Beliefs and attitudes towards intellectual disability within the UK Pakistani community as perceived by key community members

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OVERVIEW

Part 1 is a literature review investigating South Asian parents' perceptions of their child's intellectual disability, its effects on family life and views on service use. Search strategies used to identify relevant literature are specified and the results are presented in three parts. Firstly, experiences of parents regarding the process of diagnosis and provision of support are discussed. Secondly, their perceptions of the causes, symptoms and prognosis of their child's intellectual disability are presented. Lastly, the effects of having a child with an intellectual disability on parenting and family life are outlined. The findings are then summarised and implications considered.

Part 2 is a qualitative study designed to address gaps identified in the literature review, focusing on the attitudes and beliefs of the Pakistani community in the UK regarding intellectual disabilities. The results highlight the importance of taking the views of this community in account in implementing current UK policy centred on choice, independence and social inclusion for people with intellectual disabilities within a multicultural society. The results are followed by a discussion of the findings, where the study's strengths and limitations, implications for policy and service provision are also considered. Finally, a direction for future researchers is suggested.

Part 3 is a critical appraisal detailing personal reflections and considering methodological issues which arose during the study.

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PART 1: LITERATURE REVIEW

Experience of diagnosis, service provision and beliefs amongst South Asian parents of individuals with intellectual disabilities

ABSTRACT

Objective: To review the literature on South Asian parents' perceptions of their child's intellectual disability, its effects on family life and views on service use.

Method: The literature was searched using the electronic databases PsychINFO, EMBASE and Medline using the OVID interface for the period January 1995 to September 2010. This was supplemented with hand searches of relevant journals.

Results: A total of 19 relevant studies were identified. Of these, nine focused on experiences of South Asian parents regarding the process of diagnosis, support and its provision. Six examined parents' perceptions of causes, symptoms and prognosis of their child. Fourteen explored how having a child with an intellectual disability affects parenting and family life in South Asian families. Overall findings indicate high stress levels among these parents, particularly where children present with behavioural problems, concern about high levels of stigma and a general lack of awareness amongst South Asian parents about intellectual disabilities and services. They were also less satisfied with the services received mainly because of lack of information and service provision in their preferred language and unavailability of culturally appropriate services. Small samples and lack of control groups make these findings less than robust and limit their generalisability.

Conclusions: The review highlights a number of factors that appear to pose additional challenges for these parents. As much of the evidence is derived from small unrepresentative samples, further research is needed.

1. INTRODUCTION

Intellectual disabilities (ID) affect 2-3% of the population worldwide and are defined as a "reduced ability to understand new or complex information, or to learn new skills (impaired intelligence); and reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development" (Department of Health [DoH], 2001, p. 14; ICD-10, World Health Organisation [WHO], 1990).

According to the UK Census (2001), South Asians[1] constitute approximately 2,083,759 (3.5%) of the UK population which is about 50% of the UK's non-European population (Office for National Statistics [ONS], 2001). It has been suggested that the prevalence of intellectual disabilities (and especially more severe intellectual disabilities) may be up to three times higher amongst the South Asians aged five to thirty-two (Emerson et al., 1997), though this has been contested (McGrother, Bhaumik, Thorp, Watson & Taub, 2002).

Literature to date suggests that South Asian parents of individuals with intellectual disabilities have significant concerns and unmet needs (Lee, Syed & Bellis, 1998; Modood et al., 1997). There are also indications that despite the higher prevalence and high support needs in these populations, the uptake of specialist services, or community health and social resources is lower than for white families (Baxter, Poonia & Ward, 1990; Lindesay, Jagger, Hibbert, Peet & Moledina, 1997). There are various reasons for the

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[1] South Asia typically consists of India, Pakistan, Bangladesh, Nepal, Sri Lanka, Bhutan. Some definitions may also include Iran, Myanmar, Afghanistan, Tibet, the Maldives and the British Indian Ocean Territories. However in the UK, people originating from South Asia mainly are from India, Pakistan, Bangladesh, Sri Lanka and South Asians who migrated to East Africa (United Nations , 2009).

under-utilisation of services among South Asians. One of the main factors identified is the central role of parents in the care and wellbeing of their children with intellectual disabilities. A lack of knowledge amongst South Asian parents of the causes and concepts of intellectual disabilities, and of services available has been linked to a lack of service utilisation (Fatimilehin & Nadirshaw, 1994). Furthermore, religious and cultural attitudes and beliefs were found to be incongruent with those of services in the UK and this incongruence had an impact on the access of services (Katbamna, Bhakta & Parker, 2000; Westbrook, Legge & Pennay, 1993). South Asian parents of individuals with intellectual disabilities also reported feelings of shame and stigma from their community for having a family member with intellectual disability (Croot, Grant, Cooper & Mathers, 2008; Katbamna et al., 2000). Stigma towards intellectual disabilities can lead to isolation and shame (Katbamna et al., 2000); cause emotional distress in individuals with intellectual disabilities and their families; impact on service uptake by both individuals with intellectual disabilities and their carers; and can make it difficult to implement policies.

Since all of the above mentioned factors are suggested to exert an influence on the quality of life of individuals with intellectual disabilities and their families, it seems important to formally review the evidence on the views and experiences of South Asian parents of children and adults with intellectual disabilities.

1.1. Review Objectives

Since South Asian parents play a very important role in the well-being and care of their children with intellectual disabilities (Fatimilehin & Nadirshaw, 1994; Katbamna et al.,

2000), it is important to have an understanding of their experiences, beliefs and attitudes. Therefore, this paper aims to present a critical overview of the literature referring to their beliefs and attitudes regarding intellectual disabilities. It is hoped that this will expand on the current understanding of how South Asian parents perceive the intellectual disability of their child and what factors affect their relationship with their children and with services.

1.2. Review Questions

The main questions which this review will aim to answer are:

1) What experiences do South Asian parents of children with intellectual disabilities have regarding the process of diagnosis and provision of support?

2) How do they perceive the causes, symptoms and prognosis of their child with an intellectual disability?

3) How do they think having a child with an intellectual disability has affected their parenting and family life?

2. METHODS

2.1. Search Strategy

Multiple search strategies were used to identify articles that focused on beliefs and attitudes amongst South Asian parents of people with intellectual disabilities. Firstly, an electronic search of relevant databases using a combination of terms and their alternatives was conducted (Table 1). Search terms were truncated with (*) to allow for multiple spellings and ending of words. The databases PsychINFO, EMBASE and

Medline were searched using the OVID interface for the period January 1995 to September 2010.

Table 1
Search terms and number of relevant studies

Learning Disability*/ Intellectual disabilities*/ Mental Retardation*/Mental handicap*

* denotes truncation

In combination with:

Combination Terms	Total studies	No of relevant studies	Combination Terms	Total studies	No of relevant studies
South Asian*	12	3	Experience*	1136	0
Asian*	44	3	Discrimination*	205	0
India*	152	4	Coping*	250	0
Pakistan*	31	5	Effect on life*	1383	0
Bangladesh*	12	1	Prejudice*	15	0
Ethnic* Minority*	8	0	Stigma*	96	0
Parent*	1638	10	Shame*	7	0
Family*	1412	2	Pity*	5	0
Mother*	73	0	Help*	347	0
Father*	67	0	Support*	1735	1
Carer*	148	1	Cause*	955	1
Attitude*	595	3	Treat*	1083	0
Belief*	141	0	Religion*	95	0
Opinion*	39	0	Islam*	2833	0
Thoughts*	30	0	Hindu*	15	0
Knowledge*	234	0	Prognosis*	4	0
			Diagnosis*	0	0

Note: Some relevant studies were identified under several search terms.

Relevant studies were initially identified by looking at titles. The abstracts of articles whose titles appeared remotely relevant were read. In cases where the abstract was absent or did not provide sufficient detail, the full paper was read. Suitability for review was based on filtering the retrieved articles against the following criteria.

To be included in the review, studies had to:

- address at least one of the following areas, namely experiences of South Asian parents of children with intellectual disabilities regarding the process of diagnosis and provision of support; perceptions of South Asian parents regarding the causes, symptoms and prognosis of their child with an intellectual disability; effects on parenting and family life as a result of having a child with an intellectual disability.

- explicitly include views of South Asian parents of individuals with intellectual disabilities.

- be published in English between January 1995 and September 2010.

- be published in peer reviewed journals to ensure some measures of quality control.

- randomised and non-randomised experimental studies, exploratory pilot studies, qualitative and descriptive evaluations were all included. However, case studies were excluded.

Reference lists of retrieved studies were reviewed to identify further relevant studies. This reference list was also used to identify the most common journals with relevant studies. A hand-search of editions from September 2009 to September 2010 of the four journals with

the highest number of relevant articles was conducted to identify further potential relevant studies.

1. Journal of Learning Disabilities

2. Journal of Intellectual Disability Research (JIDR)

3. Disability and Society

4. Journal of Indian Academy of Applied Psychology

3. RESULTS

A total of 20 relevant studies were identified through database searches. It was not possible to obtain full articles for two of the studies. One study was identified through citation checking of the retrieved articles. No further study was identified through hand searching the journals noted. A total of 19 studies were thus included in the review. Nine studies focused on experiences of South Asian parents of the process of diagnosis, support and its provision (see Table 2, 3 & 4). Six studies examined parents' perceptions of causes, symptoms and prognosis of their children with intellectual disabilities (see Table 2, 3 & 4). Fourteen studies explored how having a child with an intellectual disability affected parenting and family life of South Asian parents (see Table 2, 3 & 4). For the purpose of this review, this literature will be grouped by their geographical location. This distinction is made firstly because of indications from previous research that South Asians are not a homogeneous group (Miles, 1992; 1995). Secondly, cross-cultural research has indicated that geographical location and acculturation is likely to play an important a role in shaping the attitudes and beliefs of any community (Berry, 1997; Ghuman, 1999). Thus,

if there is any difference in views and experiences of the South Asian parents as a result of acculturation, it will be identified and reflected on.

3.1. Studies conducted in India

3.1.1. Description of studies

A total of ten studies were conducted in India (see Table 2). Two of these studies looked at experiences of parents regarding the diagnostic process, support and experiences of seeking it. Two studies looked into the perceptions of parents regarding the causes, symptoms and prognosis of their child with an intellectual disability. Most of the studies (n = 7) addressed the affects on parenting and family life as a result of having a child with an intellectual disability.

Two studies (Edwardraj, Mumtaj, Prasad, Kurvilla & Jacob, 2010; Rao, 2001) used qualitiative methodologies while the rest used quantitative approaches. Edwardji et al. (2010) also included primary health care providers and teachers in their sample. However, their views were not considered in the review as the focus of the review was only on the experiences of parents. The sample sizes ranged from eight to 1256 with a median of 55. Six of the studies (Juyal, 2002; Padencheri & Russell, 2004; Upadhyay & Havalappanavar, 2007, 2008a, 2008b; Verma & Kishore, 2009) included both parents while three studies (Edwardraj et al., 2010; Rangaswami, 1995; Rao, 2001) only sampled mothers. One study (Parvathi & Vijaykumar, 1995) did not specify whether mothers or fathers took part. In the five studies that specified the ages of the children who were the focus of enquiry, the average child age was 12 years.

Table 2

Summary of studies conducted in India

Study	Method	Sample	Age of individuals with ID Mean (SD/Age range)	Review question the study answers
Edwardraj et al. (2010)	Focus groups	29 mothers in 3 groups 33 Health workers and teachers (not considered in the review) **Ethnic origin:** Indian	Not specified	1 & 2
Juyal (2002)	Structured interviews and questionnaires	35 mothers (of 17 male and 17 females children) 35 fathers (of 17 male and 17 females children)	Not specified	3
Padencheri & Russell (2004)	Structured quantitative interviews	23 pairs of parents of children (16 sons, 7 daughters) with ID	5.6 (SD = 4)	3
Parvathi & Vijaykumar (1995)	Structured quantitative interviews	50 Indian parents (25 with son and 25 with daughter with ID)	Males: 16.64 (S.D = 2.20) Females: 16.08 (S.D = 2.34)	3
Rangaswami (1995)	Structured questionnaires	40 Indian mothers (20 with children with behaviour problems; 20 with children without behaviour problems)	Not specified	3

Rao (2001)	Extensive interviews and participant observation	8 mothers	Not specified	2
Upadhyay & Havalappanavar (2007)	Structured interview	77 single Indian parents (58 widows, 19 widowers) 77 Indian parents living with partner	Children of single parents = 16.7 (SD = 6.8) Children of double parents = 15.7 (SD = 6.2)	3
Upadhyay & Havalappanavar (2008a)	Structured interviews + Group comparison	Both parents of 51 children with intellectual disabilities with no grandparental support Both parents of 51 children with intellectual disabilities with grandparental support	Without grandparental support = 7.1 (SD = 1.8) With grandparental support = 6.4 (SD = 1.5)	1
Upadhyay & Havalappanavar (2008b)	Structured interviews	Both parents of 628 Indian children	(4 – 30)	3
Verma & Kishore (2009)	Structured interviews	30 couples having children (23 males, 7 females) with ID	12.75 (6 – 25; SD = 4.76)	3

3.1.2. Summary of findings and limitations of studies

Edwardraj et al. (2010) conducted focus groups with 29 Indian mothers to ascertain their perceptions regarding the intellectual disability of their child and their experiences of support. Explanations such as 'poor mental development', 'impaired brain development', 'slow learner' and 'lower intelligence' were used by mothers to describe intellectual disabilities. The majority of mothers attributed their child's disability to medical causes (such as medication taken during pregnancy; fever, illness or seizures; poor antenatal care), followed by psychological causes (such as psychological trauma), environmental causes (such as lack of family support) and genetic ones (such as consanguineous marriages). Feelings of blame and guilt were often associated with causes which were considered under the mothers' control (such as consanguineous marriages or taking medication during pregnancy). The authors concluded that feelings of blame and guilt were most likely a reflection of the attitudes of the family and wider community who blamed the mothers for the disability of their child. These mothers reported experiencing a lot of stigma and lack of support from their communities, as well as feeling unsupported by their husbands and in-laws. They felt they were expected to assume all responsibility for the care of their child with intellectual disabilities and in addition fulfill other domestic responsibilities. They also felt that they were explicitly and solely blamed for their child's disability. The attitudes of family members and the wider community escalated their experiences of guilt, shame, embarrassment and isolation. Moreover, it had a negative effect on service uptake.

