DEVELOPMENT	28	she was seven, six, seven and she walked late, everything was late. She's behind, like she's fourteen, she acts like	- despite physical appearance brain age is small.
	29	she's four or five years old. That's the problem Her teacher was saying the same thing, she said it looks like she's	- comparing child to younger daughter - not able to understand as much as her!
COMPARISON TO OTHER CHILDREN	30	big but she isn't, like she said she's the same as my little daughter, but the little one still understands but Serena	- importance of time - 'late'
	31	doesn't and that's the problem.	
	32	I: And then did you find out quite quickly when she {was little?}	
	33	Kulbir: {Yes, we} found out when she was little and then they sent Serena to playgroups and then afterwards they sent	
	34	her to hospital classes for children. And then there's a school in X area, she used to go there for a couple of years	

Appendix D (page 3 of 10): Worked Interview Transcript (links to chapter 2)

35 then afterwards she go to X and then after that they kept checking her and to see if there'd been any
 36 improvement, that's it really.

37 I: And when you started getting concerned who did you go to?

38 Kulbir: When I got worried? (I: Yeh) hospital, I was worried what's wrong, and then they sent us to a doctor, the hospital
 39 doctors sent us a letter saying that they're sending us to a hospital in Birmingham for a check up and then slowly,
 40 slowly we kept going to a playgroup and we said we need a social worker, we need support for Serena and then
 41 they, you know the child benefit for disability? (I: Yes) they started giving us that. We didn't know if could get
 42 anything or not, we don't know and they told us to fill in the forms and that we have a right and we can get it.
 43 Then we started getting the money and then the hospital people asked the school what problems she has, and
 44 then we started getting carers, carers allowance. I said to them, I said what are we going to do with the money?
 45 We just want our child to be right, I'm happy with the kids you know what I mean? They should be normal, no
 46 problem. Now, she gives too much hassle, I can't leave her alone everywhere, now I can't trust anyone, you
 47 can't trust no-one, so I have to keep her with me. What am I going to do with money? If your child is ok then
 48 that's all the money you need isn't it? That's the problem, I was upset but it's ok, then my social worker said, she
 49 was explaining to me look other children are worse off, you are still lucky that Serena can walk and get about. She
 50 recently had her period, it was really hard, I can't handle it, it was really heavy and like it would last for a week to
 51 ten days. I would have to change the pads and everything, the clothes would be dirty and she doesn't know
 52 where to change the pads and then she would go into her brothers room and he would get angry, what is she
 53 doing in my room, you know what I mean? So that's why she doesn't know what I should do and what I shouldn't
 54 do. She change her clothes in front of everyone. - Child can't comprehend what's right + wrong
 55 Have you tried telling her or?

Handwritten notes on the transcript:

- Top left: why no trust? - incidents like those guys in the car?
- Top right: This mum wants her freedom, has struggles with caregiving but at the same time wants to be in control - doesn't trust anyone to look after her child! - responsibility to care? "Mrs Lopez, 3 "I have to do it!"
- Left margin notes:
 - PERSISTENCE IN SEEKING OUT SUPPORT
 - DIFFICULTY NAVIGATING SERVICE SYSTEMS
 - SEEKING HELP FROM A VARIETY OF SOURCES
 - GRIEF OVER THE LOSS OF A NORMAL CHILD
 - STRUGGLING TO COPE WITH PERMANENT DEPENDENCE OF CHILD
 - THE IMPORTANCE OF TRUST
 - FEELING LUCKY?
 - DIFFICULTIES MANAGING SOCIAL-SEXUAL DEVELOPMENT
 - DISRUPTION TO FAMILY LIFE: SIBLING CONFLICTS
- Right margin notes:
 - being persistent + maintaing uptake of services / appointments in order to receive help!
 - Story of how support received through networking + asking!
 - met knowing about entitlements - having to be having to seek out information from various professionals find out
 - wanting a normal child - regret / loss / what could have been - would more less hassle!
 - Problems trusting people to care for her child wanting to be in control - looking for relief - comparing to worse situations
 - Difficulties of managing period - Difficulties with things that a normal child could - impact on siblings - anger
 - Child can't comprehend what's right + wrong
 - mum finds that hard! manage like changing pad or having a bath.
 - Social - sexual development is a problem. She doesn't know what's appropriate + what's not!
 - Impact on other members of family, her behaviour causes tension, stress amongst family members?
 - can't leave child alone - continuous!
 - can't trust no-one, so I have to keep her with me.

Appendix D (page 4 of 10): Worked Interview Transcript (links to chapter 2)

56 Kulbir: To Serena? {I: Yeh} Yeh I explain every day. She forgets, she, like if I say to her Serena, I'm going to the children's

57 centre, she keep reminding me, keep saying, we going to children's centre, children's centre you know what I

58 mean? So I say Serena shut up, she doesn't listen to me, you know what I mean and then start getting angry and I

59 say Serena be quiet. She can't take it, like, and she gets more angry when you say to her stop, she gets worse. — rebellious.

60 She starts doing it more. — can't make her stop — struggling to manage challenging behaviours — made harder by her lack of understanding!

61 I: And then for your, because you have to look after her how does it feel?

62 Kulbir: It was really hard for me, I hadn't seen anything like this before, it's the first time in my family anyway. I said

63 what's happened to her? Like my son is fine and we are fine then how did she get this problem? Then the doctor

64 explained he said don't worry you lucky they said, she's still ok, she could've lost her arm, leg anything could have

65 been damaged, but it affected her brain they said. — comparison to children worse off provides relief. It's always others that this like doc or social worker!

66 I: And how do you feel, why do you think this happened to Serena?

67 Kulbir: The doctors said like affect, like the blood cells you have, some of them are missing in her which is why she is like

68 this, She can't get better but as she gets older, a little bit will get better but not so much. She won't be a normal

69 child, her learning disability is for all life. — acceptance of lifelong condition, acceptance that she won't be normal — but still throughout transcript sense of regret, longing for normal child.

70 I: How did you feel when they said it's (for life?)

71 Kulbir: {I was shocked} really upset, I was crying in my home, and she's got a bowel problem (I: Bowel problem, in the

72 stomach?) in the stomach, they said she could get cancer. They took her to Birmingham, they checked

73 everything, every couple of months and they said everything inside is ok. We took her, this year, was it this year?

74 Yeh I think it was this year. We took her there to get her checked and they put a camera inside her, to see if it's

75 ok, they wanted to check it hasn't grown inside, they keep checking, they have to keep checking. She had a lot of

76 constipation when she was born and they gave her medicine to make her go to the toilet, she still takes that,

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Handwritten Notes:

- STRUGGLING TO MANAGE DISRUPTIVE BEHAVIOURS
- STRUGGLING TO UNDERSTAND
- QUESTIONING LACK OF FAMILY HISTORY
- FEELING LUCKY - COULD HAVE BEEN WORSE
- DRAWING ON MEDICAL EXPLANATIONS AS A CAUSE
- ACCEPTANCE OF LIFELONG CONDITION
- INITIAL SHOCK + SADNESS
- DEALING WITH ADDITIONAL HEALTH
- Difficultly coping with behaviours!
- (annoying behaviours!)
- you can't understand it, because it's unexpected, not seen before
- First experience — never seen before makes it harder —
- Difficulty making sense of something never experienced before!
- Initial questioning of why it happened?
- seeking explanations — no family history
- relief / coping worse off!
- comparing to children why? Trying to make sense of it!
- reliance on medical explanations for a cause, seeking information to help make sense of it!
- acceptance of lifelong condition
- shock at re-ascertainment of LD.
- Additional health problems!

Appendix D (page 5 of 10): Worked Interview Transcript (links to chapter 2)

more demands on mum, harder because she is the sole caregiver! - stress!

FEELING HELPLESS

EMOTIONALLY OVERWHELMED

STRUGGLING TO MANAGE CHALLENGING BEHAVIOURS:

MORAL/MATERNAL RESPONSIBILITY TO CARE

LOSS OF OWN LIFE

WANTING A BREAK

FRUSTRATIONS WITH PERMANENT DEPENDENCE OF CHILD

DISRUPTION TO FAMILY LIFE: ARGUMENTS

INITIAL SHOCK OF FAMILY AT DIAGNOSIS

SIGNIFICANCE OF TIME: FAMILY ADJUSTMENT WAS A SLOW PROCESS

77 hmm, you're always worried really. What can we do with this type of child? If they can't look after themselves

78 Really upset, really upset to tell you the truth, it's really hard to handle her, sometimes she makes me cry, she

79 used to do that, hmm. - struggle in handling coping with disruptive behaviours. Overwhelming - upset by difficulty / struggle of managing challenging behaviours. Overwhelming - leads to crying. - used to has she know learnt to cope?

80 I: So when it's like that (Kulbir: Emotional) how do you cope?

81 Kulbir: I say Serena I'm going [laughs] you stay here, I say I'm going Serena, I'm not coming back home now, you stay on

82 your own and then she start crying, can't go. She uses F words you know, swearing, you have to, I have to do it,

83 no point, there's no other point [You have to look after.] I said to my husband I need a break, you know I never

84 been, I haven't been anywhere since I've been here because of her. I've been to India with her but, I've never

85 been anywhere else and I said I need a break myself. I said I need time as well for myself you know what I mean?

86 All the time she is with me everywhere, whenever we go somewhere she's with me, it's like she's put a spell on

87 me, like they say magic, she's always with you [laughs] do you know what I mean? And then he gets angry as well,

88 my husband sometimes, I said, you know what I mean, you know what men are like. Are you single sorry?

89 like she's missed (husband's anger!) out on aspects of her own life due to continuous - ongoing demands of care-giving. loss of own life!

90 [laughter]

91 Kulbir: Guys think like that you know what I mean, so that's the problem.

92 I: So when your husband found out about the learning disability how did they feel?

93 Kulbir: He was shocked as well, everybody was shocked when we found out, so all shocked, what's happened here? So

94 that's it really, slowly, slowly we got settled. But first of all we felt it a lot, when she wasn't walking, wasn't

95 talking, wasn't eating and things. I was from India as well so I don't know what has happened, I don't know

96 myself, I was young when I came here, I don't know what, what lifestyle is like here you know what I mean?

more demands on mum, harder because she is the sole caregiver! - stress!

- feeling helpless? - lack of independence, ability to care for themselves biggest struggle

Questioning what to do? - linked to lack of awareness / experience of disability

Questioning what to do with child inability to look after themselves - hardest part for mum

Threatening to leave - jilted

'You' and 'I' - almost as though - third person - like she's telling herself - 'you' have to do it - no other choice

wanting a break from caregiving to recover, away from stress

continuous role as caregiver - wanting a break -

feels like she has no time for herself - always has her daughter by her side!

everybody's shocked - again questioning how, why, trying to make sense of it!

Questioning what's happened

shock of others when they found out!

Initial delays impacted family 'We'

caregiving made harder because she's from India - having to find out about lifestyle - being young!

adapting family life was a slow process, restoring normality!

age and being from a different country made it harder when she first found out about diagnosis. Trying to adapt to a new country and then told child has disability makes process harder! - harder to understand disability!

Appendix D (page 6 of 10): Worked Interview Transcript (links to chapter 2)

BEING PROACTIVE IN GETTING HELP

SEEKING HELP FROM A VARIETY OF SOURCES

GETTING SUPPORT AS A SLOW PROCESS

PERSISTENCE IN SEEKING HELP

OVERCOMING INITIAL HARDSHIPS IN SEEKING SUPPORT THROUGH PERSISTENCE

THE IMPORTANCE OF TRUST

SERVICES OFFER SOME RELIEF

STRESS AS PERMANENT

97 I: So how did you find out?

98 Kulbir: About what?

99 I: About things and lifestyle here and what kind of help there is?

100 Kulbir: When you go to hospital they tell you, there's this and that, she will get this. When I took her to playgroup they

101 told me you will get this and this. I sent the forms, did everything told them that my daughter has a problem and

102 they said you will get money for this, carers allowance that's it then slowly, slowly and then I got support from

103 my social worker. She told me there's a holiday grant, that I will get that, they told me I will get that and she

104 helped me apply. They give you that every year. And then the carers support team helped me with a lot of things,

105 she helped me. Slowly, slowly I kept meeting with people and then slowly I got the support. (Slow process, kept going - having to build relationships with different people / organisations)

106 I: Did you find it quite easy getting support?

107 Kulbir: At first really hard, when you start, but then you get to know each other. Then you get trust, that there is

108 somebody to help you. Then we used to take her to X clinic, cos she really can't hear properly, they said we have

109 to do an operation. There was quite a few problems when she was little. Hmm. - slow health problems

110 I: And how do you find it now? takes time, slow process, but does work!

111 Kulbir: Yeh it's better, a little bit better, if someone supports you then it is better, you can say yeh I have support, no

112 problems. support helps a little, provides some relief - like emotional talking to social worker etc!

113 I: Is there less pressure?

114 Kulbir: Pressure is the bloody same [laughs] that's not going to go down is it? It's with me all my life, if you think about it.