Indian mothers' expectations about the future of their children with intellectual disabilities were also explored by Edwardraj et al. (2010). Some of the mothers in their focus group were undergoing parent training programmes. These mothers felt that the treatment could improve their child's condition. However, those who were not undergoing parent training expected that the child would become completely 'normal' in future and were not willing to consider treatment options unless these were likely to result in the child 'overcoming' their disability. Overall, they felt a need for more information about the management of their child and the availability of services. However, these findings need to be generalised with caution as Edwardraj et al. (2010) recruited mothers who were seeking a tertiary level service. Although the authors have not reflected on these issues, there is a possibility of differences in views and experiences of those mothers who sought service and were included in the study and those who were not. It can be speculated that maybe mothers who felt more unsupported sought services in order to help them manage their child's intellectual disability. On the other hand, there is also a possibility of increased lack of awareness regarding intellectual disability and/or support systems available in mothers who did not seek any service. It is also possible that those mothers felt more unsupported by their families and community and that resulted in lack of access. Moreover, participants were from relatively deprived socio-economic backgrounds in South India and thus the findings may not be representative of the wider Indian population.

Edwardraj et al. (2010) also did not disclose their personal background, their own perspectives and how these factors might have influenced data collection, analysis and their presentation. Although the data was independently analysed by two researchers,

respondent validation for the themes generated was not sought, which can prove very useful in expanding researchers' insight and understanding of the phenomenon (Barker & Pistrang, 2005; Elliott, Fischer & Rennie, 1999). Moreover, as mentioned earlier grounding of the data was done by providing examples relevant to each theme. However, the authors were vague in identifying the number of participants supporting or disagreeing with each theme (for instance mentioning 'most', 'majority' of participants) thus making it difficult to ascertain the generalisability of the findings.

The experiences of lack of support and stigma from family members was not found by a study conducted earlier (Upadhyaya & Havalappanavar, 2008a), where Indian parents (51 fathers and 51 mothers) of children with intellectual disabilities who had grandparental support were compared to those without grandparental support. The results indicated that the presence of grandparents was considered as valuable in reducing the stress of caring for a child with intellectual disabilities.

Rao (2001) conducted in-depth interviews and observations with eight mothers of children with intellectual disabilities in India. The author was interested in generating insights into the efforts of parents to include their children in the community. Therefore, only mothers who were taking an active role in facilitating the inclusion of their children with intellectual disabilities within their families and communities were selected. These mothers were very supportive of their children and considered their intellectual disabilities as deficits in specific skills rather than a global problem. They encouraged them to develop skills in

different areas, to become independent and adapted the environment of their children with intellectual disabilities to meet their needs.

Indian mothers in Rao's (2001) study frequently used the word 'inconvenience' to talk about their child's disability. When explored in detail, it emerged that mothers preferred to talk of the 'inconvenience' rather than use the term 'mental retardation', which had a negative and stigmatising connotation for them. They also found it easier to describe their child's intellectual or physical disability to other people using this word rather than diagnostic terms. This 'inconvenience' was considered to be present in the context of the environment. For instance, 'inconvenience' was used in the context of a difficulty that a child was having with a specific task or in a specific area because of environmental factors, such as lack of appropriate/suitable transport or others' lack of understanding of the child's needs. In short, it was not the individual who was held responsible for lacking that skill; rather it was their environment that was held responsible for the 'inconvenience'. The mothers were of the opinion that the 'inconvenience' or the difficulty did not extend to all areas of the child's activities and there were other tasks that the child could easily accomplish. The child's 'inconveniences' were not only considered as something specific rather than global, but were also considered as changeable. The significance of the 'inconvenience' was dependent on how much understanding and support the child received from the family and the ingenuity of parents in providing such support.

Rao's (2001) study had a small sample but her extensive interviews and participant observations offered new insights. Her sample was however biased as only mothers who

took an active role in facilitating the inclusion of their children with intellectual disabilities within their families and communities were recruited. Therefore, the results cannot be generalised to mothers to whom this does not apply. Neither did Rao take into account the influence of education and socio-economic status on mothers' attitudes. Similar to Edwardraj et al. (2010), Rao (2001) did not disclose her own perspective regarding intellectual disability and how this might have influenced data collection, analysis and presentation of the findings. In conclusion, Rao's (2001) study was very informative in shedding light on perceptions of South Asian parents towards the causes, symptoms and prognosis of their children's intellectual disabilities but caution is needed in generalising these results.

Rangaswami (1995) compared the attitudes of Indian mothers who had children with intellectual disability and behaviour problems (N = 20) to those whose children had intellectual disability without behaviour problems (N = 20) using the Inventory for Screening Child Psychiatric Impairment (Langner, Gerstein, McCarthy, 1976). The results suggested that the mothers of intellectually disabled children with behaviour problems had significantly higher negative attitudes and hostility towards their child. They also found it difficult to accept their child, were not hopeful about their education, future or management of their behaviour.

Juyal (2002) and Upadhyaya and Havalappanavar (2008b) found mild to moderate levels of stress in Indian parents of children with intellectual disabilities with mothers experiencing higher stress levels than fathers. Although mothers were more protective

towards their daughters, both studies found them to be more dominating and to hold more negative attitudes towards their child with an intellectual disability than fathers, who were more accepting, especially if the child was a female. Upadhyaya and Havalappanavar (2008b) also found that these negative attitudes were increased in mothers whose children displayed behavioural problems. Moreover, both parents reported moderately high financial stresses. Overall, higher stress levels were found in those parents who were aged above 35 years, had young children (age not specified by authors) with intellectual disabilities, had more than one child with intellectual disabilities and were of low socio-economic status. The child's gender, severity of disability or parental educational level did not predict parental stress though.

Parvathi and Vijayakumar (1995) compared reactions of 25 Indian parents with a son with intellectual disability to 25 Indian parents with a daughter. Family Burden Scale (Pai & Kapoor, 1981), Rating scale for emotions (Mary, 1990), Child rearing practices scale (Nizamudin, 1984; as cited in Parvathi & Vijayakumar, 1995) and Coping checklist (Moss, 1982) were used to assess parental reactions. It appeared that parents of sons were more disappointed with their child's development, while parents of daughters were more distressed because of their child's disability. However, their samples were not well matched as parents of sons were less educated, which could have had an impact on their understanding and expectations. Parents of daughters, through being more educated, may have had a greater awareness of the permanency of their child's condition and thus experienced increased distress.

The role of gender of children with intellectual disabilities on their parents' marital intimacy was explored by Padencheri and Russell (2004) using the Intimate Bond Measure (Wilhelm & Parker, 1988). They interviewed 23 parents of children (16 boys, 7 girls) with intellectual disabilities in Southern India. The only difference observed between the two groups (boys and girls) was that boys displayed more challenging behaviour. The researchers found that the intimacy between parents of girls was significantly impaired compared with parents of boys, even when challenging behaviour was statistically controlled. They found no effect of variables such as age of parents, duration of marriage, adjustment before birth of a child with an intellectual disability, consanguineous marriage and socio-economic status on the marital intimacy of parents. The authors speculated that this difference in marital intimacy between parents of boys and girls might be due to socio-economic pressures present in India, where sons are considered more desirable and economically viable and daughters a burden. Therefore, subjective appraisals of socio-economic factors by the parents of girls with intellectual disabilities may increase marital conflicts and decrease the intimacy between them.

The affects of single parenting on stress levels of Indian parents (77 single widowed parents and 77 parents living with partner) were evaluated by Upadhyay and Havalappanavar (2007). The Family Interview for Stress and Coping in Mental Retardation (FICS-MR; Girimaji et al., 1999) was used to assess parental stress. They found that parents whose partners had died showed higher levels of stress than parents living together. The authors concluded that this may be due to a lack of support or social pressures. This stress was more prevalent in emotional and social areas than in care and

financial stress. Although the stress of caring for a child with an intellectual disability was equal amongst both sexes, mothers showed more stress than fathers in all other areas such as emotional, social and financial and total stress.

Verma and Kishore (2009) indicated a specific pattern of differences in needs in 23 Indian parents of children with intellectual disabilities when they were interviewed using The Family Needs Schedule (Peshawaria et al., 1995). The results suggested that mothers expressed more needs related to emotionality, family and social areas, whereas fathers expressed more needs related to social aids and future plans for the child. They also found that the needs of parents changed with the age of the child, with parents of younger children needing more information and support regarding their child's disability. In contrast, parents of older children were focused on seeking information on sexuality, marriage, vocation and future plans for their child. Parents of daughters with intellectual disabilities expressed more concerns and need for support in areas such as information about intellectual disabilities, child management, sexuality, marriage, emotional, social and physical support and family relations. Results also indicated that the parents of children with severe intellectual disabilities needed more housing, financial and emotional support.

Most of the quantitative studies described above shared the same limitations. Therefore, they will be discussed together in this section. Firstly, the sample size of these studies ranged from eight to 1256 participants, but none reported any power analysis, which makes it difficult to ascertain the rationale behind recruiting a specific number of people

and to establish if enough participants were recruited for meaningful conclusions. Parents in all the studies were recruited via schools or mental health institutions their children were attending. This raises the issue of selection bias and makes it difficult to generalise findings to the rest of the parents of children with intellectual disabilities who might not be seeking these services because of one reason or another.

Most of the studies did not compare groups on demographic variables such as socio-economic status, education level or family size (Juyal, 2002; Padencheri & Russell, 2004; Rangaswami, 1995; Upadhyay & Havalappanavar, 2007; Upadhyay & Havalappanavar, 2008a; Upadhyay & Havalappanavar, 2008b; Verma & Kishore, 2009) which could have an impact on parental stress and coping. The only study which did consider demographic variables (Parvathi & Vijaykumar, 1995) found differences in education, occupation of father, family and income size between parents of male and female children with intellectual disabilities, all of which could have confounded the results.

Religion, which is considered to be an important factor in shaping the beliefs and attitudes regarding intellectual disability (Miles, 1992, 1995) was not considered in any of the studies. This is especially important in India where there is a significant minority of non-Hindu religions. Thus it is possible that participants in Indian studies were also from other religions such as Islam or Christianity. However, it was not possible to distinguish what role religion played in shaping the attitudes and beliefs of participants in Indian studies.

Only one study used control groups (Upadhyay & Havlappanavar, 2008a) while the others (e.g. Juyal, 2002; Parvathi & Vijaykumar, 1995; Rangaswami, 1995) compared different groups such as mothers and fathers of children with intellectual disabilities, parents of children with intellectual disabilities who were and were not in a relationship, parents of male and female children with intellectual disabilities but did not compare their results to parents of typically developing children. It is therefore difficult to establish whether the results were specific to parents of children with intellectual disabilities or to parents of Indian background.

Structured questionnaires used in most of the studies were modified, developed or validated on Indian population. However, one study (Rangaswami, 1995) did not provide any information on the psychometric properties of the measures used.

Only three studies (Padencheri & Russell, 2004; Upadhyay & Havalappanavar, 2007; Verma & Kishore, 2009) provided information on the analyses used. However, most of the studies (Juyal, 2002; Padencheri & Russell, 2004; Rangaswami, 1995; Upadhyaya & Havalappanavar, 2007; Upadhyaya & Havalappanavar, 2008b; Verma & Kishore, 2009) used multiple t-tests or correlations without correction, thus increasing the risk of Type I error. Therefore, the results of these studies need to be interpreted with caution.