Handwritten notes:

- utilising different resources to access information + support!
- Proactive, being vocal, having to be proactive + get involved
- slow process - having to be persistent + patient
- she accessed alot of support - from variety of places not just one!
- perseverance
- importance of forming relationships with staff - trust? she mentions building relationships with staff not alot! important for her!
- description of building relationships with staff / developing trust - hard at first having to persevere!
- not feeling alone, isolated!
- feeling supported - helps 'a bit'
- 'Pressure' stress - doesn't go away - lifelong!
- support doesn't remove stress! - stress/pressure will remain throughout life - why? because daughter's condition is lifelong as well!

Appendix D (page 7 of 10): Worked Interview Transcript (links to chapter 2)

115 I: Can you tell me a bit about the pressure, what type it is, because I don't know what it's like to everyday look after?

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117 Kulbir: Really hard ^{co-regiving is 'really' struggle word} actually, you know what I mean? She comes from school, when she comes from school she starts straight away, I wanna do this, I wanna do this, I want to go out. That's it Serena, sometimes I can't take it, I've got a little one as well, and when she gets one thing in her mind she sticks with it, I want to go, I want to go, now, I want to go now, you know what I mean? She doesn't stop. Keep saying, keep saying, she do my head in. Then that's it, things like that. She listens to her music, really loud music and er when she little I think er [pause] yeh I think she was seven, eight, she must be eight, I think we'd just, moved here, in this house, she was about eight and she caught a bus. She put her things in a bag, she likes weatabix, we were all asleep. She went and stood at the bus stop {I: In the night?} no in the day, 8 o'clock, I think it was about 10 o'clock, we were asleep and she got her things she said "I'm going, to my Granddads house" my father in laws, she wanted to get the bus herself and the next door white woman came and she told me, she said "I saw Serena with the carrier bag, where's she gone?" I said "I don't know" she said "I got panicked and thought I'd tell you because you probably don't know". I told my social worker and she said "oh my god" {I: Did she catch the bus?} no the white woman came and told me, so we bought her back {I: Oh yeh thank god, did you try and ask her why she went?} "I want to go" she said "On holiday, I want to go on holiday". That's just dangerous, that's why they put on safety locks, the social worker did it, she said then she can't open them. That's the problem, like this.

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132 I: So you feel like every time...

133 Kulbir: You have to watch her, you can't ever leave her alone, you can't leave her alone. You can't leave her with anyone. You have to trust somebody and then you can, otherwise not. So there's a lot of pressure, always.

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135 I: And when she goes to school?

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Appendix D (page 8 of 10): Worked Interview Transcript (links to chapter 2)

(relief from services)
RELIEF WHEN CHILD IS AT SCHOOL

CONSTANT WORRY OVER CHILD'S SAFETY

INEFFECTIVE STRATEGIES

WANTING TIME ALONE

WANTING RELIEF FOR CAREGIVERS

FEELING RESTRICTED BY

WANTING TIME ALONE

CONSTANT STRESS

WANTING TIME ALONE

136 Kulbir: I get a little relief, it's safety. Do you know what I mean? When she goes to school, the teachers will be there. So I
 137 know she's at schools there's safety, when she comes back home it starts again, that's it really. At school she's
 138 occupy, they have a timetable for everything, I can't give her a time table, I can't do a time table you know what I
 139 mean? When you come home from school do this, do that, things to do. I told the teachers, schools different too
 140 many teachers there, they can cope, I said how can I cope on my own? Really hard. I have other things
 141 housework everything. Lots of things really. *Difficultly following or maintaining interventions we timetable, routines planned at school. Having to do other household tasks! - overwhelmed by juggling caregiving home things*

142 I: So what do you think can help you the most?
 143 Kulbir: I think, in the house like what can I say? I think, I think they need to, the children that are like this, they need to
 144 send their parents on holiday, in a group, for a week, honestly for a week, we need it, I need a break for myself. *- can't replicate school environment! - difficulty coping / managing on her own - caregiving as well as other domestic things to do.*

145 They look after kids and then they send parents holiday. What do you think?
 146 I: I think it's a good idea.
 147 Kulbir: No I think, honestly, I want this, they need to do this, I can't go, otherwise can't go You know what I mean? They
 148 need a break. I need a break. *tried to get her husband* I told my husband last week I said I need a break myself you know what I mean?
 149 Too much pressure, all the time same things, listen, keep listening. I said the kids need a break and they take
 150 them, they take the kids for one week. We still don't get a break, no break. They look after kids then I can go.
 151 I: Do you use respite care? *Wanting relief from continuous pressure - stress of caregiving repetitive, ongoing nature of caregiving, behaviours - hard to cope*

152 Kulbir: Yeh my social worker told me, Serena didn't like it. She doesn't like respite. She went, they said they'll try it again
 153 because she's older it might be different, feeling different. They can stop over at night or they keep them during
 154 the day time and tea time and then they come home. It depends. I think they need to do this. I mean every year
 155 actually they need to do this, honestly, they need to send the parents on holiday Take the stress off. That's it we
 156 need relief. *relief!* don't know, if they will do it or not. *Time away from caregiving and child*

school provides relief from worrying about her safety!
So she's constantly worried at home about child's safety - very stressful!
school provides relief - mum can stop worrying about her safety!
Desperately wants a break - exhausted, tired, frustrated with caregiving! - feeling restricted unable to have a break without help / support from external services why? so she can but then not worry about safety!
Stress relief in the form of a holiday - break, change away from repetitive, constant caregiving

Appendix D (page 9 of 10): Worked Interview Transcript (links to chapter 2)

RESTRICTIONS TO OWN LIFE
CAREGIVING AS A FULL TIME JOB
FEELING OVERWHELMED

FEELING RESTRICTED - WANTING TO WORK

WANTING HER OWN LIFE

STRAINS ON FAMILY
DISRUPTIONS TO SIBLINGS LIVES

FEELING CAUGHT IN THE MIDDLE OF FAMILY DISPUTES

CONCERNS ABOUT YOUNGER SIBLING IMITATING DISRUPTIVE BEHAVIOURS

157 I: That's the biggest thing for you?

158 Kulbir: Yeh, it's like a job twenty four hours, it's a job, that's why I can't work. Look at how many appointments I have, I

159 have to go to school, take her to hospital, then I'd have to go to the centres and then I have to go to other places.

160 It's too, too much. How can I work? I can't work! Ok even if I did start work, they wouldn't give me a day off. Ok if

161 I had a day off in a month that's different, but if I said every week I need two days off I need to go here, can't

162 work. - desire to work is there, but - limitations/restrictions - Somuch time taken up just on one child - so overwhelmed by so much that has to be done multiple demands of caregiving - beyond physical + emotional!

163 I: But you'd like (to work)? - wants her own life! - something she can do for herself on her own! beyond caregiving

164 Kulbir: (I want to do something). I do want to but I can't, it's hard for me, what am I going to work for, double the stress

165 from there and here. I got housework as well you know what I mean? - wants to work - concerns about stress overload!

166 I: And what about your other children how do they do the rest of family - Had enough of family or strained

167 Kulbir: They are fed up too [laughs]. They fed up as well. My boy gets pressure. They fight, they fight with each other. I

168 say to her don't go to your brothers room, don't go to your sisters room. She goes, even though she's got her

169 own computer we bought her, we bought her, her own telly, she broke it! she don't look after the things, she's

170 got her own computer, but she still went on his and broke his things last week, she don't understand you know

171 what I mean? And then he says to me you spoil her, you don't say anything to her, she knows everything, my son

172 says to me. I have to listen to him and to her, you know what I mean? Then my husband comes and gets angry

173 you know what I mean? I say don't tell me, I then go outside and shut the door. Sometimes you know what I

174 mean? Pressure. Listening to everyone you get pressure. The little one is small and she copies Serena, she copies

175 her, if Serena swears, she starts swearing to. That's the hard thing. So I am making her stop, she says tell Serena

176 mum, tell Serena, tell Serena. I say you can understand but Serena can't, she say why don't Serena can't

concerns about disruptive behavior influencing or being picked up/ imitated by younger daughter. - doesn't want her to be the same - think it's normal

disruption to home / normality / disruptive / challenging behaviours / negative impact on whole family! - siblings anger at mother + child - 'spoil' - husbands anger

want listen. - siblings are 'fed up' - had enough

having to deal with family's issues - feeling caught in the middle!

all the impact the child with LD has had on the family, it's disruptive! no positive impacts!

child with LD has caused disruptive to normality, peace in family home! more arguments. mum feels trapped in middle which causes more stress!

routine / pattern / responsibility! has to be done!

comparing caregiving to a 24hr job

limitations / res to children on mums life due to caregiving role!

Having to listen to everyone's issues with daughter - taking on their problems, stress. - none to listen to her problems, feeling swamped by whole situation! - siblings feelings that daughter gets away with alot more

Appendix D (page 10 of 10): Worked Interview Transcript (links to chapter 2)

	177	understand mum? She ask me more questions you know what I mean [laughs]? I think when she might grow up	
	178	then she might understand, she's small yet, she's only four.	
	179	I: When she says why doesn't she know what do you say?	
FEELING OVERWHELMED	180	Kulbir: I say leave her, forget it, leave her. Let her go, and when she's naughty she says listen to mom. Serena listen to	can't handle it too much to talk! overwhelmed, too much for one person!
	181	mum, to Serena listen to mum. Hmm. It's too much, honestly, for parents it's too much. I have to give her a bath.	
	182	She's a big girl, developing, you haven't seen her, have you seen her? (I: No I haven't seen her) you haven't seen	→ embarrassment of doing personal, hands on caring with hygiene! - something she assumed, normal for a child to do themselves at her age -
FEELING UNCOMFORTABLE WITH SOCIAL-SEXUAL DEVELOPMENT	183	her, no (I: I've seen you're youngest) I think she got big and the nurses know they say she quite a big girl. Yeh	
	184	bloody hell, she is normal, my back hurts her hair, I never used to cut her hair, but I had to cut it, it was long but I	Physical heatn affected
	185	cut it short (points to shoulders). I can't give her bath every day, it's too much honestly, (shows interviewer	- physical demands of caregiving, strange for mum! Difference between physical development + mental development, hard to accept.
PHYSICAL BURDENS OF CAREGIVING	186	pictures of daughter kept in her wallet) this is when she went swimming, that's her there (I: Oh yeh she is big,	
	187	she's fourteen?) hmm, she's quite big, here look she's big (I: Oh yeh) she's got big (points to breasts) (I: Oh right,	
	188	laughs) honestly I can't believe (I: Really?) yes, 36 DD, (I: Right) yeh massive, I get embarrassed giving her a bath,	- embarrassment at giving daughter a bath due to her physical development + age.
	189	she's got taller, she tall, like us and it feels awkward for me. Have a look at this picture, she is big. (I: Yeh) she's	
FEELING UNCOMFORTABLE WITH SOCIAL-SEXUAL DEVELOPMENT.	190	big, she's 14 but she looks like she's 16. Yeh? (I: Yeh) She looks older. The teachers say she baths herself, I think	
	191	white children are different, I have to bath her properly, she just gets out, I give her body a proper rub. She said	- difference between 'white' + 'Indian' children difference between Indian way of doing things + white way!
	192	make her independent. How can I make her independent to have a bath? They don't understand, white people.	can't leave her alone!
INEFFECTIVE STRATEGIES	193	Having a bath she'll use up the whole shampoo bottle, when bathing. How can I leave her in bathroom on her-	difficultly getting child to listen! discipline due to child talking back - not listening! lack of understanding
	194	own? I have a back problem and I have to give her a bath, I do try and I say you have a go and I stand at the side	
	195	and see what she does but she tells me to get out, out of the bathroom. Then she starts talking like that in front	Physical impact of caregiving
	196	of me. It's really hard, really hard, when her period comes it's really hard honestly. Really hard, very heavy	hygiene side is hard! Physical hands on caring associated with her physical development, normal!
CULTURAL DIFFERENCES IN CHILD REARING	197	periods that she has to take tablets, to make it light and they stay for a long time, she uses a lot of pads. The	
	198	school knows, I think tena pads, they will give her those now, I have a letter. The cost of the pads was so much, I	

Culture?

feels like white!
people expect
too much of
that there
is a difference
in the way
they do things
even as simple
as having a
bath -
culturally
inappropriate,
can't be
repeated at
home!

Appendix E (page 1 of 5): Worked Focus Group Transcript (links to chapter 2)

<p>141 142 143 144 145 146 147 148 149 150 151 152 153 154 155 156 157 158 159 160 161 162 163 164</p>	<p>Pressiness / Dismissed concerns JITAL INSTINCT SOMETHING'S WRONG TRYING OUT FOR HELP! UNJUSTIFIED REASSURANCES ANGER AT BEING DISMISSED QUESTIONING AMBIGUITY ELLIGIOUS ATtributions ANGER AT BEING DISMISSED</p>	<p>The health visitor used to come to check his weight after every week or in two weeks, because his weight was 3 1/2 pounds and we told her and everybody could see, we told the consultant doctor in the hospital, we told everyone that he drinks milk and then vomits it out, but no one took notice of it. At the age of 9 months he started losing weight umm, it went down, and then his heart also stopped. He fell ill when he was 10-11 months old when he had a fever, I told everyone, I kept going, I went to the doctor and told everything, I cried and told him because I was worried about this condition, he was suffering, this is my child and he's not well, but nobody took any notice of it and said do not worry about this he will get well, children do vomit milk, he will get better, don't worry so much, everyone said that but, when he was 11 1/2 months old, he got fits with fever. His heart stopped, completely. We called an ambulance and went to hospital and told the doctor that we have to feed him milk with a spoon and syringe but they said no, they want to see what is happening... They kept him there for three days and then put tube in and said that we have to feed him 1/2 ounce in the morning and evening. For this 1/2 ounce he takes half an hour. The doctors said he is weak and will get well, he is this he is that. When he was one year old they told us that as he is not putting weight and they have to put tube for feeding. But we have told this to them when he was 5 months old. At that time they told us that this is all due to development delay, when he grows up he will talk, walk and do everything as he grows older. It's just like sister [Aalia] was saying we keep our hearts happy and carry on what else can we do? Now they are saying his legs don't work and they have given him special shoes and feeding him from a tube. Now from two years his condition has improved. He understands talk, he points to make us understand things, his brain as much as he has is ok. But still we are suffering. With a high temperature straight away he gets fits. Doctors say he does not have epilepsy but they have given epilepsy medication. We said if he does not have epilepsy then why you have given him epilepsy medication. But they said due to development delay we have prescribed this medication which will help because he doesn't walk it will control him. We told to everybody but they said to continue with this medication. It appears to you that doctors say something else but I feel the problems different. Razia: Yes but still we accept the will of God, whatever is written that is what will happen the man up there, but we make efforts and inform doctors and they should take notice of it. They should listen to parents, carers, brothers, sisters</p>	<p>Doctors saying it is ok - normal development over - contained mother! over - cautious listen to parents + keep them informed! - not just 'mistaken beliefs' - not being listened to until an emergency arises! - not being listened to until emergency arises! - nobody listened! - mothers concerns were justified! - mothers concerns about child's weight loss justified! even though doctors ignored her! - trying to stay positive + keep going - more problems - they - hospitals - some improvements after 2 years understanding Prescribed epilepsy medication, but doesn't have epilepsy! frustration - confusion about this - wasn't explained well enough by docs which makes them question! ↳ not enough information / explanation as to why certain drugs here been prescribed makes them question reliability! - despite his belief in God they still seek medical help religious attributions! God's will / fate - it is written! external attributions - makes carers feel better when they are judged by doctors / close family "conspicuous marriages" "sins, punishment" gives internal attribution to parents - blaming them for me LD! - so religion is like a coping strategy!</p>
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Appendix E (page 3 of 5): Worked Focus Group Transcript (links to chapter 2)

QUESTIONING COMPETENCY OF ASIAN DOCS
 (ANGER - FRUSTRATION - ASIAN DOCS)

FEELING LIKE A NUISANCE

FIGHTING FOR RIGHTS

ASIAN DOCS AS TRICKLE DRAIN

DISAPPOINTMENT WITH ASIAN DOCTORS

PREFERENCES FOR WHITE SERVICE PROVIDERS

Doctors frustrations at ever persistently coming to hospital for same thing again + again! They probably explained but not very well! and that's why she kept going back! As a result she has a negative opinion of Asian docs!

Feel like a pest / nuisance - rejected abandoned by doctors! helpless - interpreting experiences with doctors in racial terms! - dependent on ethnicity of doctor - Asian - leading to formal complaint - making more 'trouble'

- fears for safety of child / scared she won't know what to do!
 - fears about consequences being 'blamed' if something happens to child!

Again fears of being blamed - feeling like everyone else blames them? - or maybe media has played a role - seeing it on TV?
 Stay about how good white service providers are!

- comparing white to Asian people!
 - comparison of white vs Asian people - forgiven for sometimes not helping! - having thoughts that they deserve from why? racism, etc?
 'better than our people?'
 is it because they were ambulance people not doctors?

This is also processed
 a expression of community issues about service providers!

look at Hatten 2010 - experiences of racism - sceptical + cynical about intentions / motivations of service providers!

negative experiences / interactions with doctors + Asian community (close family) their parent blaming judgemental attitudes have left them feeling sceptical about the intentions of Asian service providers?

190 were but they were Asian. They told me you know what the problem with your son is and why do you keep bringing
 191 him to the hospital time and again. Why do you not keep him at home? Keep him at home and look after him. He is
 192 child, we do not want to kill him at home when his heart beat and breathing stops. If something happens, the
 193 government will not spare us of this neglect. saying that if this happened why did not you ask for help. Then when we
 194 ask for help, then one time I got a questionnaire from the hospital, and I filled the questionnaire completely and
 195 complained about that Asian. I made a complaint that all those Asian doctors you have brought here, they create
 196 trouble for us and lot of our people complained against them. - formal complaint against Asian doctors
 197 So you're saying the Asian community - Asian community - fair from expected more? - angrily going

198 Razia: (Because they) let us down. Because me, now for the last 7 years I have been going to hospital (Kabir: The doctors
 199 do it as well). About 5 days ago we called an ambulance for my smallest child he had to go to hospital, there was a
 200 lot of ice outside, so we phoned the ambulance and told them he has got fits and got blue and then they said if the
 201 ambulance isn't with you in the next five minutes then you should apply a special medication drop by drop so that his
 202 breathing goes back. I never realised but he was sitting in such a way that he became very stiff, I was making his
 203 breakfast and when I saw him after a minute, I had a look at him, picked him up and then put him on the floor, his lips
 204 became blue very badly and then my daughter in law said mum don't keep waiting for the 5 minutes, give it straight
 205 away, even if it's been 1 or 2 minutes and so I gave it to him and then my child's breathing came back. My other
 206 children called the ambulance and the ambulance came in one hour due to heavy snow. Then two Ambulances
 207 came and they helped us a lot. The Ambulance could not come to our house due to a hill and closed road. They
 208 helped us a lot they said we can not bring the ambulance to the house because the road is blocked so they picked
 209 him up themselves and took my child to the hospital. These people help us a lot, the ones that are white. If some
 210 times they do not help us we do not mind it, sometimes we think they do not like us, but they help us a lot, they are
 211 better than our people. - forgiving

212 Kabir: This

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Appendix E (page 4 of 5): Worked Focus Group Transcript (links to chapter 2)

214 Aalia: No this is not correct, everybody is not same, there are different ones as well, some do, not all are the same. Our people are also very helpful. I'm not saying that they don't, some people behave like that with everybody, they do not behave like this only with us. Why should we say that our people act like this with us? There are some, our people who helped us a lot and we feel if there was a (Razia: No, there are some good ones) a white person in their place we might not be able to get the help they provided us. Every person is different.

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219 Razia: But whenever I got to the hospital, whoever is there, the manager, the doctor there behaviour is always the same. They should do something. Always same - Asian doctors meet

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221 Lata: Never mind the doctors, even our close relative comes to our house, they also do not like these types of children. consequences for child! Doctors - all the same!

222 (Razia: They talk about us). Close family. The child is already unwell and they come and make them feel worse. They blame us of our past deeds and God has given us punishment. internal attributions - blame! Even families mistreat! Some families negative thoughts about child + causes!

223 So families do this... time more negative! this is what causes them to have their own affirmations (Gods will etc) - being blamed!

224 Families treat us worse. 2 worse man doctors which are more positive - ignore families - TIME! - WRITE LISIS!

225 Razia: But we should not take notice of what our family say and let them say what they want to say. - emphasises what they want - children to get better!

226 Aalia: No, we are of the view that our children should get medical facilities in time and we do not want anything else. They should give proper care and treatment to our children. We do not want anything else, we just want our children to get better whatever they need, most importantly their medical problems that they have, they should look after those properly, we do not say anything else, what else do ask them for, everyone has his own fate.

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230 Asif: If you do a survey in India and Pakistan and you will find 0.5% disabled children and 90% marriages are held in the families, 90% of marriages in Pakistan are within families. I am saying about Pakistan and do not know about India. Here the percentage of disabled children is 10-15% and they say this is due to marriages in the families. But the possibility of this disability is lack of care at the time of birth or wrong medicine given afterwards. Previously, about 30 years ago, there were mixtures with no information leaflet and they gave my child the wrong medicine. Now medicines are modern with information leaflet mentioning their side effects and everybody can read this information. (Razia: Yes, they give you full information). They gave my child wrong medicine, sodium Valpour, give 6 grams in the

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not all the same! related to competency as a doctor rather than race! } Bad doctors are bad doctors in general - not race related!

Some reliance on Asian service providers - wife facilitator of support group! Asian key worker? - tasnoom? chair of group must be diplomatic?

reversal of argument - individualisation, reflections on help provided by 'low people' which would not have suffered if it had been a white person?

disagreeing - not all Asian people are like Razia! - more general not just aimed at Asian people!

reversed argument some Asian people do help - and if it was a white person they wouldn't be as helpful!

Even families mistreat! Some families negative thoughts about child + causes!

Dislike children!

Coping/relief for being blamed!

emphasises what they want - children to get better!

Time! - WRITE LISIS!

emphasises what they want - children to get better!

parental ages - where do he get from from? - incidence of disability higher in UK!

cause - LACK OF CARE DURING BIRTH! wrong meds!

Lack of info lead to doctors giving wrong medicine!

Belief that his child was given wrong medicine, comparing past and now more information now!

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causation is biological by lack of care + wrong medicine } mistrust in services, questioning competency of midwives.

Medicalisation of LD - child needs tx - needs assistance!

Medical model used to view cause, prognosis + tx

cause = brain lack of care, medication!

tx = medication!

Siblings - under/demanding - realise parents over tired! - assistants to parents.

COMPETENCY MORE IMPORTANT THAN RACE IN SERVICE DELIVERY

BADLY BEHAVED ASIAN DOCTORS?

BEING BLAMED BY FAMILIES

COPING WITH BLAME: DISCREPANT COMMENTS

DESIRE FOR TIMELY SERVICES

COPING: SEARCHING/HOPING FOR A CURE

COPING: NEGATIVE ATTRIBUTIONS/BLAMING WRONG MEDS

Appendix E (page 5 of 5): Worked Focus Group Transcript (links to chapter 2)

Questioning competency of Doctors!

doctors purposely want to see families suffer - why? they don't MUST them - feel let down!

Very few doctors are cynical/negative about doctors - want to see family suffer.

Too late - found out it's wrong Meds!

-negligence - They see it as disease - can be treated! - disease! - had's which try to deal with it!

- Endless chain of letters!

- waiting to get help for child!

- weight gain - parents blamed! - children not mobile - doctors should be responsible! - more tests needed - (I) illness

- frustrations - don't know what is being written in reports! - higher authorities - not being informed!

- not a true representation of what they said!

- Status/ Authority higher - refers - concerns dismissed, - Anger at not knowing - something to hide? - Agains benefits?

QUESTIONING COMPETENCY AND MOTIVES OF DOCTORS

LD AS A DISEASE?

COPING: SEARCHING/LOOKING FOR A CURE

FEELING ABANDONED BY DOCTORS

FACING BARRIERS: WAITING/DELAYS

HELPLESSNESS ANGER AT BUREAUCRATIC SERVICE

BEING BLAMED

COPING? ← SEARCHING/LOOKING FOR A CURE

WAITING TO BE HEARD THE BEING HEARD

BUREAUCRATIC SERVICES

SOMETHING TO HIDE? SERVICES

238 morning and 6 grams at night and now we came to know it is the wrong one but it is too late. Very few doctors are

239 good, most of the doctors and hospitals are not good, they say they are suffering, let them do the more suffer.

240 Razia: Yes, yes. [pause] (But we just...)

241 Aalia: (They have discharged patients) many years ago who have died by saying there is (no treatment for this disease)

242 There is no treatment. — Cureability - limited knowledge of CD - focus on TX! — disease! — had's which try to deal with it!

243 Razia: (They do not have to say like this, that there is no treatment). You can put efforts for the treatment and should see TX - Cureability!

244 the persons regularly. This is not fair to discharge and no after care planning. it's the parents problem, it's your fate

245 deal with it, they shouldn't do that, that is not fair. — transcribe - after 12 - not as much help! — 'problem' - feel responsible? abandoned?

246 E: Yes!

247 Aalia: Doctors and Social workers write letters to the hospital. Family doctor says that he has written to the hospital, social

248 worker says she has written a report to the hospital and you have to wait for hospital appointments. It is now three

249 years, their letters did not reach them and the condition of our children is deteriorating. — waiting to get help for child!

250 Razia: And a person who is disabled and can not move and is inactive, it is natural that his weight will increase, it's not like

251 they will stop eating, they will eat regular meals, maybe they'll eat a little or a lot, and they say that mothers and

252 fathers don't give them healthy food, we do, but they are always sitting and they cannot get up and that's why their

253 weight will increase. It is the responsibility of the doctors to take notice of it and take regular tests to find out

254 undetected illness, they should do tests for all the possible illnesses, so that no illnesses are missed. It is possible

255 that undetected last week's illness could be detected next week. It is not fair to leave it for years altogether.