3.2. Studies conducted in Pakistan

3.2.1. Description of studies

A total of three studies were conducted in Pakistan (see Table 3). A study by Mirza, Tareen, Davidson and Rahman (2009) addressed all three review questions while the other two studies (Ansari, 2002; Sabih & Sajid, 2008) focused on the effects on parenting and family life as a result of having a child with an intellectual disability.

One study (Mirza et al., 2009) mixed quantitative and qualitiative methodologies while the other two used quantitative approaches. As in Edwardji et al.'s (2010) study, Mirza et al. (2009) in addition to parents, included primary health care providers, teachers and faith healers in their sample. However, their views were not considered in the review as the focus of the review was only on the experiences of parents.

Table 3

Summary of studies conducted in Pakistan

Study	Method	Sample	Age of individuals with ID Mean (SD/Age range)	Review question the study answers
Ansari (2002)	Quantitative study but method not specified	50 Pakistani mothers and 50 Pakistani fathers of 20 typically developing children 20 deaf children 20 blind children 20 children with physical disabilities 20 children with intellectual disabilities	Not specified	3
Mirza et al. (2009)	Structured and semi-structured interviews, quantitative survey	100 surveys of carers 16 in depth interviews of carers 7 Carers' focus groups 10 interviews of key primary mental health care providers (excluded in review as not relevant to the research questions) ***Ethnic origin:*** Pakistani	Survey: 16.08 (13.78-19.19) Interviews: Not available	1, 2 & 3
Sabih & Sajid (2008)	Structured interview	30 pairs of parents of children with autism	(4 – 18)	3

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3.2.2. Summary of findings and limitations of studies

Mirza et al. (2009) conducted in depth interviews and focus groups with carers of individuals with intellectual disabilities to explore management of intellectual disabilities in Pakistan. A general lack of information regarding intellectual disability amongst carers was reported, where it contributed to delayed diagnosis and lack of service utilisation. Furthermore, carers in rural areas had a lot of difficulty accessing services as these were located only in major cities. In the absence of formal health and social support institutions, the main sources for guidance and solace for a lot of parents were traditional healers and school teachers.

Theological explanations were commonly given by parents in Mirza et al.'s (2009) study. Parents believed that having a child with an intellectual disability was a gift from God and thus it was a pious act of faith to look after such a child to the best of their abilities. Some also felt that supernatural causes or poverty had influenced their child's development.

Parental concerns and expectations towards their child's future were also explored by Mirza et al. (2009). Parents reported worries about their child's future (53%) and fears of violence towards others by their child (30%). Concerns were also raised about stigma, possible abuse and neglect towards their intellectually disabled children from their next of kin and community. Parents' expectations of the future were influenced by their understanding of the child's disability, which in turn also had an impact on service uptake. The majority of these parents did not have much hope for their child's future. They felt that apart from divine help, nothing could improve their child's condition and their main role

was to look after their child's basic needs. The results of this study are very informative. However, they need to be generalised to the rest of the Pakistani population with caution as Mirza et al. (2009) only recruited participants from the Punjab (a province in Pakistan), which is the largest and best resourced of all provinces. Therefore, lack of awareness and lack of services may be of even greater concern in areas which are more deprived. Moreover, Mirza et al. (2009) tried to recruit a representative sample consisting of participants from primary, secondary and tertiary care, the primary care sample was purposive which can create a selection bias. They also did not disclose their assumptions and beliefs regarding intellectual disabilities and their impact on data generation and presentation. They used different researchers to reach a consensus regarding analysis. However, the results were not validated with the respondents which may have added to the strength of the analysis (Barker & Pistrang, 2005; Elliott et al., 1999).

Mothers living in Pakistan also reported higher stress levels than fathers as a result of caring for their children with intellectual disabilities (Sabih & Sajid, 2008). Similar to previously mentioned studies, parents of younger children (4 – 9 years) and daughters experienced significantly higher stress levels than parents of children of older children (10 – 18 years) and parents of sons. There were however major limitations in this study. Similar to studies conducted in India, the sample size was not justified and there was no control group, which makes it difficult to ascertain whether the results were specific to parents of children with intellectual disabilities. The sample was recruited from different hospitals and mental health institutions creating a possible bias in selection and disregarding the experiences of those not seeking services. Moreover, effects of socio-

economic factors, educational levels, level of support etc were not taken into account. Neither did the authors provide any information on psychometric properties of the measures used.

Pakistani parents were found to have a warmer and more accepting attitude towards those children whose disability was visible when Ansari (2003) compared the attitudes of 100 parents of children with different disabilities (intellectual disabilities, deafness, blindness, physical disability) to parents of typically developing children. He used an Urdu version of Rohner's Parental Acceptance-Rejection Questionnaire (Rohner, 1986). Parents were more comfortable with physical disabilities compared to intellectual ones. Of note, there was no difference between the two groups in terms of parents' warmth and acceptance of their child, nor was the child's gender important. However, mothers were more rejecting towards their child with intellectual disabilities than fathers. Ansari concluded that this may be in line with earlier evidence by Miles and Miles (1993; as cited in Ansari, 2002) and Shahzadi (2000; as cited in Ansari, 2002) that mothers are usually blamed in Pakistani society for their children's problems. Mothers also have greater responsibility towards their children but are considered to have less authority than their husbands. Therefore, Ansari (2002) concludes mothers may feel the need to behave in a more authoritarian manner to discipline the child leading them to be perceived as more rejecting towards their children. The results of this study need to be generalised with caution as the authors provided no information about the design used, sampling procedure or demographics of the sample.

3.3. Studies conducted in the UK

3.3.1. Description of studies

A total of six studies were conducted in the UK (see Table 4). All of these studies looked at experiences of South Asian parents regarding the diagnostic process, support and experiences of seekingsupport. Three studies looked into the perceptions of South Asian parents regarding the causes, symptoms and prognosis of their child with an intellectual disability (Bywaters, Ali, Fazil, Wallace & Singh, 2003; Croot et al., 2008; Hatton et al., 2010) and four studies addressed the effects on parenting and family life of having a child with an intellectual disability (Bywaters et al., 2003; Croot et al., 2008; Hatton et al., 1998; Hatton et al,. 2010).

Four of the six studies used qualitative methodologies (Bywaters et al., 2003; Croot et al., 2008; Hatton, Akram, Robertson, Shah & Emerson, 2003; Hatton et al., 2010), one used a quantitative approach (McGrother et al., 2003) and one used both qualitative and quantitative methods (Hatton, Azmi, Caine & Emerson, 1998).

The sample size of South Asian participants in these studies ranged from seven to 206. All the studies included both parents as participants. The age range of individuals with intellectual disabilities who were the focus of enquiry was 1 – 61 years with an average of 16.35 years. One study did not specify the age (Hatton et al., 2010).

Table 4

Summary of studies conducted in the UK

Study	*Method*	*Sample*	*Age of individuals with ID Mean (SD/Age range)*	*Review question the study answers*
Bywaters et al. (2003)	Semi-structured interviews	Total = 19 **Ethnic Origin:** 3 Pakistani mothers 11 Mothers and fathers from Pakistani origin 5 Mothers and fathers from Bangladeshi origin	10.57 (5-19)	1, 2 & 3
Croot et al. (2008)	Semi-structured interviews	Total = 18 **Ethnic Origin:** 9 Pakistani mothers; 6 Pakistani fathers and 1 Pakistani Grandfather 1 Afghani mother and 1 Afghani father	9.2 (4-16)	1, 2 & 3
Hatton et al. (1998)	Structured interviews	54 carers (49 Mothers; 2 fathers; 1 sister and 2 wives)	22 (14 - 43)	1 & 3

		Ethnic Origin: 34 Pakistani 2 Indian 9 Bangladeshi 9 East African originating from Indian subcontinent		
Hatton et al. (2003)	Semi-structured interviews and Cross-sectional survey	*Phase 1:* 26 interviews (19 mothers, 1 father, 5 couples, 3 others) *Phase 2:* 136 interviews (123 mothers, 11 fathers, 18 others) *Phase 3:* 20 parents from phase 1. *Ethnic origin:* Pakistani, Indian, Bangladeshi, East African Asian	*Phase 1:* 11.1 (2-19) *Phase 2:* 11.5 (1-21)	1
Hatton et al. (2010)	Semi-structured interviews	7 South Asian families (mostly parents, some other family members) 7 White British families (all parents)	Not specified	1, 2 & 3
McGrother et al. (2002)	Structured interviews + Group comparison	2540 individuals with ID and their carers *Ethnic Origin:* 206 South Asians 2334 White British	South Asian: 33.7 (20-61) White British: 41.2 (20-93)	1

3.3.2. Summary of findings and limitations of studies

Hatton et al. (1998) interviewed 54 carers of individuals with intellectual disabilities using structured interviews to assess the level of support and stress in carers. In addition to demographic information, they collected information using the Disability Assessment Schedule (Holmes, Shah & Wing, 1982), Client Service Receipt Inventory (Personal Social Services Research Unit, 1990) and Malaise Inventory (Rutter, Tizard & Whitmore, 1970). They also sought suggestions from carers for improving services for people with intellectual disabilities. The results suggested inadequate formal (i.e., by social and health services) and informal (i.e., by family, friends and community) support networks available for South Asian families living in the UK compared to white British people. This is of concern given that only half of the participants preferred to seek support from their extended families in time of crisis rather than services. In addition, very few of those who welcomed support from their extended family members had them living locally or assisting with care of their children with intellectual disabilities. Apart from day services, there were reports of significantly lower awareness and uptake of psychiatric services, residential and respite care among South Asians. Hatton et al. (1998) suggested that South Asian parents were more likely to be aware of different services if they could speak and write English, if their child with intellectual disabilities was difficult to supervise, if the household income was higher and if they had lived in the UK for a longer period of time. Uptake of services was dependant not only on awareness regarding the services in question, but was also affected by a lack of trust about the quality of care; cultural inappropriateness of existing services in terms of diet, activities and the gender of staff; and in some instances

racial discrimination within services and dissatisfaction with the availability of or amount of provision South Asian parents were receiving.

South Asian parents felt that their children with intellectual disabilities were highly dependent on them and this had a negative effect on their family and social life (Hatton et al., 1998). The increased dependency often left them feeling that they had to put the needs of their child above their own. About 80% reported physical and mental health problems, including back problems, chest pains, feelings of tiredness and depression. They also reported increased stress, worry about their child's future, feelings of isolation and feeling trapped. In contrast, families who were receiving support from family, friends and services reported a more positive outlook (Hatton et al., 1998).

The majority of participants in Hatton et al.'s (1998) study were from low socio-economic backgrounds, were Muslims (85%) and/or of Pakistani origin (63%). This raises doubts about the generalisability of the findings to the wider South Asian population.

A cross-sectional comparison between South Asian (N = 206) and white British (N = 2334) individuals known to the Leicestershire Learning Disability Register was conducted in 1991 by McGrother et al. (2002) to assess service need and use amongst South Asian. The information was collected with the use of semi-structured interviews with carers. The results suggested that South Asians were less aware of services available and made significant lower use of psychiatric services, residential care and respite care than their

white British counterparts. Financial strain and caring stress was also reported to be higher among South Asian parents.

While McGrother et al. (2002) compared South Asians to White British parents, there were major differences in the two groups in terms of number of participants (South Asian parents = 206; White British parents = 2334) and socioeconomic status, with South Asians being of significantly lower socio-economic status than the white British sample. The study was a cross-sectional epidemiological study over an 11 year period (from 1987 to 1998). Service structures and demographics of the population such as migration patterns, educational levels and socio-economic status are likely to have changed over such a long period, yet the authors did not discuss the potential implications of such changes for their findings.

Parental understanding and acceptance of their child's disability, identification of the emotional and practical needs of parents, increasing uptake of informal and formal supports and increasing satisfaction with the services received are deemed to be affected by the process of disclosure of the child's intellectual disability to the parents (Hatton et al., 1998, 2003). Hatton et al. (2003) explored experiences of South Asian parents regarding the process of disclosure of diagnosis of intellectual disabilities using in-depth interviews. The results suggested variable experiences by parents during the disclosure process, ranging from very good to very poor. They concluded that examples of good disclosure practice included a prompt disclosure in the appropriate language, clear information about the child's disability and the practical implications for the family,

disclosure being handled in an emotionally supportive way and linked to the provision of support services and, finally conducted with both parents present. Although the overall level of satisfaction with the disclosure process was similarly moderate among South Asians (48%) as in previous studies with White British families (Sloper & Turner, 1993), they found that good disclosure practice was less common (14.7%) for the South Asian families participating in the study (Hatton et al., 2003).