256 Asif: Central government is sitting there, here is director of social services, assistant directors and managers. They are

257 writing reports, we do not know what they are writing and sending these reports to higher authorities. If someone

258 contacts us then we can come to know. If some higher officer came then we can tell them and then it is possible our

259 concerns can reach to the concerned authorities. You will write report and actually this report will go to manager,

260 director, assistant director and we do not know what they write.

261 Aalia: Whilst we are waiting for it to reach the different people the shape of the report completely changes! — not a true representation of what they said!

262 [Laughter]

Appendix F: Interview schedule (links to chapter 3, study 1)

Questions	Prompts
	<i>* Why did you join?</i>
What made you want to join this support group?	<i>* Can you tell me a little about your child?</i>
Why do you find it helpful?	<i>* What do you like about coming here?</i>
Where did you go for support before this group?	<i>* Did you have any other support or help?</i>
What do you find enjoyable about caring for your child?	<i>* What parts do you enjoy most?</i>
What do you find difficult about caring for your child?	<i>* What things do you find hard to do and why?</i>
	<i>* Do you know what caused your child's impairments? (use word that parents use to describe impairment)</i>
What do you think caused your child's impairments?	
How did you find out about your child's impairments?	<i>* When did you first realise?</i>
	<i>* What did you do?</i>
What role does your family play in helping care for your child?	<i>* How do family and friends react to your child?</i>
	<i>* How does that make you feel?</i>
	<i>* What would you like for your child in the future?</i>

General prompts: ** Can you tell me a bit more about that? *how did that make you feel?*

[Redacted]

Appendix G (page 2 of 2): Ethical approval confirmation (links to study 1 & study 2)

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- [Redacted list item]
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Appendix H (page 1 of 3): Participant Information Sheet (links to chapter 3, study 1)

PARTICIPANT INFORMATION SHEET

UNIVERSITY OF
BIRMINGHAM

Study I: Discussion Group

*Title of Project: British South Asian Carers' and their Children with Developmental
Disabilities*

Researcher: Kuljit Heer

I would like to invite you to take part in a research study. Before you decide if you would like to take part you need to understand why this research is being done and what it would involve for you. Please take the time to read through the following information carefully. If there is anything that is not clear or you would like more information you can talk to the researcher.

The researcher will call you in the next few days to give you more information about the study and ask you if you would like to take part. The researcher will be given your telephone number by the Health and Social Service Team, providing you are happy with this.

• **What is the purpose of this research?**

The aim of this research is to find out about South Asian families who have a child with developmental disabilities. We want to find out how South Asian parents' feel about caring for their child and how it affects their daily lives and their families. The purpose of this research is to support the development of learning disability services which are better able to support South Asian service users.

• **Why have I been invited to take part?**

You have been invited to take part because you care for a child with developmental disabilities. It is up to you if you want to take part. This information sheet is for you to keep and I will discuss the study with you in detail before you make your decision.

• **What would be involved?**

If you agree to take part you will be invited to attend a group discussion with some other carers who, like yourself, are South Asian and have a child with developmental disabilities. The group discussion will be quite informal. I would like to know about your experiences of caring for your child. The group discussion will be held on[date] at[location] and will last for approximately 2 hours.

When we meet for the group discussion I will ask each of you to fill in a consent form to say that you agree to participate in this research.

Appendix H (page 2 of 3): Participant Information Sheet (links to chapter 3, study 1)

- **What will happen to the information?**

With your permission, I will audio-record the group discussion. After the group discussion I will make a detailed written copy of what was said (a transcript) which will be used when analysing all the data collected for this study. I will then write a report which will be assessed as part of my PhD. I would be happy to send you a research summary of the findings if you would like to receive this. Access to the entire research project may be arranged through the University of Birmingham. I also hope to write articles for scientific journals and to give presentations to carers' groups and mental health professionals to raise awareness of this research.

- **Will the things we say be kept private?**

When I create the transcript, I will change your names and the names of anybody else that you mention. The transcripts will be looked at by myself and relevant research staff at the University of Birmingham to ensure that the analysis is a fair representation of the data. Interview extracts may be used in the write-up or publication of results but these will not identify any carers as participants in this research. I will ask you for permission to use them. The original recordings will be kept in a secure place at the University of Birmingham. Any information collected will remain anonymous using identification numbers and only the researcher (Kuljit Heer) will know your identity. If child protection issues or any other issues of concern arise the researcher may have to report these.

- **I do not speak English can I still take part?**

The researcher can speak English and Punjabi. If you do not speak English or Punjabi, a translator/interpreter will be used, providing you are happy with this.

- **What will happen if I do not want to carry on with the study?**

If you do agree to take part you will be free to withdraw at any time before or during the focus group, without giving a reason. Any information that you withdraw will not be used in the analysis or write-up of this research and will be destroyed immediately.

- **Expenses and payments**

You will be refunded any expenses you have from taking part in this research (e.g. travel and childcare costs).

- **Who is the researcher?**

My name is **Kuljit Heer** and I am a doctoral researcher at the University of Birmingham. I have clearance from the Criminal Records Bureau to work with children and vulnerable adults. This research is being carried out in collaboration with Dr Michael Larkin and Dr John Rose Lecturers at the University. The research is also being supervised By Ivan Burchess, Consultant Clinical Psychologist at Wolverhampton City Primary Care Trust.

Appendix H (page 3 of 3): Participant Information Sheet (links to chapter 3, study 1)

The research has been looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity.

Thank you for taking the time to consider this research study. If you think you might be interested in taking part please contact me to discuss the research in more detail. We can discuss the study over the telephone and I am happy to arrange a personal visit if you feel this would be beneficial.

You can contact me (Kuljit Heer) at any time on:

Tel:

Email: 

Appendix J (page 1 of 3): Additional Quotes (links to chapter 3, study 1)

Master theme	Sub-theme	Quote	Participant
Making sense of the disability	<i>"God's choice"</i>	<p>"Me, in myself I am happy, I feel fortunate, it might be a test or something. I am happy with God's choice, I am happy with my fate."</p> <p>"My daughter, she says 'why has God done this? why didn't God leave him ok?' I said 'it's up to God, why he did this.'"</p> <p>"We accept the will of God, whatever is written that is what will happen, the man up there, but we make efforts and inform doctors and they should take notice of it."</p>	<p>Mrs Hussain</p> <p>Mrs Bhuppal</p> <p>Mrs Rahman</p>
	<i>A problem with epilepsy, 'bad' behaviour and speech</i>	<p>"Her behaviour, when the fits are about to happen, two or three days before her behaviour gets bad, like she starts talking by herself sometimes."</p> <p>"He caused a lot of trouble, he did trouble before he started taking his medicines."</p> <p>"It feels to me as if he struggles with his talking, he does try but it doesn't come out right."</p>	<p>Mrs Virk</p> <p>Mrs Bhuppal</p> <p>Mrs Bhuppal</p>
	<i>Struggling to get a diagnosis</i>	<p>"For a lot of years she was on a waiting list, and then she got her turn, and then they told us she had fits, we didn't know what we should do or shouldn't do."</p> <p>"If the doctor doesn't notice then there's nothing you can do. What can we do when doctors do not take any notice, when they say that he will get well then we think it is our mistaken belief."</p> <p>"He was 5 months old when we came to know that something is wrong with him. But no one took any notice of it."</p>	<p>Mrs Virk</p> <p>Mrs Hussain</p> <p>Mr Rasheed</p>
	<i>Medical negligence as a cause</i>	<p>"The reason for this disability is the lack of care at the time of birth or wrong medicine given afterwards."</p> <p>"They give the wrong medication. They do not know and are prescribing wrong medicines!"</p>	<p>Mr Ahmed</p> <p>Aalia</p>

Appendix J (page 2 of 3): Additional Quotes (links to chapter 3, study 1)

Master theme	Sub-theme	Quote	Participant
Feeling let down by services	n/a	“They should listen to parents, carers, brothers and sisters, and those who are living with and looking after these people who have problems, listen to them. They are the ones that are with them day and night, listen to them.”	Mrs Hussain
		“Very few doctors are good, most of the doctors and hospitals are not good, they say they are suffering, let them do more suffering.”	Mr Rasheed
		“Everybody have a problem with the GP, if the GP is good then everything is alright, you will get physio and everything will go well.”	Mrs Akhtar
		“Our Asian people, im not saying 100 % here you know, but some neglect from birth, you can see in maternity units the nurses, midwives don’t know anything.”	Mr Ahmed
		“I got a feedback questionnaire from the hospital and filled it out completely and complained, I made a complaint that all those Asian doctors you have bought here, they create trouble for us and a lot of our people complained against them.”	Mrs Hussain
		“Indian people don’t care, I think, they don't care, that's why they don't help if they are Indian doctors or nurses.”	Mr Bhuppal
Stigma and Isolation	n/a	“The Asian community they are bloody funny people! They look at him and think if the child sits with them they will become like that.”	Mr Samra
		“Even our close relatives comes to our house, they also do not like these types of children. They blame us for our past deeds and God has given us punishment. Families treat us worse.”	Mrs Rahman

Appendix J (page 3 of 3): Additional Quotes (links to chapter 3, study 1)

Master theme	Sub-theme	Quote	Participant
Looking to the future	<i>Concerns for future well-being</i>	<p>“Who knows how long we will live and what will happen to our children after this?”</p> <p>“Yes, we want the same, that if we die who will look after him? Who will look after him?”</p>	<p>Mr Rasheed</p> <p>Mr Samra</p>
	<i>Wanting help v's giving up</i>	<p>“It is like this with us, we are on waiting lists, doctors do not see our children, then what is the use of providing this information?”</p> <p>“I do not know how many times they have made an appointment and when the appointment is due they cancel it saying they can not manage it they cancel it.”</p> <p>“What are doctors going to do anyway?”</p> <p>“Family doctors say that he has written to the hospital, social workers say that they have written a report to the hospital and you have to wait for hospital appointments. It is now three years, their letters did not reach them and the condition of our child is deteriorating. What's the point?”</p>	<p>Mr Ahmed</p> <p>Mrs Akhtar</p> <p>Mr Rasheed</p> <p>Mrs Rahman</p>

PARTICIPANT INFORMATION SHEET

UNIVERSITY OF
BIRMINGHAM

Study 2: Interviews

Title of Project: British South Asian Carers' and their Children with Developmental
Disabilities

Researcher: Kuljit Heer

I would like to invite you to take part in a project. Before you decide if you would like to take part you need to understand why this project is being done and what it would involve for you. Please read through this information sheet carefully. If there is anything that is not clear or if you would like more information you can talk to the researcher.

The researcher will call you in the next few days to give you more information about the study and ask you if you would like to take part.

• **Why is this project being done?**

The project aims to find out about South Asian families who have a child with developmental disabilities. We want to find out how South Asian parents' feel about caring for their child and how it affects their lives. The project will help to develop better learning disability services which can support South Asian people.

• **Why have I been invited to take part?**

You have been invited to take part because you care for a child with developmental disabilities. It is up to you if you want to take part.

• **What would be involved?**

I would like to talk to you about your experiences of caring for your child with developmental disabilities. I would like to know how you feel about your child's disability and how it affects your family. I would like to ask you some questions about these things. We can arrange a time and place that is best for you. I can talk to you at your home or at an NHS meeting room. It will take no longer than 2 hours.

Appendix L: Participant Consent Form (links to chapter 4, study 2)

CONSENT FORM: Study 2: Interviews

**UNIVERSITY OF
BIRMINGHAM**

Title of Project: British South Asian Carers' and their Children with Developmental Disabilities

Name of Researcher: Kuljit Heer

**Please initial
box**

1. I confirm that I have read and understand the information sheet dated.....
(version.....) for the above study. I have had the opportunity to consider the
information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any
time without giving any reason, without my medical care or legal rights being affected.
3. I understand that the data collected during the study may be looked at by individuals
from the University of Birmingham, regulatory authorities or from the NHS Trust,
where it is relevant to my taking part in this research. I give permission for these
individuals to have access to my study data.
4. I understand that any data collected will remain confidential. Unless child protection
issues arise, in which case the researcher will be obliged to report this.
5. I agree that information and resultant data collected may be published providing it remains
anonymous. I understand that the researcher will get in touch with me before publishing
any direct interview extracts.
6. I understand that if it is necessary a interpreter/translator will be used.
7. I agree to take part in the above study.

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Request for summary of study

After the study has been finished a summary report will be written. If you would like a copy of this summary please tick the box. The summary report will be sent to your home address once it is available.