Two areas of concern unique to South Asian parents regarding the disclosure process were identified by Hatton et al. (2003). The first aspect was who imparted the diagnosis. Although 91% of South Asian parents received a diagnosis of their child from a specialist consultant, GP or health visitor soon after assessment, a significant minority (9%) received a diagnosis from a special education needs provision where the child had already been placed. Although Hatton et al. (2003) did not comment on the significance of this finding, it suggests a possible delay in the diagnosis or its clear communication to the parents. The second area of concern was the language used with the parents in providing diagnosis and care. Parents almost without exception preferred to be given their child's diagnosis in their first language, which for all but one family was not English. Ninety two percent of the parents also preferred written material to be in their own language. In contrast, the majority of the disclosures were conducted in English (67%) and most of the written information was also only available in English (88%). About half of the parents were able to understand the information they received and were satisfied with the technical level of the language. However, about 20% found the information too difficult to understand and retain. These dificulties were more prominent among Indian and Pakistani

parents when compared to Bangladeshi parents. About 40% of the parents also said they would have welcomed support after disclosure, but this was available to only 5% of the parents. Although about 40% of the parents mentioned racism and discrimination in service provison as a major reason for services not being used by South Asians, this was not viewed as the cause of poor disclosure practice.

The results of Hatton et al.'s (2003) study however need to be treated with as the majority of participants were of Pakistani origin and thus the findings may well not apply to all South Asians in the UK. Moreover, factors such as socio-economic status, level of support available, number of children with intellectual disabilities which can have an impact of the awareness and access of service were not taken into account in the analysis or interpretation of the results.

Bywaters et al. (2003) interviewed Pakistani and Bangladeshi parents regarding their experiences of support and stigmatisation from their community. Only a minority of participants did receive some highly valued emotional and practical support from neighbours, friends and family. Overall, they reported experiencing a lack of support, stigma and prejudice from their extended families and community. Some parents felt that members of their community were fearful that their child's intellectual disability was contagious. Others experienced their community as blaming and critical towards them. The parents concerned were very distressed by stigmatising and discriminatory attitudes of their community and felt excluded. Moreover, the families who reported increased stigma were less likely to use services than others. South Asian parents also complained

of a lack of support and understanding and of being ridiculed by their own communities. These perceptions had an effect on their engagement with their community and thus led them to feel isolated and vulnerable. Their willingness to take their children on visits to other people's homes was frequently affected as a result of stigma from their communities. In addition, the practical problems of transport where children had additional physical disabilities added to this reluctance.

Bywaters et al. (2003) also explored perceptions of South Asian regarding the causes of intellectual disabilities and expectations towards their child's future. Findings suggest a range of biomedical (such as genetic influences) and theological (such as gift, test, punishment or curse from God) factors. In general, parents expected that their child's impairment would have a considerable effect on their future lives particularly that they were less likely to be independent and get married. However, they did not have many expectations from services and felt that they themselves were more likely to care for them. Some parents were not satisfied with social services, especially when they were unable to help them with improving their housing situation or when it was not possible for services to meet respite care needs. For instance, one parent needed six weeks of respite to visit her home country but only one week respite was available (Bywaters et al., 2003). Overall, parents felt a need for more information about the management of their child and the availability of services.

Croot et al. (2003) examined beliefs about the causes of intellectual disability among Pakistani families living in the UK. All participants made reference to theological

explanations about their child's disability. . However, several parents also gave biomedical or other explanations. While consanguineous marriage was named as a possible cause by parents in Bywaters et al.'s (2003) study, none of the parents in Croot et al.'s study (2008) put this forward marriage as an explanation, despite a number of them being married to close relatives. The authors also noted that parents often initially gave theological explanations but resorted to biomedical discourse when they felt blamed or stigmatised by their community. The presence of both theological and biomedical explanations is in contrast with the study conducted by Bywaters et al. (2003), where a single explanation for the child's disability was given by parents. Only a minority gave theologically based explanations, and these were limited to ideas about disability as a curse, test or punishment from God or simply as 'God's will'. Theological explanations in Croot et al.'s (2008) study were broader and also included ideas such as a child with intellectual disability representing a "gift or blessing from God" or a chance for parents to receive future rewards and salvation from God. Main biological explanations given by parents in both studies included a lack of oxygen during birth, deficiency in the child's nervous system, mother's illness during pregnancy, the child's illness in infancy, side-effects of medication or the failure of a doctor to diagnose the child's illness swiftly enough. Some mothers blamed themselves and felt that their carelessness during pregnancy was the cause of their child's disability.

Negative perceptions and stigma from their own community were also reported by participants in Croot et al.'s (2008) study. They experienced their community as blaming and critical towards them. The parents were very distressed by these stigmatising and

discriminatory attitudes of their community, felt excluded and as a result had resentment and negative views towards them. Moreover, similar to participants in Bywaters et al. (2003), families who experienced increased shame and stigma were less likely to use services than others.

Hatton et al. (2010) conducted semi-structured interviews with South Asian carers to understand the perceptions of challenging behaviour of the family member with an intellectual disability. These results were then compared with white British carers. The results suggested that while both South Asian and white British parents described problem behaviours displayed by their children with intellectual disabilities as difficult within the context of family life, South Asian parents tended to draw on narrower explanations about the causes of their child's behaviours. They mainly attributed these problems to attitude problems, personality difficulties, motivational problems or a desire to cause conflict.

Experiences of support and its provision and impact on family life as a result of having a family member with intellectual disabilities was also explored (Hatton et al., 2010). Lack of understanding and support, negative perceptions and stigma from their own community as reported by studies mentioned earlier were also reported by some of the South Asian participants in Hatton et al.'s (2010) study. These perceptions had an effect on their engagement with their community, thus led them to feel isolated and vulnerable. There were also reports of limited service support in terms of timing, duration, flexibility and relevance. Constant change of staff was another source of dissatisfaction. Some families

reported a constant sense of struggle to get and keep support from the services. Difficulties and negative experiences of support from services led to a sense of frustration, uncertainty and mistrust.

A common limitation in most of the studies (except Croot et al., 2008) conducted in the UK were that they considered South Asians as one group and no distinction was made about differences in attitudes, beliefs and experiences of parents from different ethnicities, religions and cultures. The potential effect of generation or number of years in the UK, socio-economic status and educational levels was also not specifically considered in any of the studies. For instance, in Bywaters et al.'s (2003) and Hatton et al.'s (2003) studies the majority of participants were of Pakistani origin. In Croot et al.'s study (2008), although all the participants were of Pakistani origin, most (69%) were born outside the UK. There is a possibility that individuals brought up in the UK, urban areas in Pakistan or indeed other South Asian countries may have different ideas about intellectual disabilities, which in turn can have an impact on experiences of diagnosis and support seeking. However, these aspects were completely ignored in all of the studies.

All the qualitative studies (Bywaters et al., 2003; Croot et al., 2008; Hatton et al., 1998, 2003, 2010) shared a few common limitations when evaluated in the light of key recommendations for conducting and presenting a qualitative research (Barker & Pistrang, 2005; Elliott et al., 1999; Mays & Pope, 2000). Similar to previously mentioned qualitative studies, researchers' personal background, perspectives, assumptions or beliefs and how these influenced data collection, analysis and presentation were not

mentioned in any of the studies. Three studies (Croot et al., 2008; Hatton et al., 2003; Hatton et al., 2010) used consensus methods to analyse the data while the other two did not elaborate on how the credibility of results was checked. Triangulation methods to validate findings (May & Pope, 2000) were also not used by any of the studies.

4. DISCUSSION

(Miles (1992, 1995) suggests that South Asians are heterogeneous in terms of their attitudes and beliefs regarding intellectual disability. Moreover, there are indications from cross-cultural research that geographical location is likely to play an important role in the acculturation of values and norms of a particular community which in turn is likely to influence the attitudes and beliefs of any particular group (Berry, 1997; Berry, 2001; Ghuman, 1999, 2000). However, if acculturation is considered in detail, it has to take into account a number of individual (such as age, gender, education, pre-acculturation status, migration, motivation, expectations, language, religion, personality) and group (such as dominant society's and society of origin's attitude; level of support; political and economic situation) factors which may be pertinent (Berry & Sam, 1996; Ward, 1996). This section will therefore consider such factors while discussing the studies reviewed.

The evidence reviewed indicates that a variety of explanations about the causes of intellectual disabilities were provided by parents regardless of their country of origin or country of residence. These explanations consisted of theological, biological and environmental explanations. However, none of the studies took into account individual or group variables (such as religion, education, generational differences, society's attitudes)

which are known to affect the development of causal explanations (Berry, 1997; Miles, 1992, 1995). For instance; Indian studies did not mention the religious status of their participants. Although Hinduism is the dominant religion in India, other religions such as Islam, Christianity and Sikhism are a significant minority (Office of The Registrar General and Census Commissioner, 2011). Thus, it is possible that a number of participants in the Indian studies were of different religions and their beliefs and attitudes were influenced by their respective religion. It is also possible that as a result of religious affiliation, Muslims living in India have very similar explanations to Muslims living in Pakistan or the UK. On the other hand, acculturation of dominant religious and cultural ideas and practices could also be present among minority groups living in India. However, the affect of religion, nationality or geographical location can not be verified as no distinction was made in studies conducted in India. Similarly, studies conducted in Pakistan also did not mention the religious status of participants. All studies except one (Hatton et al., 2003) conducted in the UK mentioned participants' religion. However, none of them looked at this aspect in detail in terms of how religious affiliation may affect causal explanations and/or attitudes towards intellectual disabilities.

There was also a tendency amongst researchers in the UK to cluster together all South Asians in one group instead of examining possible differences by religion and nationality (e.g. Bywaters et al., 2003; Hatton et al., 1998; McGrother et al., 2002). Detailed analyses of religious and cultural constructions of intellectual disabilities (Berry & Dalal, 1996; Miles 1992; 1995) indicate that there is marked variation among South Asians, both in terms of understanding of intellectual disabilities and treatment of individuals with intellectual

disabilities. Therefore, in order to get a clearer understanding of attitudes of South Asians towards intellectual disabilities, it is vital to take into account geographical and religious differences instead of clustering South Asians as one group.

In addition to religion and culture, other important factors such as generational differences and degree of acculturation were also ignored. This is especially relevant to the studies conducted in the UK where participants were of different generations, had been in the UK for variable number of years and had different opportunities to acculturate. In the studies under review, it was not possible to ascertain the role of acculturation on beliefs and attitudes of the parents. This is because there was not much demographic information about the participants and none of the studies measured to what extent participants had integrated with Western ideas by using scales such as the Acculturation Scale (Ghuman, 1975, 1997, 1999). Without such information it is very difficult to ascertain what differences there are between participants of studies conducted in the UK, India or Pakistan, and to what extent differing results are due to cultural factors or other variables, such as socio-economic background or education.

It was interesting to note that mothers reported higher stress levels, feelings of blame and a higher sense of responsibility for their child's upbringing especially in the Indian and Pakistani studies. Edwardraj et al. (2010) also reported that mothers were explicitly blamed for their child's disability by their family and community members. Parents' reactions were also different for male and female children. For instance, Parvathi and Vijayakumar (1995) mentioned that parents of male children were more disappointed and

parents of female children showed more distress at children's delayed development. These differences could be a result of socio-economic pressures present in developing countries in South Asia, where sons are considered more desirable and economically viable and daughters a burden. Moreover, a sense of blame towards the mother could be a result of dominant discourses present in such countries where the primary role of a woman is considered to provide a healthy son to the family (Miles, 2002). It is also worth noting that although parents from the UK studies reported blame and stigma from their communities, no study looked into the differences between mothers and fathers or the role of gender of the child with an intellectual disability. Thus, it cannot be determined whether gender differences which are found in studies conducted in India and Pakistan are also applicable in the UK where socio-economic conditions are very different, as are potentially discourses about disability.

Parents' expectations of their children's future varied a lot ranging from expecting minimal changes to the child 'overcoming' their disability altogether. Although there are marked differences in service provision between the UK and the other two countries, overall a lack of awareness and utilisation of services was found. In the UK, parents were more aware of day care services and therefore used these more often. Overall, South Asian parents were less satisfied than white British parents with services received. In India and Pakistan, the main reason of dissatisfaction with services seemed to be a lack of provision and access to services. However, in the UK, the main reason for this dissatisfaction seemed to be a lack of availability of information and services in preferred non-English languages and the cultural inappropriateness of services. There were also suggestions

that good practice in diagnosing intellectual disabilities was less common for South Asian families than for their white British counterparts. The main reasons for this lack of good practice were that disclosures were not presented at the right time and in the parents' preferred language (Bywaters et al., 2003; Hatton et al., 2003). The lack of language resources in services is an important issue which can not only negatively affect diagnosis but also the future care of individuals with intellectual disabilities. Studies have established that South Asian parents tend to have much less awareness of residential and respite care services. Hatton et al. (1998) noted that participants were more likely to be aware of services if they can speak and write English and this in turn has an impact on service utilisation. However, there has not been any research which controlled for other variables, such as socioeconomic status and parents' educational attainments and investigated the importance of language using a rigorous methodology.

Low socioeconomic status has also been associated with low uptake of services (Hatton et al., 1998). However, as mentioned earlier no research has controlled for this factor or explored their effects on service uptake.

South Asian parents both living in South Asian countries and in the UK reported experiencing a lot of stigma and lack of support from their communities and sometimes from their immediate family members. This increased their feelings of shame, guilt and exclusion and also had a negative effect on service uptake (Bywaters et al., 2003; Croot et al., 2008; Edwardraj et al., 2010). There are however no published studies on the attitudes and beliefs towards intellectual disabilities among the South Asian general

population. Findings also suggest that stigmatising attitudes may not only be present in the wider community but also in the parents and close family members of children with intellectual disabilities (Edwardraj et al., 2010). Thus, it is vital to understand the prevalence of stimatising attitudes in the South Asian community, what factors influence levels of stigma and the effects of stigma.

4.1 Future research

This review has highlighted a number of issues which should be addressed in future research. There is a need to consider methodological issues that would make it possible to generalise the findings to the wider South Asian population living in the UK. As noted, geographical, acculturation, religious and socioeconomic factors will also need to be taken into consideration in future research. Moreover, it is important to consider how cultural, religious and socioeconomic factors affect the beliefs, attitudes and experiences of parents. Since a lot of studies have suggested that parents experience stigma and shame from their communities, it is important to understand what the beliefs and attitudes of the general population in South Asian communities are.

5. REFERENCES

Ansari, Z. A. (2002). Parental Acceptance-Rejection of Disabled Children in Non-Urban Pakistan. *North American Journal of Psychology, 4*, 121-128.

Barker, C., & Pistrang, N. (2005). Quality criteria under methodological pluralism: Implications for conducting and evaluating study. *American Journal of Community Psychology, 35*(3/4), 201-212.

Berry, J., & Dalal, A. (1996). *Disability attitudes, beliefs and behaviours: Report on an international project in community based rehabilitation.* Report submitted to International Centre for the Advancement of Community Based Rehabilitation.

Berry, J. W., & Sam. D. (1996). Acculturation and adaptation. In J. W. Berry, M. H. Segall, & C. Kagitcibasi (Eds.), *Handbook* of *Cross-Cultural Psychology (3rd ed.). Social Behavior and Applications.* Boston: Allyn & Bacon.

Berry, J. W. (1997). Immigration, acculturation and adaptation. *Applied Psychology: An international review,* 46 (1), 5 – 68.

Berry, J. W. (2001). A Psychology of Immigration. *Journal of Social Issues, 57* (3), 615 – 631.

Baxter, C., Poonia, K., & Ward, L. (1990). *Double Discrimination. Issues and Services for People with Learning Difficulties from Black and Ethnic Minority Communities.* London: King's Fund Centre.

Bywaters, P., Ali, Z., Fazil, Q., Wallace, L., & Singh, G. (2003). Attitudes towards learning disability amongst Pakistani and Bangladeshi parents of disabled children in the UK: considerations for service providers and the disability movement. *Health Soc Care Community, 11,* 502-509.

Croot, E. J., Grant, G., & Cooper, C. L. (2008). Perceptions of the causes of childhood disability among Pakistani families living in the UK. *Health and Social Care in the Community, 16*, 606-613.

Department of Health. (2001). Valuing People: A new strategy for learning disability for the 21st century. London: HMSO.

Edwardraj, S., Muntaj, K., Prasad, J. H., & Jacob, K. S. (2010). Perceptions about intellectual disabilities: a qualitative study from Vellore, South India. *Journal of Intellectual disabilities Research, 54*, 736-748.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative study studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215-229.

Emerson, E., Azmi, S., Hatton, C., Caine, A., Parrott, J., & Wolstenholme, J. (1997). Is there an increased prevalence of severe learning disabilities among British Asians? *Ethnicity & Health, 2*, 317-321.

Fatimilehin, I., & Nadirshaw, Z. (1994). A Cross-cultural study of parental attitudes and beliefs about learning disability. *Mental Handicap Research, 7*, 202-227.

Ghuman, P.A.S. (1975) *The cultural context of thinking*. Slough, Bucks: National Foundation for Educational Research.

Ghuman, P.A.S. (1997). Assimilation or integration? A study of Asian adolescents. *Educational Research, 39* (1), 23 - 36.

Ghuman, P.A.S. (1999). *Asian adolescents in the West*. Leicester: The British Psychological Society.

Ghuman, P. A. S. (2000). Acculturation of South Asian adolescents in Australia. *British Journal of Educational Psychology, 70*, 305 - 316.

Girimaji, S. R., Srinath, S., Sheshadri, S., & Krishna, S. (1999). Family interview for stress and coping in mental retardation (FISC-MR): A tool to study stress and coping in families of children with mental retardation. *Indian Journal of Psychiatry, 41*, 341-349.

Hatton, C., Azmi, S., Caine, A., & Emerson, E. (1998). Informal carers of Adolescents and adults with learning difficulties from the South Asian communities: Family circumstances, service support and carer stress. *British Journal of Social Work, 28*, 821 - 837.

Hatton, C., Akram, Y., Robertson, J., Shah, R., & Emerson, E. (2003). The disclosure process and its impact on South Asian families with a child with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *16*, 177-188.

Hatton, C., Emerson, E., Kirby, S., Kotwal, H., Baines S., Hutchinson, C., Dobson, C., & Marks, B. (2010). Majority and minority ethnic family carers of adults with intellectual disabilities: Perceptions of challenging behaviour and family impact. *Journal of Applied Research in Intellectual Disabilities, 23*, 63 – 74.

Holmes, N., Shah, A., & Wing, L. (1982). The Disability Assessment Schedule: a brief screening device for use with the mentally retarded. *Psychological Medicine, 12*, 879 – 890.

Juyal, S. L. (2002). Impact of parental attitude on adjustment pattern of their mentally handicapped children. *Journal of Personality and Clinical Studies, 18*, 97 – 104.

Katbamna, S., Bhakta, P., & Parker, G. (2000). Perceptions of disability and care-giving relationships in South Asian communities. In W. I. U. Ahmad (Eds.), *Ethnicity, Disability and Chronic Illness* (pp. 123–138). Buckingham: Open University Press.

Langner, T. S., Gerstein, T. D., & McCarthy, E. D. (1976). A screening inventory for assessing psychiatric impairment in children 6 to 18. *Journal of Consulting and Clinical Psychology, 44*, 286.

Lee, B., Syed, Q., & Bellis, M. (1998). *Improving the Health of Black and Ethnic Minority Communities: A North West of England Perspective*. Liverpool: Sexual Health and Environmental Epidemiology Unit.

Lindesay, J., Jagger, C., Hibbert, M. J., Peet, S. M., & Moledina, F. (1997). Knowledge, uptake and availability of health and social services among Asian Gujurati and white elderly persons. *Ethnicity and Health, 2,* 59-69.

Madood, T., Berthoud, R., Lakey, J., Nazroo, J., Smith, P., Virdee, S et al. (1997). Ethnic Minorities in Britian: Diversity and Disadvantages. London: Policy Studies Institute.

Mary, N. L. (1990). Reactions of black, Hispanic and White mothers to having a child with handicap. *Mental Retardation, 28*, 63 – 70.

Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal, 320*, 50 – 52.

McGrother, C. W., Bhaumik, S., Thorp., C. F., Watson, J. M., & Taub, N. A. (2002). Prevalence, morbidity and service need among South Asian and White adults with intellectual disabilities in Leicestershire, UK. *Journal of Intellectual disabilities Research, 46*, 299-309.

Mirza, I., Tareen, A., Davidson, L. L., & Rahman, A. (2009). Community management of intellectual disabilities in Pakistan: a mixed methods of study. *Journal of Intellectual disabilities Research, 53*, 559-570.

Miles, M. (1992). Concepts of mental retardation in Pakistan: Toward cross-cultural and historical perspectives. *Disability, Handicap & Society, 7*, 235-254.

Miles, M. (1995). Disability in an eastern religious context: historical perspectives. *Disability & Society, 10*, 49-69.

Miles, C. (2002). On Working in Peshawar with Disabled Children and Families. *Journal of Religion, Disability & Health, 6* (2), 145-148.

Moss, R. H. (1982). Coping with acute health crises. In C. G. Millon & R. Meagher (Eds.), *Handbook of Clinical Health Psychology*. New York: Plenum Press.

Office for National Statistics (2001). *2001 National Census*. London: ONS.

Office of The Registrar General and Census Commissioner (2011). India: New Delhi.

Padencheri, S., Swamidhas, P., & Russell, S. (2004). The role of gender of children with intellectual disabilities and their parents in marital intimacy in Southern India. *Journal of Learning Disabilities, 8*, 131 – 140.

Pai, S., & Kapur, R. L. (1981). The burden on the family of a psychiatric patient: Development of an interview schedule. *British Journal of Psychiatry, 138*, 330.

Parvathi, A. N., & Vijayakumar, V. S. R. (1995). Gender of the mentally retarded and associated parental reactions. *Psychological Studies, 40*, 87-92.

Peshawaria, R., Menon, D. K., Ganguly, R., Roy, S., Pillay, R. P. R. S., & Gupta, A. (1995). *Understanding Indian families having persons with mental retardation*. Secunderabad, India: National Institute for the Mentally Handicapped.

Rangaswami, K. (1995). Parental attitude towards mentally retarded children. *Indian Journal of Clinical Psychology, 22*, 20 - 23.

Rao, S. (2001). 'A little inconvenience': perspectives of Bengali families of children with disabilities on labeling and inclusion. *Disability & Society, 16*, 531 – 548.

Ritchie, J., Spencer, L., & O'Connor, W. (2003). *Carrying out Qualitative Analysis in Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage

Rohner, R. P. (1986). *The warmth dimension: Foundations of parental acceptance-rejection theory.* Beverly Hills CA: Sage.

Rutter, M., Tizard, J., & Whitmore, K. (1970). *Education, Health and Behaviour.* Harlow, Longman.

Sabih, F., & Sajid, W. B. (2008). There is significant stress among parents having children with autism. *Rawal Medical Journal, 33*, 214 – 216.

Sloper, P., & Turner, S. (1993). Determinants of parental satisfaction with disclosure of disability. *Developmental Medicine and Child Neurology, 35*, 816 – 825.

Upadhyay, G. R., & Havalappanavar, N.B. (2007). Stress among single parent families of mentally retarded children. *Journal of the Indian Academy of Applied Psychology, 33*, 47-51.

Upadhyay, G. R., & Havalappanavar, N.B. (2008a). Grandparental support for parents of mentally retarded children. *Journal of the Indian Academy of Applied Psychology, 34*, 137-141.

Upadhyay, G. R., & Havalappanavar, N.B. (2008b). Stress in parents of the mentally challenged. *Journal of the Indian Academy of Applied Psychology, 34*, 53-59.

Verma, R. K., & Kishore, M. T. (2009). Needs of Indian parents having children with intellectual disabilities. *International Journal of Rehabilitation Research, 32*, 71-76.

Ward, C. (1996). Acculturation. In D. Landis & R. Bhagat (Eds.), *Handbook of intercultural training* (2nd ed., pp. 124–147). Thousand Oaks, CA: Sage.

Westbrook, M.T., Legge, V., & Pennay, M. (1993). Attitudes towards disabilities in a multi-cultural society. *Social Science and Medicine, 36*, 615–623.

Wilhelm, K., & Parker, G. (1988). The development of a measure of intimate bonds, *Psychological Medicine, 18*, 225-234.

World Health Organisation. (1990). International Classification of Diseases (ICD)- 10. Geneva: World Health Organisation.

PART 2: EMPIRICAL PAPER

Beliefs and attitudes towards intellectual disability within the UK Pakistani

community as perceived by key community members

ABSTRACT

Background: Current UK policies aim to promote choice, independence and social inclusion for people with intellectual disabilities. However, in order to accomplish these objectives amongst the Pakistani community in the UK, it is vital to understand their attitudes and beliefs towards intellectual disability. So far, our understanding of these issues is very limited as there is no research on the general Pakistani population in the UK. The aim of this study was thus to increase our understanding in this area.

Materials and Methods: Fifteen participants were recruited for the study. These participants were key members in the Pakistani community in the UK, including teachers, religious leaders, health professionals and politicians. Council databases, personal and professional links as well as snowballing were used to recruit them. A semi-structured interview schedule was used to interview participants. Information gained from interviews was analysed using thematic analysis, in line with Braun and Clarke's (2006) outline of the approach.