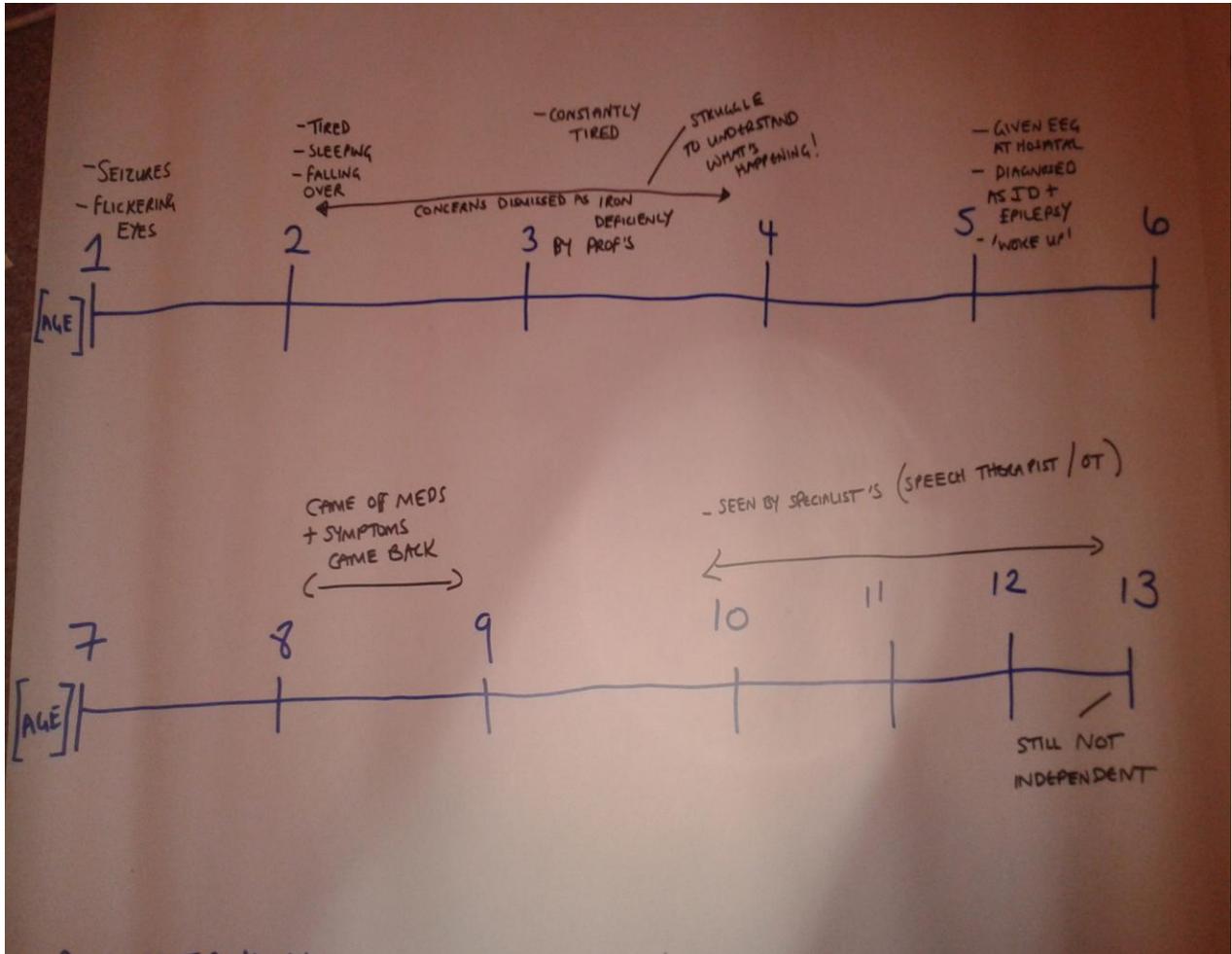
**Please tick
the box**

When completed, 1 for participant; 1 for researcher site file

Appendix M: Interview Schedule (links to chapter 4, study 2)

Area of interest	Question and prompts (*X'- to be replaced by child's name)
<i>Background Information</i>	<ul style="list-style-type: none"> • Age • Details of child with I/DD • Number of children • Country of birth • Time since immigration (where applicable) • Religion • Languages written and spoken • Education • Partner details (country of birth/ languages spoken)
<i>Recognition of Delays</i>	<p><i>Can you tell me about X*?</i></p> <p>(Prompts: Can you tell me about their I/DD?; How did you come to find out about the I/DD? What kind of symptoms does X have?; How does the I/DD impact X?)</p>
<i>Impact of the Disability</i>	<p><i>Can you tell me what it's like caring for X?</i></p> <p>(Prompts: On a typical day?; What do you enjoy?; What do you find difficult?; What kind of help or support do you get?)</p> <p><i>How do people (family/friends) respond to X?</i></p> <p>(Prompts: How do they act?; Why do you think they react like this?; How does that make you feel?)</p> <p><i>How do the rest of your family (father, siblings) feel about X?</i></p> <p>(Prompts: What are their relationships like?)</p>
<i>Belief Systems</i>	<p><i>What do you think caused X's I/DD?</i></p> <p>(Prompts: How did you feel when you found out the diagnosis?; Is there anything you think could help X?)</p> <p><i>What do you hope for your child's future?</i></p> <p>(Prompt: Is there anything you think can help your child?; What would you like for your child when they are older?)</p>
<i>Service Interactions</i>	<p><i>How do you find services?</i></p> <p>(Prompt: What do you think is good/helpful?; Is there anything you think could be better?)</p>

Appendix N: Example Timeline from Interview (links to chapter 4, study 2)



The picture above is the timeline drawn during the interview with Sanjit. The timeline depicts the symptoms of intellectual/developmental disability present at different age intervals, as well as the services accessed.

Appendix O (page 1 of 7): Additional Quotes (links to chapter 4, study 2)

Master theme	Sub theme	Quote	Participant
<p>M 1: Living with loss, uncertainty and overwhelming responsibility</p>	<p><i>An uncertain future</i></p>	<p>“Sometimes I just don’t know how he’s gonna turn out because I don’t know how much understanding of these things he’s actually gonna have. The fact that he doesn’t kind of understand the things the way we do, I mean at this point he doesn’t so to me it just seems like, is he gonna be like that? Always confused?”</p>	<p>Khlaida</p>
		<p>“I’m thinking about the future, about what she’ll do. I’m worried, she’s nearly fourteen and she can’t work. She doesn’t know anything yet. We can’t even get her married. She will have to stay with me. I’m worried what will happen in the future. Ok now she’s a child and we can see to her, but what will happen to her in the future?”</p>	<p>Kulbir</p>
		<p>“There’s so many different things that she might not be doing. But then, but it’s not guaranteed, she might be ok.”</p>	<p>Adeela</p>
		<p>“I do want her to learn so much more so that she can live independently and hopefully with a little help from the school and so forth, we’ll get her that. Make her mentally progress, as well as physically, so she can live an independent life.”</p>	<p>Sanjit</p>
		<p>“No ideas what to expect, life goes by and new experiences happen every day so we don’t know what’s going to happen. See what happens and then we just prepare ourselves for that stage.”</p>	<p>Kabir</p>
		<p>“I want that he should take care of himself, get a good education and he should not be dependent on anyone. But who knows what will happen?”</p>	<p>Asim</p>

Appendix O (page 2 of 7): Additional Quotes (links to chapter 4, study 2)

Master theme	Sub theme	Quote	Participant
<p>M 1: Living with loss, uncertainty and overwhelming responsibility</p>	<p><i>Concurrent losses</i></p>	<p>“We were really upset, like my son was normal and my younger daughter she was normal too, and they said ‘one out of a million children are like this’. We just want our child to be right, I’m happy with the kids you know what I mean? They should be normal.”</p>	<p>Kulbir</p>
		<p>“I used to be a taxi driver and that was a good job for me actually, but now I can't work because me and my wife, we both just do caring.”</p>	<p>Kabir</p>
		<p>“You do miss having that social life that you used to before. I do miss my friends, going out, you know even just going to the cinemas to watch a movie or going out to eat with them , now it’s just where are we gonna get a babysitter from?”</p>	<p>Khalida</p>
		<p>“It is difficult and my daughter feels like I ignore her, you know sometimes she feels like, that’s her time and Asim wants me to you know put him in my lap and it’s like sometimes she feels jealous.”</p>	<p>Nazia</p>
		<p>“We never get to have a family outing, to somewhere like a beach or what we want, on our time, as a family we can’t go, because there’s too many things we have to do during the day with the children so we can’t go.”</p>	<p>Adeela</p>

Appendix O (page 3 of 7): Additional Quotes (links to chapter 4, study 2)

Master theme	Sub theme	Quote	Participant
<p>M 1: Living with loss, uncertainty and overwhelming responsibility</p>	<p><i>Fears about vulnerability of child</i></p>	<p>“There’s a lot she doesn’t understand about the world and money is one of them, and interactions with kids as well, that’s another problem of hers at school, she doesn’t understand them. They don’t understand her and they clash then, people clash with her all the time.”</p>	<p>Sanjit</p>
		<p>“She doesn’t know how to make conversation, she’ll say anything. Like you know some children are a certain age, they know what to say and when to say it, but she won’t.”</p>	<p>Adeela</p>
		<p>“I can’t leave her alone, I don’t know what she’ll do, I have to keep her with me.”</p>	<p>Kulbir</p>
		<p>“He never really sits still. He’s got a behaviour problem as well you know he throws things, whatever he’s got, even water bottles or plates or anything whatever he got.”</p>	<p>Nazia</p>
		<p>“He does stuff that is quite dangerous. He’ll open the wardrobes and climb into them and try and climb up them and everything.”</p>	<p>Khalida</p>

Appendix O (page 4 of 7): Additional Quotes (links to chapter 4, study 2)

Master theme	Sub theme	Quote	Participant
<p>M 1: Living with loss, uncertainty and overwhelming responsibility</p>	<p><i>Struggling to cope</i></p>	<p>“It is hard, I do find it really hard to cope, some days it can be really, really bad and I just think ‘oh my god this is like a big nightmare’, but then some days he’s not too bad, he just gets on with whatever he’s doing.”</p>	<p>Khalida</p>
		<p>“Sometimes I start crying [laughs]. Once it was the weekend, my husband was at work and I was on my own and my daughter started crying, the little one started crying as well and Asim was like oh my God! too much and I started crying, I didn’t know what to do.”</p>	<p>Nazia</p>
		<p>“I get angry. I tidy everything up and she doesn’t pick things up herself she just leaves them on the floor. How many times can I repeat that? If you think about it. I get sick of it.”</p>	<p>Kulbir</p>
		<p>“It’s constant with her, you know, I’m with her twenty for seven.”</p>	<p>Sanjit</p>
<p>M 2: Learning about disability and facing stigma</p>	<p><i>"Everything was delayed"</i></p>	<p>“When he was reaching towards two, you’d call him and he wasn’t listening, it was like he was deaf, everyone kept on saying he was deaf and I was like ‘no, he can hear a coke bottle open and the crisps crunching’, he’ll come running when he hears them and that’s when we realised there was something wrong.”</p>	<p>Khalida</p>
		<p>“Well it emerged early, he had developmental problems, learning difficulty, after two or three weeks he didn’t smile, he was a little bit lazy, he would just sit in my lap and suck his thumb all day long.”</p>	<p>Nazia</p>
		<p>“When she was born she couldn’t hear everything developed late. Everything late, like speaking, walked late, everything was late.”</p>	<p>Kulbir</p>
		<p>“First I used to get annoyed with relatives cos I used to think that there’s nothing wrong with her, why are these people saying this?’ And now I regret that I felt like they were wrong, when it wasn’t them who was wrong.”</p>	<p>Adeela</p>

Appendix O (page 5 of 7): Additional Quotes (links to chapter 4, study 2)

Master theme	Sub theme	Quote	Participant
M 2: Learning about disability and facing stigma	<i>Struggling to understand the diagnosis</i>	<p>“They didn’t explain to me what it was and then I came home and I was telling my sister, ‘he’s autistic, he’s only autistic’, this is how I was saying it ‘he’s only autistic’ [laughs] like as if it’s something so minor.”</p> <p>“One thing that was in my head was ‘why me? Why you know, everything is going on with my little son?’ It was very difficult, I can’t describe it you know.”</p> <p>“Everybody was shocked when we found out. Slowly we got settled. But first of all we felt it a lot, when she wasn’t walking, wasn’t talking, wasn’t eating and things.”</p> <p>“When I first got the letter, saying Laveena’s has got epilepsy. I thought ‘oh my God! What the hell!’ [laughs], the world’s come to an end sort of thing.”</p>	<p>Khalida</p> <p>Nazia</p> <p>Kulbir</p> <p>Sanjit</p>
	<i>"They just don't understand it"</i>	<p>“Sometimes I get depressed you know when other people look at him and say ‘what’s wrong with him?’ or the way they talk sometimes, it’s with sympathy, it’s the way they talk.”</p> <p>“Obviously we can come to terms with it because we understand it’s a normal thing, there’s many people in the world who’ve got a disability. To them they must think that no-one else’s child has got it cos they don’t see that many people, they don’t go out, how are they gonna find out it’s normal if you’re not mixing with those people, you’re not seeing those people?”</p> <p>“It’s a lack of understanding, they’re a bit ignorant to it, yeh they don’t realise.”</p> <p>“They don’t know the condition, because what I know no-one else knows about. Even my wife don’t know as much about the condition as I know it, because I know and deal with the medical things and everything.”</p>	<p>Nazia</p> <p>Adeela</p> <p>Sanjit</p> <p>Kabir</p>

Appendix O (page 6 of 7): Additional Quotes (links to chapter 4, study 2)