Results: Thematic analysis yielded five themes indicating widespread lack of awareness regarding the concept of 'intellectual disability'. This interacted with cultural and theological factors leading to stigma, exclusion and dependence of individuals with intellectual disabilities. In some instances, however, inclusion, sympathy and acceptance were promoted.

Conclusions: The findings highlight the need for raising awareness in the Pakistani community regarding intellectual disability and the importance of culturally sensitive support.

1. INTRODUCTION

This study explored beliefs and attitudes towards intellectual disability among lay people of Pakistani origin living in the UK. Intellectual disability (also called 'learning disability' in the UK) is defined "as a reduced ability to understand new or complex information, or to learn new skills (impaired intelligence); and a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development" (Department of Health [DoH], 2001, p. 14; ICD-10, World Health Organisation [WHO], 1990). Intellectual disabilities affect 2-3% of the population worldwide. In England, it is estimated that approximately 1.2 million people have mild or moderate forms of intellectual disabilities and about 210,000 severe and profound intellectual disabilities. It is predicted that in England, there will be an increase in the total number of people with intellectual disabilities of 7% by 2011 and 11% by 2021 (Emerson & Hatton, 2004) due to factors such as increased life expectancy and survival rates of individuals with intellectual disabilities and greater prevalence among some minority ethnic populations particularly of South Asian[1] origin (DoH; 2001).

1.1. Current policies regarding intellectual disabilities in UK

Current policy in the UK is based on 'Valuing People' and 'Valuing People Now' (DoH, 2001; 2007; 2009). These have at their heart four main principles, namely social inclusion, greater choice, independence and rights of people with intellectual disabilities.

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[1]South Asia typically consists of India, Pakistan, Bangladesh, Nepal, Sri Lanka, Bhutan. Some definitions may also include Iran, Myanmar, Afghanistan, Tibet, the Maldives and the British Indian Ocean Territories. However in the UK, people originating from South Asia mainly are from India, Pakistan, Bangladesh, Sri Lanka and South Asians who migrated to East Africa (United Nations, 2009).

'Valuing People' (DH, 2001) acknowledges that people with intellectual disabilities from Black and minority ethnic communities (BME) are at particular risk of discrimination in gaining access to appropriate health care. It is noted that problems arise when professionals are insensitive to or not aware of cultural and/or language issues of minority ethnic communities or make inaccurate assumptions about how they would like to care for their relatives with intellectual disabilities. It recommends that the National Health Service (NHS) promotes equality for people with intellectual disabilities from BME communities in accordance with its new general duty under the Race Relations (Amendment) Act 2000. A 2005 review of progress since the publication of 'Valuing People' concluded that in many places there was not much change in the lives of people with intellectual disabilities, especially ones with more complex support needs and those from minority ethnic communities (Greig, 2005).

1.2. Intellectual disabilities amongst South Asians in the UK

According to the UK Census (2001), there are approximately 2.3 million British Asians, constituting 3.9% of the UK population. Amongst those, almost 1.1 million (2.7% of the population) are of Indian origin, 747,285 people of Pakistani origin (1.5%), 283,063 of Bangladeshi origin (0.5%), and 247,664 'other' Asian (0.4%) (Office for National Statistics [ONS], 2001).

It has been suggested that the prevalence of intellectual disabilities (and especially more severe intellectual disabilities) may be up to three times higher amongst young South Asians (aged five to 32) than their white British counterparts (Emerson et al., 1997),

although this has been contested by McGrother, Bhaumik, Thorp, Watson and Taub (2002). It has also been suggested that South Asian families with a member with intellectual disabilities are particularly disadvantaged in terms of housing, income, employment and health (Chamba, Ahmad, Hirst, Lawton & Beresford, 1999; Hatton, Azmi, Caine & Emerson, 1998). Despite a possible higher prevalence and high support needs in this population, the uptake of specialist services (Lee, Syed & Bellis, 1998; Modood et al., 1997), or community health and social resources (Baxter, Poonia & Ward, 1990; Lindesay, Jagger, Hibbert, Peet & Moledina, 1997) is lower than for white families. Various reasons for the under-utilisation of services among South Asians have been identified, including a lack of knowledge of the causes and concepts of intellectual disabilities, and of services available (Fatimilehin & Nadirshaw, 1994); religious and cultural attitudes and beliefs that are incongruent with those of services (Katbamna, Bhakta & Parker, 2000; Westbrook, Legge & Pennay, 1993); feelings of shame for having a family member with an intellectual disability (Katbamna et al., 2000); a lack of culturally appropriate service provision (Bywaters, Ali, Fazil, Wallace & Singh, 2003); negative stereotypical views held by some professionals and service providers about BME communities (Butt & Mirza, 1996; Chamba et al., 1999; Mir, Nocon, Ahmad & Jones, 2001); and in some cases, availability of extensive family support (Bywaters et al., 2003).

South Asian families with a member with intellectual disabilities also report significant stigma and negative stereotypes within their own communities (Mir et al., 2001). Understanding more about the stigma associated with intellectual disabilities among lay people is important as it can lead to isolation and shame (Katbamna et al., 2000), cause

emotional distress in individuals with intellectual disabilities and their families, affect service uptake and can make it difficult to implement policies (Ali, Strydom & Williams, 2008). There is however only one published study which has tested these claims at general population level and found widespread confusion among South Asians about the concept of 'intellectual disability' and lack of knowledge about its causes. The study revealed that although participants expressed many positive beliefs, on closer analysis ambivalent and even hostile attitudes were evident (Coles & Scior, in press).

1.3. Intellectual disabilities in a Pakistani context

Pakistan is a diverse country with more than sixty languages. Majority (96.28%) of the population is Muslim while 1.9% are Hindus, 1.6% Christians, 0.2% Ahmadi and 0.001% Sikhs (ONS, 2001).

As mentioned earlier, the prevalence of intellectual disabilities amongst young Pakistanis may be up to three times higher (Emerson et al., 1997). This makes it important to learn more about the attitudes and beliefs of the Pakistani population about intellectual disabilites. However, to date, no research has been conducted on attitudes and beliefs of the general Pakistani population in the UK. Even of the research conducted on Pakistani family members, that which concerns people with intellectual disabilities is minimal. One of the reasons for the lack of research may be the overall modest amount of research conducted on ethnic minorities. In addition, there is a tendency amongst researchers to cluster together all South Asians into one category instead of looking at one specific ethnicity (e.g. Bywaters et al., 2003; McGrother et al., 2002). This ignores the fact that

South Asians are a very heterogeneous group, with marked cultural and religious diversity (Miles, 1992; 1995) and thus may view intellectual disabilities differently. There may also be differences amongst different South Asian cultures in terms of how they accept or integrate individuals with intellectual disabilities (Berry & Dalal, 1996; Miles, 1992). Therefore, in order to get a clearer understanding of attitudes of South Asians towards intellectual disabilities, it is vital to take into account cultural, geographical and religious differences and focus on each ethnicity instead of clustering them as one group.

There has been some research conducted on Pakistani carers which suggests a lack of knowledge amongst them about the causes and management of intellectual disabilities (Croot, Grant & Cooper, 2008; Mirza et al., 2009). Parents in these studies were aware of negative views within Pakistani culture towards disability and felt that people with disabilities were excluded from their community. Moreover, the families who experienced increased shame and stigma were less likely to use services than others. A recently published study (Yousafzai, Farrukh & Khan, 2011) on mothers in Pakistan suggests that having a child with intellectual disabilities enabled the mothers to become more independent in terms of seeking health and educational services. However, they faced a lot of anxiety and stress as a result of stigmatisation by family members and the community, a lack of support for them as carers and a lack of appropriate services for health, rehabilitation and education of their children with disabilities.

Miles (1992) did some pioneering work in exploring the concept of intellectual disabilities in Pakistan. He suggested that there are major differences between Western and Eastern

cultures regarding the identification of intellectual disabilities. For example, in Pakistan, where only 30% of adults have learnt to read, inability to read would hardly indicate intellectual disability. Instead, more emphasis is placed on whether the individual can understand and follow cultural norms. Similarly, causes for behavioural and memory problems are usually attributed to stubbornness, disobedience or weak memory instead of any potential underlying disorder. He also conducted a survey of 286 urban and rural people in Pakistan. The respondents provided a variety of explanations for intellectual disabilities ranging from medical (51%) to non-medical reasons (49%). However, medical reasons were four times more likely to be given by urban than rural respondents (Miles, 1983, as cited in Miles, 1992).

Miles (2002) reflected on her experience of working in Peshawar, Pakistan with children with intellectual disabilities and their families. She experienced a general lack of awareness about intellectual disabilities among these families. Some parents attributed problems to spirits, "jinns" or curses. Other families regarded their child's problem as 'the will of Allah'. Although consanguineous marriages were very common in Peshawar, there was a lack of understanding of their genetic risks. It was quite common to blame the intellectual disability on mothers whose primary role was considered to provide a healthy son to the family. Furthermore, there was not much independence given to people with intellectual disabilities, especially to girls. However, this was a reflection of common practices in the community, while most parents were reported to give devoted care to their child. However, those who had to care for large families did not have enough time or resources to care effectively for a child with intellectual disability. Most of the parents were

very appreciative of any professional support and made use of the strategies provided by the health professionals. Families also sought help from "healing persons" in shrines, sometimes in conjunction with the help from health professionals.

1.4. Factors influencing beliefs and attitudes regarding intellectual disabilities

It has been suggested that Islam holds a fairly benevolent view of disability, viewing it as a test from Allah and thus opportunity to prove one's strength of faith (Morad, Nasri & Merrick, 2001). However, the impact of Islamic teachings on shaping Pakistani attitudes has not been clear in the limited research conducted (Miles, 1992; 1995; Morad, Nasri & Merrick, 2001). In addition to ethnicity and religion, other factors influencing beliefs and attitudes regarding intellectual disabilities have been identified by research across the world. The results suggest that more favourable attitudes are found amongst: Western cultures (Henry, Duvdevany, Keys & Balcazar, 2004; Scior, Kan, McLoughlin & Sheridan, 2010), younger people (Sinson, 1993; Tak-fai Lau & Cheung, 1999), females (Yuker & Block, 1986), relatives of individuals with intellectual disabilities (Markova & Jahoda, 1992), those with higher education and more knowledge of intellectual disabilities (Rees, Spreen & Harnadek, 1991; Tak-fai Lau & Cheung, 1999) and those with high level, quality interactions with individuals with intellectual disabilities (Parsons, Elkins, & Sigafoos, 2000). Some of these findings are, however, contradictory. For instance, some researchers reported that contact with individuals with intellectual disabilities gave rise to or reinforced negative attitudes (Goodman, Gottlieb & Harrison, 1972; Gottlieb & Budoff, 1973) or produced no significant change (Graffi & Minnes, 1988; Hagen, Powell, & Adams, 1983). Similarly, Kobe and Mulik (1995) found that while education and direct

contact improved knowledge about intellectual disabilities, it had little influence on fundamental attitudes and beliefs about intellectual disabilities.

1.5. Rationale of the study

In order to accomplish the objectives of current policies amongst the Pakistani community in the UK, it is vital to understand prevalent beliefs and attitudes towards intellectual disability within this community. The limited research on families and carers of individuals with intellectual disabilities suggests low awareness and uptake of services by individuals from Pakistani backgrounds (Hatton et al., 1998), as well as the stigmatisation and exclusion of individuals with intellectual disabilities by their community members (Croot et al., 2008; Mirza et al., 2009). However, since there is no research on the general Pakistani population, our understanding of the attitudes and beliefs prevalent in the Pakistani community is very limited and thus the information provided by family members of individuals with intellectual disabilities cannot be verified. There is only one survey available which was conducted in Pakistan 27 years ago and it reviewed the concept of intellectual disabilities in the general Pakistani population (Miles, 1983, as cited in Miles, 1992). Therefore, it is difficult to generalise the results of that survey to the Pakistani population in the UK, in a different context and after such a long time. The proposed study aims to build on the sparse information available so far and to address some of the gaps through the use of qualitative research methods, which allow the exploration of under-researched areas in detail and the evaluation of diverse cultural beliefs (Barker, Pistrang & Elliott, 2003).

1.6. Research questions

1. What understanding do Pakistani lay people in the UK have about intellectual disabilities?

2. What are the prevalent beliefs and attitudes among this community regarding causes of intellectual disabilities?

3. How does the Pakistani community respond to people with intellectual disabilities and what views are prevalent regarding their need for support and prospects for the future?

The potential impact of contextual factors, including age, gender, acculturation and education on beliefs and attitudes will be explored in the process of answering the above questions.

2. METHODS

2.1. Participants

Fifteen participants were recruited for the study. These participants were key members in the Pakistani community in the UK including teachers, religious leaders, health professionals and politicians (see Table 1). Six participants were recruited through personal contacts and three through professional contacts. The other six participants were contacted via email or telephone after finding their information from relevant databases such as council databases, a directory of Islamic centres and the NHS database. The focus of recruitment was on identifying potential participants who held a role of responsibility or leadership within the Pakistani community (n = 13). A further two participants were not of

Pakistani origin themselves but had very regular contact with the Pakistani community and had a close understanding of the community's culture and religion. The main reason for focusing on key Pakistani community members was that it was hoped this would generate a fairly comprehensive picture of the beliefs and attitudes common within the UK Pakistani community. All participants had extensive contact and links within the Pakistani community and therefore had been able to observe a range of beliefs and attitudes present within the community both on a professional and a personal level. All participants were Muslims and thus had an understanding of religious aspects in shaping the attitudes and beliefs of their community. A similarly comprehensive picture was unlikely to be gained by recruiting a convenience sample of members of the Pakistani community, unless one could recruit large numbers which was not possible within the constraints of this study. Moreover, previous research on other communities has adopted a similar approach and generated meaningful results (Cinnirella & Loewenthal, 1999; Kisanji, 1995).

Table 1

Characteristics of sample

Participants	Participants' characteristics				Characteristics of section of community participant has close contact with		Recruitment method
	Gender	Generation	Ethnic origin	Professional role	Generation with most contact	Rural/urban Pakistani background	
P01	Female	2nd	Pakistani	Health psychologist	2nd and 3rd	Urban	Personal contacts
P02	Female	2nd	Pakistani	Social worker	1st to 3rd	Both	Personal contacts
P03	Male	3rd	Pakistani	Councillor	1st to 4th	Both	Council database
P04	Male	1st	Pakistani	Councillor	1st to 3rd	Both	Council database
P05	Male	1st	Pakistani	Councillor	1st to 4th	Both	Council database
P06	Female	2nd	Indian	Clinical psychologist	1st and 2nd	Both	Professional contacts
P07	Female	2nd	Pakistani	Clinical psychologist	1st and 2nd	Urban	Personal contacts
P08	Female	2nd	Pakistani	Teacher	Mostly 2nd and 3rd	Both	Personal contacts
P09	Male	1st	Pakistani	Religious leader	Mostly 1st	Urban	Database of Islamic centres
P10	Male	2nd	Pakistani	General practitioner	1st and 2nd	Both	Personal contacts
P11	Female	2nd	Pakistani	Trainee clinical psychologist	1st and 2nd	Both	Professional contacts

P12	Female	2nd	Pakistani	Family support worker	1st and 2nd	Urban	NHS database
P13	Female	2nd	Pakistani	Social worker	1st and 2nd	Both	Personal contacts
P14	Male	1st	Kenyan Indian	Religious leader	1st to 5th	Urban	Database of Islamic centres
P15	Female	2nd	Pakistani	Family therapist	1st to 3rd	Urban	Professional contacts

2.2. Procedure

As personal and professional links were used to recruit participants, potential participants as well as individuals/organisations that might have contact with potential participants were contacted. A total of 90 potential participants were contacted directly via email (n = 83) or phone (n = 7). Another 282 individuals or organisations (such as schools) who might know of potential participants were contacted via email. The ones contacted by email were sent an information sheet (see Appendix A1 & A2). A brief overview of the study was given over the phone to those contacted by telephone.

The response rates of participants is outlined below (see Table 2), and indicates the significant difficulties in recruitment of participants with whom I did not have personal contact. For instance, a large number of individuals (n = 199) were contacted with limited success. Similarly, for the purpose of recruiting teachers, 79 schools were identified which had teachers from Pakistani backgrounds. According to school policy, all the head teachers were contacted asking them to invite staff members from a Pakistani background to participate in the study. However, only two replies were received, one showing no interest in the study and the second agreeing in the beginning, but later on not replying despite my efforts. A large number (n = 72) of local councillors were also emailed. Although the response rate was much better than for teachers, it was not high. Five showed an interest in the study and agreed to participate. However, in the end, I was not able to contact two of them.

Table 2

Response rate of participants according to each recruitment method

Recruitment methods	Contact method		Total contacted	Response rate
	email	*phone*		
Personal contacts	√		11	6
Council database	√		72	3
Database of Islamic centres		√	7	2
Schools	√		79	0
NHS database	√		4	1
Individuals in contacts with potential participants	√		199	3

A brief overview of the study was also given to all the participants at the beginning of the interview. Thereafter, written consent was obtained for the study and audio-recording (see Appendix B1 & B2). Participants were given a choice between English, Urdu or Punjabi as their preferred language for the interview. One participant (P09) opted to complete the interview in Urdu. All the documents pertinent to recruitment and the interview process were translated into Urdu by the researcher. All other interviews were conducted in English. Interviews were recorded and transcribed; the interview in Urdu was translated into English and then transcribed.

Participants were presented a box of chocolates as a thank you gift after the interview. They were also asked if they were interested in receiving a summary of results of the study once it was completed.

2.3. Materials

A semi-structured interview schedule was designed for the study (see Appendix C1 & C2), guided by the literature. For instance, questions about shame were based on suggestions of high levels of shame experienced by family members of individuals with intellectual disabilities (Bywaters et al., 2009). Questions regarding stigma were drawn from accounts of individuals with intellectual disabilities and their families, stating that they experience significant negative stereotypes and exclusion from their community (Bywaters et al., 2009). Questions regarding help seeking were drawn from the literature suggesting lower uptake of specialist services by individuals with intellectual disabilities and their families from a Pakistani background (Madood et al., 1997). Similarly, questions about causal beliefs related to reports of increased beliefs in fate and supernatural causes (Miles, 1992; Mirza et al., 2009). The interview schedule was piloted with two clinical psychologists of Pakistani origin and changes were made in light of their feedback.

A variety of terms to define intellectual disability (such as learning disability, mental retardation, mental handicap) were used in the interview. The use of these terms was dependent on participants' preferences and understanding.

Two vignettes (See Appendix D1, D2, E1 & E2) were part of the semi-structured interview and were used to facilitate a conversation about different understandings of intellectual disabilities, as well as the language used within the community to talk about this. These vignettes were developed in the light of findings from previous literature on the Pakistani community suggesting differences between Eastern and Western cultures in identification of intellectual disabilities. It has also been suggested that in Eastern cultures intellectual disability is identified through an ability to understand and follow cultural norms and values and ability to fulfill the assigned roles (Miles, 1992; 2002). Therefore, the vignettes focused on describing actual behaviour and how a person with an intellectual disability might present in the community. A diagnostic label was not provided as the aim was to facilitate discussion about the difficulties in identification of intellectual disabilities and any associated stigma in the Pakistani community especially when intellectual disability is not easily identifiable.

2.4. Conceptual framework and analysis

A wide range of conceptual frameworks are used to analyse qualitative research (Ryan & Bernard, 2000). They are roughly divided into two camps. The first camp includes methods like interpretative phenomenological analysis, discourse analysis, grounded theory and narrative analysis. These methods are guided by a particular theory or epistemological position. The second camp involves methods like thematic analysis that are independent of a particular theory or epistemology. Thematic analysis has been used widely in clinical and health psychology studies (Bywaters et al., 2003; Cinnirella & Loewenthal, 1999; Croot et al., 2008) and was used in this study to understand and

analyse the information gained through interviews. This analytic approach relies more on the descriptive representation of the participants' statements rather than interpretation.

Within thematic analysis, a researcher can take different positions, for instance, an essentialist or realist stance reports experiences, meaning and reality of the participants whereas a constructionist approach examines the way in which events, realities, meanings and experiences are the effects of a range of discourses operating within society (Braun & Clarke, 2006). In the current study, where there is a dearth of knowledge about the beliefs and attitudes towards intellectual disabilities in Pakistani culture, an essentialist or realist method was considered more appropriate. The aim of the study was to explore themes pertaining to beliefs and attitudes regarding intellectual disabilities. The themes were informed by the concept of intellectual disabilities and the existing cross-cultural literature but were not theory driven.

Braun and Clarke's (2006) outline of the process of thematic analysis (Appendix F) was followed while analysing the data. Detailed reading and re-reading of the transcripts led to the generation of initial codes. The evidence for each code was collated, discussed and revised with my supervisor (Appendix G). The revised table for initial codes is given in Appendix (H). The next stage consisted of collating codes into overarching themes (see Appendix H), which were again reviewed with my supervisor. All the transcripts were again read to review and revise the themes. Thereafter, final themes were defined (see Appendix I) and interview extracts were selected to illustrate them.

2.5. Credibility checks

In order to ensure the credibility of the themes, credibility checks were utilised (Elliott, Fischer & Rennie, 1999). My supervisor was involved at each stage of the analysis. She audited three transcripts and emerging themes were critically discussed and agreed upon before finalising them.

2.6. Researcher's perspective

Guidelines for good practice in qualitative research encourage authors to specify their theoretical orientations, personal experience and training, values and expectations pertaining to the area under investigation (Elliott et al., 1999). As part of my Clinical Psychology training, I have recognised the importance of different support systems in maximising the quality of life of individuals with intellectual disabilities. I value the efforts of current policies to promote social inclusion, independence and choice. However, being from a Pakistani background myself, I am also aware of cultural norms within Pakistani society (such as value given to joint family systems, encouragement for interdependence in the family as opposed to independence which is encouraged in Western societies, and a strong gender division), which can play an important role in the lives of individuals with intellectual disabilities. Furthermore, I know from direct experience that the implementation of policies requires careful thought in the context of the Pakistani community, due to potential clashes of values and practices.

Before starting interviewing the participants, I considered how my Pakistani background might influence the interview process. In my view, the fact that I speak the language and

am aware of cultural norms and practices could benefit the interview process in terms of engagement and facilitation of the discussion. However, these factors also raised the possibility that I would place less emphasis on issues I had more knowledge of because of my familiarity with the topic and assumption of a shared meaning with the participants. Similarly, there was also a possibility for me to place greater emphasis on issues I had less knowledge of because of my personal interest in understanding them. This potential bias was considered while developing the interview schedule and adequate prompts were included for each topic which needed to be explored to answer the research questions.

2.7. Ethical considerations

Ethical approval was obtained from University College London Research Ethics Committee (see Appendix J). Confidentiality was maintained within the usual confines.

3. RESULTS

Analysis of the interview transcripts yielded five over-arching themes which describe beliefs and attitudes towards intellectual disabilities in the Pakistani community (see Table 3). Each theme is briefly described and illustrated with excerpts from transcripts. The source of each quote is indicated by the participant's number (for instance P01). '…' denotes material omitted from the quote. Text within square brackets '[ ]' signifies clarifications added by the author.

Table 3

Distribution of themes amongst participants

Master and sub themes	P01	P02	P03	P04	P05	P06	P07	P08	P09	P10	P11	P12	P13	P14	P15
1. Awareness of intellectual disabilities															
1.1. Lack of differentiated terms and awareness regarding intellectual disabilities	o	o	o	o	o	o	o	o	o	o	o	o	o	o	o
1.2. Lack of awareness and access to professional support	o	o	o	o		o	o	o	o	o	o	o	o	o	o
2. Range of explanatory models															
2.1. Biological explanations		o	o	o		o	o	o	o	o	o	o	o	o	o
2.2. Environmental explanations			o		o		o		o			o	o		o
2.3. Theological explanations	o	o		o	o	o		o	o	o		o	o	o	o
3. Beliefs about prognosis															
3.1. Hope for normality and acceptance	o	o					o				o				
3.2. Tragedy and bleak future	o	o		o		o	o	o	o	o	o	o	o		
3.3. Worries about marriage	o	o		o	O	o	o	o	o	o	o	o	o	o	o
4. Community responses															
4.1. Stigma and negative attitudes		o		o	o		o	o	o	o	o	o	o	o	o
4.2. Sympathy and politeness	o	o	o	o	o			o		o	o		o		o
4.3. Inclusion versus exclusion	o	o	o	o	o	o	o	o	o	o	o	o	o	o	o
4.4. Views on independence	o	o	o	o	o	o	o	o	o	o	o	o	o	o	o
5. Sources of help	o	o	o	O	O	O	o	o	o	o	o	o	o	o	o

3.1. Awareness of intellectual disabilities

A lack of understanding about intellectual disabilities was reported by all participants, particularly of terminologies used in the UK to explain intellectual disabilities. The Pakistani community was also described as unable to identify symptoms and as showing lack of awareness of professional support available.

3.1.1. Lack of differentiated terms and awareness regarding intellectual disabilities

Few people were reported to use Western terminologies to explain intellectual disabilities. Five participants reported that 'pagal' (mad) was used as an umbrella term to define all 'mental disorders' in the Pakistani community.

> *They say that the person is 'Pagal'* [*mad*]. *That is the main explanation given that the child is mad (P09).*

There was however some disagreement among participants whether this term was applied to all people with intellectual disabilities or only those with more severe disabilities.