Master theme	Sub theme	Quote	Participant
<p>M 2: Learning about disability and facing stigma</p>	<p><i>"There's a stigma attached to things like disability"</i></p>	<p>"It's only when he's getting out the house or something or wants to run off, that gets a bit irritating because you don't know what the neighbours are gonna react like. I think a lot of people don't know how autism is and it's hard to explain."</p>	Khalida
		<p>"You know when other people look at you, I feel like you know they're just criticising us, that's what Asians do. We never had any support from family."</p>	Nazia
		<p>"Some people who don't have children or have never seen children with disability they will say something that will really hurt you from the inside and you'll get really upset with it, so to me, I think that it depends on who you're meeting."</p>	Adeela
		<p>"It's always been like that, form day dot [laughs] it's been like that. You know, 'they've got a bad illness', you know 'don't go near them'. It's just that mentality of Indian people."</p>	Sanjit
	<p><i>"They have their own beliefs"</i></p>	<p>"Sometimes they've got so many other beliefs, you know going to shrines and things and 'oh if you go there that'll help."</p>	Khalida
		<p>"My parents used to say do this, do that and I never done it, because I never thought that their remedies would work."</p>	Adeela
		<p>"There's a place near my dad's village, in India, there's a temple and apparently if you go there and you are blessed then, X (name of child) will be better and I do believe that process might work, if you do believe it."</p>	Sanjit
		<p>"Our family they think 'oh so and so person went to this hot country' and things like that, and came back better and things like that".</p>	Kabir

Appendix O (page 7 of 7): Additional Quotes (links to chapter 4, study 2)

Master theme	Sub theme	Quote	Participant
<p>MIII: Choosing to cope</p>	<p><i>Coming to terms with life as a caregiver</i></p>	<p>“I have to do it even if I don’t want to, you know you could be having a really bad day but I still have to get up and make their food and feed em and everything.”</p>	<p>Khalida</p>
		<p>“Well yeh it is hard but, what can I say? You keep going.”</p>	<p>Nazia</p>
		<p>“I have to do it, there’s no other point. You have to look after them.”</p>	<p>Kulbir</p>
		<p>“It’s something that you have to do. It’s not like it’s something you can leave.”</p>	<p>Adeela</p>
		<p>“You just learn to deal with it don’t you? It’s there you know, it’s not gonna go away.”</p>	<p>Sanjit</p>
		<p>“They are my own children and if I do not look after them, then who will do that?”</p>	<p>Asim</p>
	<p><i>Adapting to a new culture</i></p>	<p>“When it’s not your first language it’s always different and it is very difficult because, it’s different.”</p>	<p>Nazia</p>
		<p>“I never ask for help, it’s very rare when I can’t do it, otherwise I do it myself.”</p>	<p>Kabir</p>
		<p>“I think some people just don’t have confidence, but once you start doing it you get confidence.”</p>	<p>Kabir</p>
		<p>“I regularly go to the school to learn English, Math and literacy so that I can help my children and talk to services and schools. If there is any question which I do not know then I go to the services and ask them, they say that I am the first parent who come forward for this type of help and she says it is very good that I come and ask these things, but other parents feel shy. I want to give maximum benefits to my children.”</p>	<p>Asim</p>

Appendix P (page 1 of 2): Participant Information Sheet (links to chapter 5, study 3)

PARTICIPANT INFORMATION SHEET

UNIVERSITY OF
BIRMINGHAM

Study 3: Focus Groups, India

Title of Project: South Asian Carers' and their Children with Developmental Disabilities

Researcher: Kuljit Heer

I would like to invite you to take part in a project. Before you decide if you would like to take part you need to understand why this project is being done and what it would involve for you. Please read through this information sheet carefully. If there is anything that is not clear or if you would like more information you can talk to the researcher.

• **Why is this project being done?**

The project aims to find out about South Asian families who have a child with developmental disabilities. We want to find out how South Asian parents' feel about caring for their child and how it affects their lives. The project will help to develop better learning disability services which can support South Asian people.

• **Why have I been invited to take part?**

You have been invited to take part because you care for a child with developmental disabilities. It is up to you if you want to take part.

• **What would be involved?**

I would like to talk to you about your experiences of caring for your child with developmental disabilities. I would like to know how you feel about your child's disability and how it affects your family. I would like to ask you some questions about these things. We can arrange a time and place that is best for you. It will take about an hour.

• **What will happen after that?**

If you don't mind I will record what you say. I will also type out a copy of what you say. I can show you this copy if you would like to see it. I will then write a report for the project.

• **Will the things I say be kept private?**

I may want to use some things you say in my project report and articles. I will ask you before I use them. I will not use your names. Everything you say will be anonymous.

Appendix P (page 2 of 2): Participant Information Sheet (links to chapter 5, study 3)

- **Are there any risks by taking part?**

You may feel a little stressed talking about your child. If this happens you can ask to stop. There is also support from professional workers if you need it.

- **What will happen if I do not want to carry on?**

You can stop being involved in the project at anytime. You do not have to give me a reason to stop. It is up to you. If you want to stop I will not use anything you say in the project.

- **Who is the researcher?**

My name is **Kuljit Heer**. I am a doctoral researcher at the University of Birmingham, United Kingdom. I have a Criminal Records Bureau check which says I can work with children and vulnerable adults. This project is being done with Dr Michael Larkin and Dr John Rose Lecturers at the University. The project is also being helped By Ivan Burchess, Consultant Clinical Psychologist at Wolverhampton City Primary Care Trust.

Thank you for reading this information. You contact me to talk about the project. We can talk about the study on the telephone. I can also talk to you face to face about the project if you would prefer this.

██████████

██████████

████████████████████

Appendix R: Interview Schedule (links to chapter 5, study 3)

1) Can you tell me about how you started working for X (name of service)?

Prompt: - Did you have involvement with other services?

2) What types of delays does your own child have?

Prompt: - When did you first come to notice these delays (or use word parent used)?

3) When you first arrived at X (name of service) what was your thinking like about your child's delays (or use word parent used)?

Prompt: - About causation & treatment

4) How has X (name of service) helped/supported you?

5) Do you have support from family and friends?

Prompt: - how do they feel about your child's delays (or use word parents used)?

6) Would things be very different if you did not have X (name of service)?

Prompt: - What is the biggest help?

Appendix S (page 1 of 5): Additional Quotes (links to chapter 5, study 3)

Master Theme	Sub-themes	Quotes	Participant	Group
Making a decision to get help	<i>Struggling to make sense of the differences</i>	"I was very concerned about her behaviour and her stress levels."	Smitha	1
		Aanchal: "Firstly we were shocked and somehow puzzled. We couldn't understand it. We didn't know about autism at all. We did not know anything. We looked in the dictionary to find out the meaning" Bhuvi: "Same for us! I was baffled. I never heard that autism word. My husband got lots of books but he also did not know. 'What is this?'"	Aanchal & Bhuvi	2
		"Lots of people used to tell us all sorts of things about his delays, that he has this and that. We were really puzzled and shocked and we did not understand what to do."	Aanchal	2
		"My son is quite high functioning, he had some behavioural issues obviously, but I was dealing with him, I was ignoring them. When he was 4 and a half I was worried like, 'why he is not learning as like a 4 and a half year old child should be doing?'"	Deepa	2
		"Well, I was usually told that I'm a hyper mother, being a first time mother and family said 'there's really nothing wrong he's just developing late, everybody has their different times of developing, he's an individual.'"	Jaya	3
		"We just thought he was delayed, I mean boys get delayed. And you know the other subtleties, about reaction to change and not having certain kinds of social skills, we kind of tied it up with the speaking late so maybe, you know, 'when speech comes everything else will fall into place.'"	Pooja	3
		"My in laws used to do a lot of pooja (praying) and they used stones, like if he will wear the stone he will be ok. That was the initial phase. Now they have to accept what I am doing. They still feel that if speech will come he will be ok"	Geeta	3

Appendix S (page 2 of 5): Additional Quotes (links to chapter 5, study 3)

Master Theme	Sub-themes	Quotes	Participant	Group
<p>Making a decision to get help</p>	<p><i>Making a commitment to get help</i></p>	<p>"It was a dilemma for us deciding what to do and what not to do. Then we decided that this is the place. When we first visited, we talked to the staff and they were very helpful. They had knowledge so we thought that 'this is the place.'"</p>	<p>Krishna</p>	<p>1</p>
		<p>"I hit the internet, I was surfing about learning disabilities and then I came to learn about autism on the net. I wanted to know more about autism. I was like 'maybe all those symptoms are matching with my son so could he be an autistic child?' That's when I found the service and I went to get help."</p>	<p>Deepa</p>	<p>2</p>
		<p>"We wanted a therapy for our child so that he can be included in society. We found out about the service through internet and we moved here."</p>	<p>Pooja</p>	<p>3</p>

Appendix S (page 3 of 5): Additional Quotes (links to chapter 5, study 3)

Master Theme	Sub-themes	Quotes	Participant	Group
Seeing autism disabilities from a new perspective	<i>Regaining control as a parent</i>	"When I came to the service, I really came to know what I have to do with my daughter. At least now we are confident."	Smitha	1
		"I know how to handle my son as well as myself and I am able to answer my own questions and my own queries. So that is wonderful."	Deepa	2
		"When I'm at home sometimes, he has tantrums and I know how to handle them. I get his hand and say sit down, you have to do this work."	Bhuvi	2
		"After coming here I am able to handle Ajay very well, I take him to the mall. He is very well behaved. So much happiness."	Bhuvi	2
	<i>Seeing a change</i>	"After coming to the centre I found that it has definitely brought change in her."	Smitha	1
		"He has improved a lot. He is getting the help and he's changed a lot."	Krishna	1
		"I didn't know what to do, but then I saw this programme which is DSE which AFA is running. So I instantly registered myself for the course and this has brought so many changes in myself and my son it's just amazing."	Deepa	2
		"In Arun there has been a lot of improvement, a real big improvement. He used to hit himself, he used to run here and there. He never used to sit down at all. After coming to the service he has improved a lot. He has learned a lot of things. He never used to imitate. Now he starts imitating. He has started following instructions."	Aanchal	2
		"My son, he follows all the rules, he has settled down, no behaviour problem."	Bhuvi	2
		"There was a tremendous change in my son's behaviour, development of academics, communication, before that he didn't communicate."	Geeta	3

Appendix S (page 4 of 5): Additional Quotes (links to chapter 5, study 3)

Master Theme	Sub-themes	Quotes	Participant	Group
Seeing disabilities from a new perspective	<i>Being part of something</i>	"The mother and child programme was very helpful and later I did the special educator's course from the centre."	Kirshna	1
		"People come to me and they ask questions about autism and I answer them, I keep helping them. It's very satisfying, I feel like I'm doing something."	Kirshna	1
		"Here you can be relieved of your tension, we can share our ideas. Here all parents give wonderful ideas. We're friends, we're chatting. It is a parent organisation and it's a special bond between parents."	Smitha	1
		"We get opportunities to learn to keep bettering ourselves and you know being provided platforms to do so. So that's something else."	Pooja	3
		"It interests me so much that I did the mother and child course. Then I was totally influenced by the positivity here and everything going the right way."	Geeta	3
		"It is the only place in the country and I'm not afraid of being quoted on this, where our children are accepted and loved for what they are and not for what people want them to be. When you have that, almost all your battle's won, because you go home happy, your son, your child goes home happy. It's an awesome place for parents, especially for mothers, if the mother is happy, the child will be happy. The change of attitude it's also merry. You know X {group trainer} she's a Guru, a mentor, a friend and somebody we all really look up to, and she's never really let us down."	Jaya	3
		"It has basically brought lots of confidence in us. I don't know where I would have been. You know I would have been in a different kind of a job. It has brought really a lot of confidence and kind of empowered us not only I mean with autism but otherwise also."	Lekha	3

Appendix S (page 5 of 5): Additional Quotes (links to chapter 5, study 3)

Master Theme	Sub-themes	Quotes	Participant	Group
Seeing disabilities from a new perspective	<i>“It’s a completely different world outside”</i>	<p>Krishna: "It wasn't that difficult when he was a child. Now he has grown up he acts different and everybody looks at him." Smitha: "There is not much awareness in India." Krishna: "Yeah. They don't understand." Smitha: "There is not much awareness."</p>	Krishna & Smitha	1
		<p>"Some people think that they are going to do nothing in their life, it's the thought process like they think negatively."</p>	Smitha	1
		<p>"There are people who believe in astrology and they keep on doing all those things, but it doesn't really help. Later on they come to here, but only as a last resort."</p>	Krishna	1
		<p>"If you talk about Indian society and Indian community by and large people are not very aware about autism."</p>	Deepa	1
		<p>" I'm sure, I think it's a completely different world outside, go to any small city, go to your hometown Jallandar or a rural village and see how much change you see."</p>	Aanchal	3
		<p>"A lot of people when they first come here they have tried the baba's and going to these prayers and things like that."</p>	Sandya	3

Appendix T (page 1 of 3): Participant Information Sheet (links to chapter 6, study 4)

Participant Information Sheet

UNIVERSITY OF
BIRMINGHAM

Study 4: Staff Focus Groups

Perceptions of learning disability staff towards South Asian Communities (Focus Groups)

You are being invited to participate in a research study about the above topic. This information sheet will provide you with some details about the research and what will be involved if you decide to take part.

What is the purpose of the study?

The purpose of the study is to understand more about the experiences and perceptions of staff towards South Asian families who care for individuals with developmental disabilities. The researcher would like to find out more about your experiences and perceptions of working with this group.

Why have I been chosen?

You have been chosen to participate in this study because you work with people with learning disabilities and their families and your manager has said I could contact you. You can still take part even if you have not worked with South Asian families because we are interested in different perspectives.

Do I have to take part?

You are under no obligation to take part in this study. You will be given this information sheet to keep and at least 24 hours to consider whether you would like to take part in the study. You will then be asked to give your written consent to participate in the research. You are free to withdraw from the study without giving any reason. If you choose not to take part, that is fine and if you do agree to take part you can withdraw from the study at any time you wish, these decisions will not have any consequences for you or your work.

What will happen if I take part?

If you decide to take part in the study, please get in touch with the researcher (contact details on next page).

What do I have to do?

The study involves filling out a brief background questionnaire about your age, gender, training etc. You will be asked to come to a discussion group along with some other staff members who you may or may not know. During the discussion group, the researcher will ask a number of questions about the groups' experiences of working with South Asian families. There are no right or wrong answers.

The group discussion will take place in a private room at your place of work, within working hours. The discussion will be recorded with an audio digital recorder and the researcher may also take written notes.

Appendix T (page 2 of 3): Participant Information Sheet (links to chapter 6, study 4)

After the discussion, the recording of the session will be transcribed. If you wish to have a copy of the research report, this will be sent at your request.

What are the possible disadvantages and risks of taking part?

It is not anticipated that there will be any disadvantages or risks to taking part in the research. However, there is a slight possibility that you may become emotionally distressed talking about your experiences. In the first instance, you will be encouraged to seek the support of your clinical manager who has agreed to be available

for support. Alternatively, you will be able to talk to psychologists with experience of working with this service user group, if you so wish to discuss any further issues.

Please note that if you were to disclose any instances of malpractice, the interviewer would have to report this to the appropriate authorities.

What are the possible benefits of taking part?

Taking part in the research will give you an opportunity to discuss your experiences and for these to be considered by other people. You will not be financially reimbursed for taking part in this study.

What happens when the research study stops?

If the research were to stop, participants will be contacted and informed of this by the researcher. A report will be written once the research is finished.

What if there is a problem?

If there are any problems, or you have any concerns about the research, you should initially contact the researcher who will try to answer your questions (see contact details below). If your concerns are not answered satisfactorily and you wish to complain, you can do this through the NHS Complaints Procedure.

Please remember that you can withdraw at any time if you wish and any information relevant to you will be destroyed.

Will my taking part in the study be kept confidential?

All information collected during the course of the research will be kept anonymous. All identifiable information will be removed from both written and computer held data and from the final report. Verbatim quotes will be used in the final report, but again these will be kept anonymous. The only people who will see unedited data will be members of the research team. All material will be destroyed three years after the research is completed. Data collected during the study may be looked at by individuals from the University of Birmingham, regulatory authorities or from the NHS Trust.

Appendix V: Interview Schedule (links to chapter 6, study 4)

1. If you were told that you would be working with a South Asian family what would your expectations be?
Prompts:
 - *Are there any distinctive features about South Asian culture for you?*
 - *What would you do to prepare?*
 - *If participants say religion/culture- ask for examples they've experienced*
2. Do you think culture/religion impacts how South Asian families understand disabilities? (If so how?)
Prompts:
 - *What do they think caused LD?*
3. Do you think culture/religion impacts how South Asian families respond to disabilities? (If so how?)
Prompts:
 - *I.e. the types of interventions they see out or the way in which they provide care?*
4. Do you think that there are differences between first (immigrants) and second generation (British born but SA heritage) South Asians in terms of how they understand and respond to intellectual disabilities?
5. When you work with South Asian families who do you primarily work with, why do you think that is?
Prompts:
 - *Which member of the family? Why?*
 - *If they say whole family is involved- ask whether that influences how they work with families?*
6. What do you think are the needs of South Asian families caring for a child with intellectual disabilities?
Prompts:
 - *Do you think the needs of the child are fully understood by South Asian parents?*
7. What is it like working with South Asian families?
Prompts:
 - *Is there anything you find difficult?*
 - *Do you think it is different to working with families from other backgrounds? (e.g. White families), if so how?*
 - *Experiences of working with interpreters/translators?*
8. What do you think could improve the way you work with South Asian families?
Prompts:
 - *Do you think there are enough resources to help you?*
 - *If you wanted to find out more about a certain culture where would you go?*
9. If your service was in a rural area and you didn't have so much cultural work what do you think would be different?

Appendix W: Background Questionnaire (links to chapter 6, study 4)

**UNIVERSITY OF
BIRMINGHAM**

Perceptions of Learning disability staff towards South Asian Communities (Focus Groups)

Background Questionnaire

We would like you to provide the following information so that we have a general description of the people who have been interviewed. It will help us to provide a description of participants who have participated in the interviews.

Age _____ years

Gender _____

Ethnicity _____

Length of time as an employee in services for people with learning disabilities
_____ (years/months)

Length of time at this organisation _____ (years/months)

Approximate length of time in current role _____ (years/months)

How many South Asian families have you worked with in the last 6 months (approx)? _____

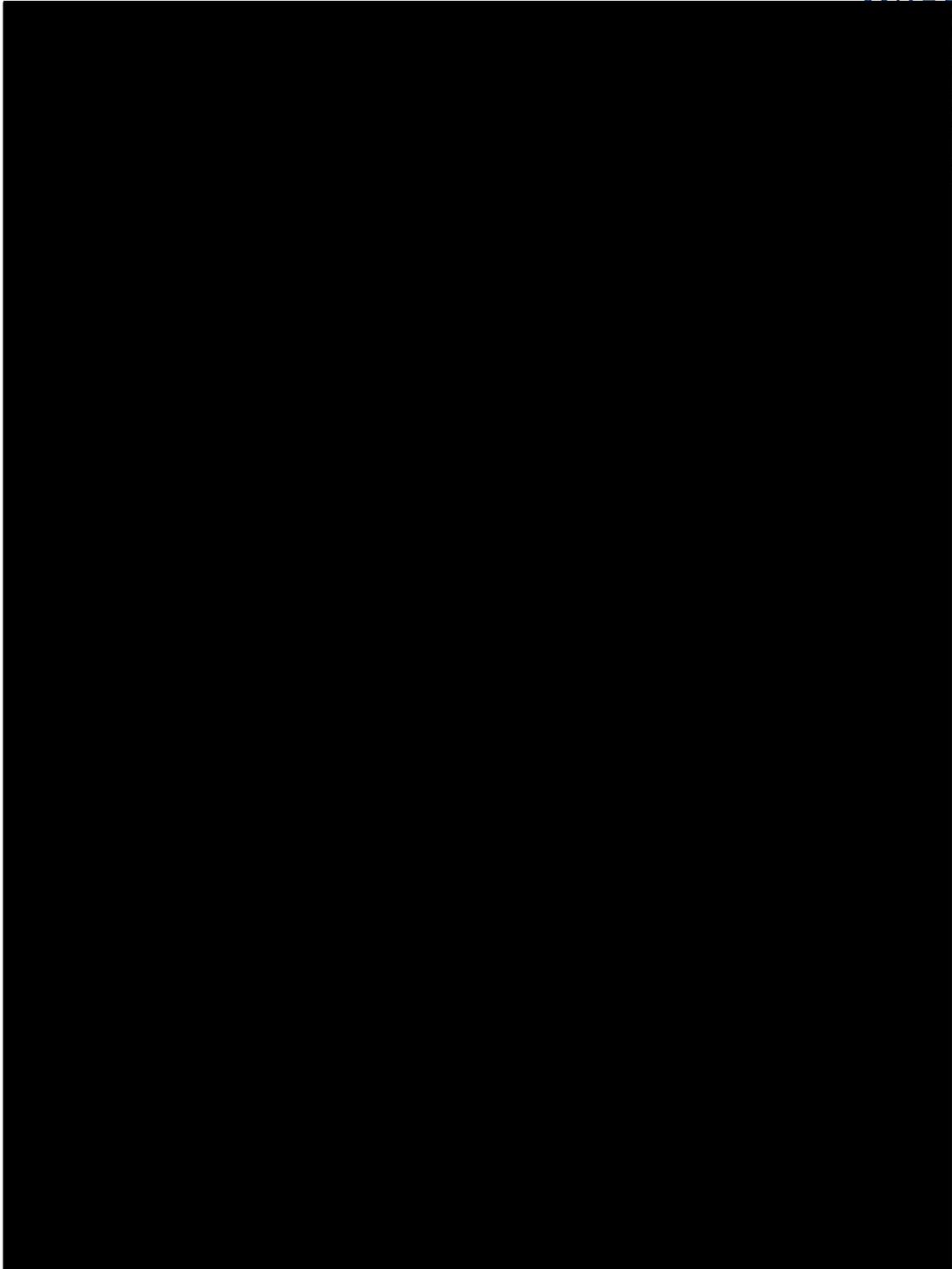
Qualifications

Training received (including any cultural training)

Thank you

Miss Kuljit Heer
School of Psychology
University of Birmingham
Birmingham

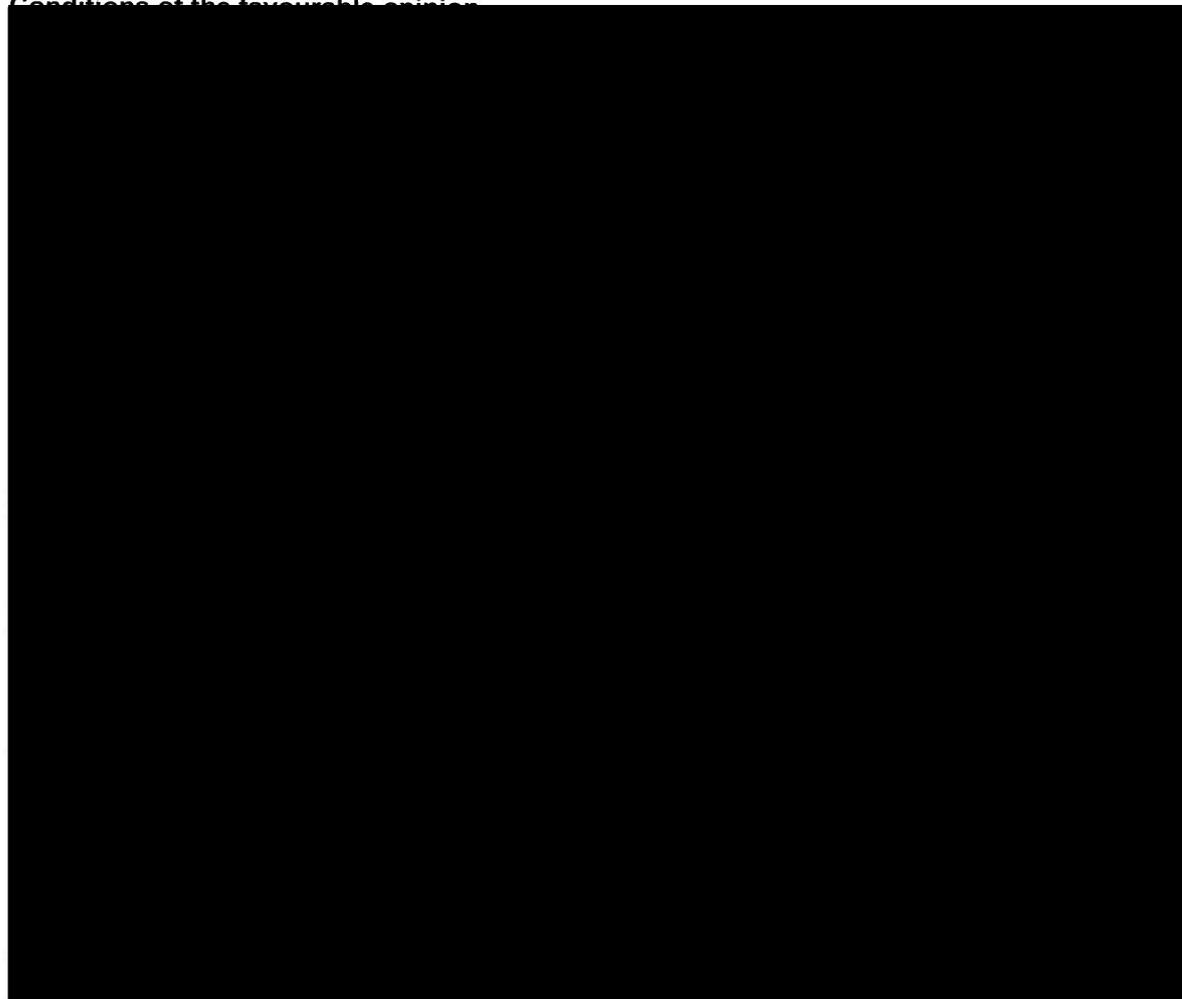
Appendix X (page 1 of 3): Ethical Approval Letter (links to chapter 6, study 4)



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the study (see “Conditions of the favourable opinion” below).

Conditions of the favourable opinion



The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV	v1	01 September 2010
Protocol	v1	01 September 2010
CV - Academic Supervisor		17 September 2010
Focus Group - ground rules	v1	01 September 2010
REC application		03 September 2010
Covering Letter		01 September 2010
Letter from Sponsor		19 September 2010
Interview Schedules/Topic Guides	v1	01 September 2010
Participant Information Sheet: PIS	v1	01 September 2010
Participant Consent Form: Consent Form (focus group)	v1	01 September 2010
Questionnaire: Background Questionnaire	v1	01 September 2010
Evidence of insurance or indemnity		19 August 2010
Referees or other scientific critique report		12 August 2010



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Appendix Y (page 1 of 7): Additional Quotes (links to chapter 5, study 3)

Master theme	Sub-theme	Quotes	Participant	Group
Language as a primary barrier	<i>Challenges faced when using interpreters</i>	“It depends on the interpreter really, because some really understand what you’re trying to put across and they’ll be able to do that really well, whereas I think perhaps other people don’t and it doesn’t always work.”	Joanne	1
		“It was quite funny because the interpreter turned up and started talking to the parent and he (parent) was just like staring at the interpreter with an expression like I don’t really know what you’re saying, it was just really bizarre and then when he left the parent told me there’s sixteen different dialects to his language [laughs] [Group gasp]. And I just didn’t know that and just assumed that one interpreter would be enough.”	Brigid	1
		“Things I’d think about when working with South Asian families would be establishing their preferred language and assessing whether an interpreter would be required. So that would probably be the first thought.”	David	2
		“I’ve found that it was easy to get an interpreter to come on the initial visit but it was harder to find someone to interpret written information, so with any recommendations or treatment plans were quite hard to get somebody to commit to spending what would probably equate to a couple of hours.”	Jacky	2
		“When working with South Asian families I think the first thing that I’d be thinking about would be any issues with language, ‘would they be able to understand me? Is there anybody in their family to speak English, to make sure that I will be able to communicate with them?’”	Jane	3
		“I’ve only been to one meeting with a South Asian family where they used an interpreter and I found it quite difficult to be honest, because the interpreter put a mixture of words in or it’s completely different to what you’re trying to say. So I found myself looking at the mum’s facial expression and I found it very difficult to know if she was getting the right information and I felt quite uncomfortable to be honest.”	Dawn	3
		“You lose a lot when you have an interpreter and in a therapeutic setting you can’t really have a three way thing because you lose so much information and you want to avoid sharing personal information.”	Amrit	4
		“I don’t know how useful they were or if they were telling me exactly what the person was saying. It’s always worrying when the person speaks for about three or four minutes and the interpreter simply says he said ‘yes’ [laughter]. Something is not quite right.”	Imran	5
		“Maybe if the interpreters get more training in kind of like concepts of mental health, LD whatever it is you know about.”	Sukhdeep	5

Appendix Y (page 2 of 7): Additional Quotes (links to chapter 5, study 3)

Master theme	Sub-theme	Quotes	Participant	Group
Language as a primary barrier	<i>Using informal interpreting methods</i>	“For me it’s probably something that developed based on experience and I think my experience working with South Asian families is that there seems to be somebody within the household who does the translation and it only sort of hits me sometimes when there isn’t somebody who is able to do that and you think we can’t communicate and I think that’s when you start to check.”	David	2
		“At my last job even if there was a family member you’d still use the interpretation service because you knew that they would say everything that you said and they would report back everything that the family said. But the family members quite often seem to not interpret everything because they would be taking information themselves and talking with you and not always including the people you want to talk to.”	Penny	2
		“That information should be there for the referrer so we would be able to find that out, you know we’ll be told whether I need an interpreter or whether a family member will do that, or whether language isn’t a problem.”	Ben	3
		“One of the most important things would be looking at how they communicate, so is English their first language? If it is a different language which language is it? Is it something I can speak or one of my colleagues can speak?”	Amrit	4
		“Because I can speak both languages it’s sometimes easier for them to sort of have a conversation with me than one of the other staff nurses, you got a lot more out of them as well.”	Zara	5

Appendix Y (page 3 of 7): Additional Quotes (links to chapter 5, study 3)

Master theme	Sub-theme	Quotes	Participant	Group
Striving to engage	<i>Frustration at barriers</i>	“I’ve always found that the first generation always encourage the family to go to them (the family) to seek emotional support, because I remember suggesting counselling for one family member and they said ‘if she needs that support we’ll give it to her within the family and that’s what her husbands there for, that’s what her mother in-laws there for.’ So sometimes I find that they like to support each other within the family, a lot more.”	Brigid	1
		“I think they do the best as they can within the home and it’s when it gets to breaking point then it’s like ‘ok now I need help from somebody.’ Whether that’s because they don’t know the services exist because our leaflets maybe aren’t accessible I don’t know. The majority of the South Asian families I’ve worked with they’ve sort of left it till the last minute.”	Rachel	1
		“A lot of our work is in the home and knowing what would be acceptable within the home environment or to ask somebody to do something like to demonstrate how we’d get them off the bed or how they get themselves in and out the shower or dressed or whatever, would perhaps be very different to doing it with the Caucasian families.”	Jacky	2
		“Again as a generalisation I think maybe my experience over the years is a lot of Asian families seem much more contained and sort of less reliant on other things and my experience of working has been that what seems to be more helpful is practical help.”	David	2
		“When you do home visits you get uncles and aunties coming in, but beforehand we do tell them about confidentiality. I work mostly with the mums, aunties or sisters.”	Anju	4
		“I think maybe it’s sticking to your own, maybe absorbing, fear of services, fear of what happens when you go to a service, you don’t speak the language, kids might get taken away to care and things like that you know, loss of control perhaps which goes against keeping it in the family and you know you keep it within the community.”	Sukhdeep	5

Appendix Y (page 4 of 7): Additional Quotes (links to chapter 5, study 3)

Master theme	Sub-theme	Quotes	Participant	Group
Striving to engage	<i>Struggling with engagement and progress</i>	<p>“I was thinking about accepting the learning disability. I’ve been working with a South Asian family and there is a young boy with a learning disability and autism and I think that mum has this hope for him that one day he will improve and he won’t be as autistic or his learning disability won’t be that apparent. She’s got lots of theories that these holistic therapies will help and he will improve and so I think it’s quite hard really because she doesn’t really accept the disability, she’s just hoping that one day he’ll be like the rest of the family.”</p>	Sharon	1
		<p>“The underlying theme seems to be about getting better, getting out and then being able to get married, it appears sometimes as though there isn’t a great deal of understanding about the persons condition and the longer term impact of that.”</p>	Laura	2
		<p>Ben: “I think every family is different but I’ve worked with families who will say that ‘it’s God’s will’ that their child has a learning disability and it’s their responsibility to look after them and they can’t give that responsibility to anyone else including us.” Tom: “We don’t engage the families much on these discussions though do we really? Well I don’t anyway about you know religious and spiritual sides. Ben: We don’t engage any family like that, really.”</p>	Ben & Tom	3
		<p>“There’s a parent who knows her son has got disabilities but, I feel like she doesn’t want to know about it. When she does take him out she tells her family that ‘he’s very naughty’ and when they ask if he’s got a disability she denies it, she says ‘he’s just very naughty, very hyper.’”</p>	Anju	4
		<p>“Don’t you think there’s a denial from the family? They probably think that they’ve got a mental condition or disability but they don’t sort of see how that can affect them in the long term, they’re thinking in the short term and things will be alright. So maybe it’s the fact that they’re not expecting that somebody is actually going to stay like this.”</p>	Zara	5

Appendix Y (page 5 of 7): Additional Quotes (links to chapter 5, study 3)

Master theme	Sub-theme	Quotes	Participant	Group
Striving to engage	<i>Managing diversity</i>	“Second generations might be more westernised and more happy to do and go with whatever really, just more open to suggestions and for the professionals to be getting involved and you know referrals to be made and things, so there aren’t really any barriers.”	Joanne	1
		“It’s not making the assumption that just because this persons from a particular culture that all the things that you’ve been taught in your equality and diversity course automatically applies to them, it doesn’t mean to say that we have to agree with all the sorts of things that you’d automatically think of with that cultural label.”	Laura	2
		“I don’t think it’d be particularly different no matter what their background was. I’d like to think that in our services, it’s about the individual, you look at their needs and treat them accordingly.”	Paul	3
		“Naturally as you’ve grown up you know about Indian culture, Muslim culture and the differences and things like that but I think you learn more on the job when you go to the houses, because even though you might be going to a Muslim family or whatever background they are, in each family everyone is slightly different so you’re gonna have different values, different beliefs, some might actually be very westernised, so you just kind of take it as it comes.”	Amrit	4
		“I think rightly or wrongly culture would inform my thinking, but it wouldn’t particularly make me work differently, I guess I’d have to assess that when I get there you know and you would be thinking before you get to the house ‘maybe they’re traditional maybe they’re not’, those things do come into play when you get there.”	Sukhdeep	5

Appendix Y (page 6 of 7): Additional Quotes (links to chapter 5, study 3)

Master theme	Sub-theme	Quotes	Participant	Group
Striving to engage	<i>Making it work</i>	“Sometimes parents understand the strategies you’re putting in place and they might agree, but sometimes there might be conflicts between the parents of the child and the grandparents. Whether things are done how they used to be done, how they’ve bought up their children and taking advice from us. So I think maybe find out where the power and the authority is really in the family.”	Rachel	1
		Tom: “It’s quite helpful, we do have an Indian assistant psychologist and I’ve been trying to use him, particularly with his language skills, I’m not sure it makes a huge difference.” Ben: “I mean whether it helps to overcome the barriers to actually accessing services I’m not sure that it does. It seems more fundamental than language.”	Tom & Ben	3
		“I think that’s where your assumptions are challenged because they might be from the same background but everyone’s different, so you just have to adapt yourself to however that family is, to work effectively with them.”	Amrit	4
		“Sometimes they just need that little push and telling them there are services they can access, we’re here to help but if you don’t talk to us we cannot do anything for you.”	Anju	4
		“You do anything to help really and meet the individuals needs, it was easier for me to sort of do the assessments, understanding the cultural background and what’s important and how they eat and everything for that person, its like having that knowledge, it was easier for me to do it rather than somebody else, because I’m Pakistani myself I know what it’s gonna be like.”	Zara	5

Appendix Y (page 7 of 7): Additional Quotes (links to chapter 5, study 3)

Master theme	Sub-theme	Quotes	Participant	Group
Striving to engage	<i>Looking for a way forward</i>	“I think more education and awareness (group agreement) about disability and autism, cos I think sometimes it’s a bit mystical isn’t it? That umm, there might be different beliefs hat it’s, it’s caused by a particular illness that can be cured or umm they can have a, go to a religious person for it to be cured . It’s almost quite rejecting of the child as well, I dunno that’s difficult. Cos that would makes things a lot easier if there was acceptance there.”	Sharon	1
		“I think for myself I need to be more aware of the different cultures, I don’t think that I really know an awful lot about what is and what isn’t acceptable and I think we need to build a resource because that’s something that could be quite valuable for us as a team.”	Jacky	2
		Ben: “I don’t think we have enough staff of Asian backgrounds who understand, who can help the rest of us, I think that’s a deficiency of our service here. Paul: I’d agree with that particularly in our service, I don’t think there is or it doesn’t really reflect the population of the Borough in our service make-up.”	Ben & Paul	3
		“It would be quite good if we could have some materials that were bilingual or in Urdu, Mirpuri or Punjabi, cos then you could leave them with some resources you know like psycho-education to explain the nature of the problem.”	Amrit	4
		“In my experience you have people in the community who know everything and it’s about getting those people to share that knowledge with the other carers through word of mouth. I think communication is important, it’s building on the relationship, it’s building that trust.”	Anju	4
		“Religiosity can be one of the manifestations of mental illness, so that sounds like a good focus to have an impact, maybe even some sort of worker who could be based in places of worship that would be a good idea, they could have an educative role and also act as a first contact, they could signpost people on a voluntary basis rather than forcing them.”	Imran	5

Appendix Z: Dissemination of results

Published papers

Heer, K., Rose, J. & Larkin, M. (2012): Understanding the experiences and needs of South Asian families caring for a child with learning disabilities in the United Kingdom: An experiential–contextual framework. *Disability & Society*.

doi:10.1080/09687599.2012.699276

Heer, K., Larkin, M., Burchess, I. & Rose, J. (2012) The cultural context of care-giving: Qualitative accounts from South Asian parents who care for a child with intellectual disabilities in the UK. *Advances in Mental Health and Learning Disabilities*, 6(4), 179-191.

Presentations at conferences

International Association for the Scientific Study of Intellectual Disabilities (IASSID), Rome, 2010. [Poster].

The Third Qualitative Research on Mental Health Conference (QRMH3), Nottingham, 2010. [Oral presentation as part of symposium].

Interpretative Phenomenological Analysis (IPA) Conference, Belfast, 2009. [Oral presentation].

University of Birmingham, Graduate School Poster Conference, Birmingham, 2009. [Poster].