> *You know in a way I think there is almost like a threshold. Where if it is more severe than you are categorised in the 'pagals' ... if it is like mild-to-moderate then may be it is considered more just part of the normal continuum, so you know this guy is normal, yes he is just slow (P06).*

Some other commonly used terms to describe intellectual disabilities as observed by nine participants were 'retard', 'gadha' (donkey), 'idiot', 'spastic', 'mongol', 'saeen' (simple minded), 'deaf', 'dumb' and 'possessed'.

> *They will use … retard, idiot you know that kinds of things, a bit of spastic. He is a bit simple, bit slow like terms … Mongol, that is the other one. It is an awful term, but that is when I mean when people I think tend to be with Down syndrome … And they do not really understand that it is quite a harsh term (P07).*

There was agreement that the community was generally unaware of the concept of intellectual disabilities. Furthermore, an inability to identify common symptoms was reported especially when they were not physically apparent. In these cases, participants described a number of incidences where a person with an intellectual disability was classified as odd, naughty, silly, spoiled, lazy or pretending.

> *Yes, they are aware of the terms, but it is very difficult to educate them … and I feel actually psychologically that they are not in tune (P15).*

> *I think if it is severe and quite visible … I think it might be easier for them to explain ... and I think that might elicit a bit more sympathy and a bit more understanding that it has gone outside of their control and they were born like this and this is not their fault (P11).*

> *We think that if someone is Pagal or has intellectual disability, he should be disabled in everything and if he is doing some things correctly then we would say that this person … is bluffing/pretending (P09).*

> *He is a naughty boy, such a naughty boy, his parents are just out of it, they just have not controlled him. They are really bad parents (P07).*

Five participants mentioned that the Pakistani community appeared more able to understand common mental health problems such as depression and anxiety than intellectual disabilities or severe mental health problems such as psychosis.

> *I think depression is a bit more understandable in Pakistani community. I think, you know, there is a language for it and people have terms that they can use for depression … depression and anxiety I think they think it is like normal reactions to life events (P11).*

Pakistanis born and bred in the UK were reported to be more aware of intellectual disabilities than first-generation Pakistanis.

I think yes there is a difference because my generation would be more attuned to, where we understand what you mean by that mad). [intellectual disabilities/learning disabilities] whereas one generation back would not understand, they would probably need more descriptive explanation (P12).

3.1.2. Lack of awareness and access to professional support

The Pakistani community was reported to be unaware about services available for individuals with intellectual disabilities and their families. They were also not sure how to access professional support.

I do not think we are that clever about knowing the services. We are very good at you know DLA, not DLA, even benefits and stuff like that … It tends to be that the school has picked up on the difficulties rather than the parents have and it is the school who have said okay let us link in with say a place like this (P07).

A number of factors contributing to the lack of awareness and access to services were identified by participants. These included being a first-generation Pakistani and being new to the UK, a lack of education, the language barrier and a tendency to put off the problem as much as possible.

I think, maybe not as much for the first generation, but I think the fact that the second and all generations after that have practically grown up in a British environment and in British community, their understanding of this is a lot more, they are educated a lot more … so I believe the more educated they are, the more support they are able to provide and the correct support (P03).

I have seen families where they have used the older siblings to interpret. Parents, neither are they aware of what is available and nor do they have language skills set. Yeah, I think language does make a difference (P01)

With the labour worker families, they would try and put off the problem as much as they can that no, no, it will go away, it will go away … (P02).

The main reason given for the low uptake of services, especially respite care, as expressed by four participants, was shame at accessing help outside the family network.

On the whole I think there is a lot of emphasis on the family support and trying not to access support from others because it is quite a shameful experience like you cannot look after your family yourself, like you have to invite strangers into your world and your social world and I think on the whole it is quite a private experience (P11).

3.2. Range of explanatory models

Intellectual disabilities were considered to be attributable to a variety of biological, environmental and theological explanations. Each of these explanatory models is discussed below in detail.

3.2.1. Biological explanations

The biological explanations for intellectual disabilities included genetic disorder, infection and consanguineous marriages.

I think from the people I know ... it probably would be more a medical thing (P11).

Sometimes if somebody is a bit mad you know, oh yes, they have got insect [in the brain] or something dirty in their minds that has made him go all funny (P12).

The community in Luton. I think you do have this notion going around ... I am not too sure if the older community would think so, but I think the younger generation mostly would say … if they are cousins and they married, maybe that result in children having disabilities (P08).

Three participants however suggested that the community was unaware of the genetic effects of consanguineous marriages.

Yeah, we have a larger number of disabilities among the Asian community in every single town … but a lot of that is probably inbreeding, cousin marrying the first cousins and that has gone on for generations and after certain bit, these things will appear, you know that is all genetic ... It is preventable, but I do not think our community is aware of it (P04).

3.2.2. Environmental explanations

Environmental explanations given by three participants included cold showers, caesarean birth, early mistreatment of a child, the wrong diet and accidents. All these factors were believed to have an influence on brain development.

> *Sometimes there are medical reasons. Like the example of the child I gave you whose car had an accident, he was normal. He was given shower with cold water at an early age. Because of that his brain did not grow. His brain development stopped at 2-3 years old and he is now 27yrs old … or if someone is mistreated at an early age, wrong diet was given or was given a shower, or an injection like that was given (P09).*

> *But yes some people would blame it on. There is a lot of blame culture. It will be that or somebody fed you something while you were pregnant (P12).*

Five participants had heard the Pakistani community blaming parents for not bringing up their children properly and thinking intellectual disabilities in their children was a result. Inconsistent schooling was another factor mentioned by one participant.

> *Our community would think that the child is very rude. His parents have not trained him and will bear negative thoughts towards him (P09).*

> *I mean if it is something that has been assessed later on, for example if the child has been diagnosed at the age of 9 then it may be that especially in-laws will come back and say well may be you did not do this right, or you did not do that right in terms of questioning the parents upbringing. You know, you should have done this rather than as opposed to putting the child in front of the TV all the time. You know something like that that is another excuse that I have come across (P13).*

3.2.3. Theological explanations

God was referred to in explanations of intellectual disabilities; they were, for instance, considered to be a gift from God or Allah's will (reported by four participants), a test from God (reported by three participants) and God's punishment or curse (reported by eight participants).

> *You know, this is just kind of a gift from God and this is her life and this was her, how do you say, her destiny was such and that is how it is (P15).*

But then there are like religious perspective, it is like you know this is a test, some people may be born blind, some people may be born with one arm and some people are just born with some more mental challenges and so that is one explanation (P06).

Our people can be cruel sometimes. They think that the mother or father might have been naughty and done something (Interviewer: sinned.) yeah, and there is a curse on them, but that is not general, but I would say that mainly people can be unkind and say things like that (P05).

I think blaming probably comes from internal, you know when you have like an internal grudge or internal problem then the blaming comes in … I think that it probably comes from you know in-laws or people who do not like the person and they say ... 'serves them right' (P13).

One participant felt that most of the Pakistani community followed Islam as a religion and as a result were less reliant on superstitions. However, the majority felt that supernatural explanations such as magic, evil eye and possession by "Jinns" were very common despite the religious background. These supernatural explanations were more prevalent in cases where individuals with intellectual disabilities displayed challenging behaviours.

They are not going to say that they are possessed or something like that because as Muslims they are probably not as superstitious as maybe some other cultures (P02).

Still the magic thing goes on because you have got those influential grandmothers who are still around and those grandmothers of my age, in their 60s, are still believing that … because that is lack of again education you see, because they were brought up completely illiterate. They had seen their grandmothers doing these traditional things, they believed in it to be true and there is nothing you can do (P04).

So it is like maybe someone's put like a "Nazar" like an evil eye on them even like while they were in there like mother's womb or something. So that is one of the explanations (P06).

I think depending on what the disability is maybe and how the child is behaving. If it causes the child or the individual to behave in maybe a frantic manner, not in a calm way. Let's say if they have fits or if they are aggressive or if it causes their behaviour to change drastically I think you would also hear the fact that okay maybe they are possessed, by a Jinn, and that is one of the reasons why they are behaving in such a manner so you have that as well within the community (P08).

3.3. Beliefs about prognosis

Participants reported a variety of beliefs about prognosis ranging from the hope for total 'normality' to no hope at all for the future of individuals with intellectual disabilities.

3.3.1. Hope for 'normality' and acceptance

Some members of the Pakistani community believed that people with intellectual disabilities would grow out of it. Fewer worries and more hopes for normality were particularly reported if the person with an intellectual disability was young.

> *I think the majority of Asians will say that, he is young, he is child, he will get over it and it is not going to last for ever. He is a child. He is of that age that he is playing (P02).*

3.3.2. Tragedy and bleak future

Participants reported that intellectual disability is viewed as a tragedy by the Pakistani community, whose members tend to feel sorry for the parents of a child with an intellectual disability. Such feelings for the parents most probably result from prevalent beliefs that people with intellectual disabilities have a bleak future and will be a burden for their families. One participant also reported that the Pakistani community generally focused on negatives and therefore was unable to concentrate on the future of a person with intellectual disability.

> *I think that people admire them. They also feel sorry for them, so like 'Toba' [God forbid] hopefully like this kind of thing will never happen to us. It seems like quite an ordeal and they have to have a lot of patience and that it's a massive commitment … so there is support for the parents, but there is a feeling of 'I feel sorry for the parents' (P06).*

> *I think many of them would think that this girl is going to be difficult for the parents. It is going to be difficult for them to manage her independence, her future, her possible marriage, her getting a job, her having a place in society … Yeah, no future (P01).*

Well, I have heard people say, people with these kinds of difficulties they will probably die when their parents die. There is kind of hope almost of that actually because they would not be able to look after themselves and historically our generations have come from cultures where these kind of services do not exist, supported accommodation and whatever. Or they get abused and things like that so it is actually better because they will end upon the street, begging … so it is better that they just die with them (P07).

Perceptions of the prognosis of individuals with intellectual disabilities had an impact on the community's expectations. For instance, four participants commented that sometimes the Pakistani community thought that only basic needs of individuals with intellectual disabilities needed to be met, while at other times, they were compared against the standards held for everyone.

Bottom of Maslow's triangle, clothes on their back, feed on the table (P07).

I do not think they look at it in terms of an individual. They just look at everyone. There is like a bench mark for everyone and by the time you are 16 you should have accomplished this and by the time you are 20 you certainly should know how to do that (P13).

3.3.3. Worries about marriage

All participants reported worries within the community regarding marriage. Seven participants mentioned that marriage was seen as a priority for everyone including individuals with intellectual disabilities. For them, marriage was considered a guarantee of future security, especially when parents were dead or unable to provide support. Arranged marriages from Pakistan were deemed to be the most common and easiest option to achieve this aim. However, even arranged marriages were reported by eight participants to be quite difficult as individuals with intellectual disabilities faced a lot of stigma and exclusion from their community.

Yeah, I think marriage is a very important aspect of these people's lives and certainly for the parents, it would be a big reason or cause of their worry … Everyone will try to look for

a boy for Sara [person in vignette]. She might not even want a boy, but yeah I think that is how the community might perceive it (P06).

Let's get them married off and their husband will look after or their wife will look after them, more so if it is a girl to get her married off. Because if it is a guy then no girl is going to marry him … and the girl from back home in the village who probably wants a secondary gain of getting a passport or something or coming to England will marry him (P07).

I think there is a stigma like what am I going to do with this person, like even maybe we get by if it is sort of kind of mild-to-moderate, but then like what is the effect of that going to be on my kids, I do not want to have kids with this person because there is something wrong (P06).

The worries about marriage and difficulties seeking it were common for people suffering from mental health problems.

They are embarrassed. I mean, can you imagine an Asian woman saying my 25 year old daughter has got a mental health problem, who is not even married yet [Interviewer: Yeah, so the prospects of marriage will go off the window]. Yes, straight away (P04).

Four participants talked about difficulties following an arranged marriage involving a person with intellectual disabilities.

I know of two boys who have got learning disabilities, but they went to Pakistan and they married. Their wives have come over here and it is really difficult because … it has been about six months to a year now and the daughter-in-law does not really want to sleep with him in the same room and the mother-in-law is saying you go back there otherwise I will send you to Pakistan and she does not want to go back (P02).

Parents got her married in Pakistan and it was all really quick and then all fell apart because they came here, they realised that she is a bit slow and then never I have saw him again, they just got divorced and this child has never known his father (P12).

Having a family member with an intellectual disability was also perceived to have a negative impact on their siblings' marriage prospects by ten participants, while two participants disagreed. This negative impact of siblings' marriage prospects was said to be especially prominent in arranged marriages. The main reason explained by participants was that in arranged marriages, two individuals with a marriage proposal

under consideration are usually not romantically affiliated and decision of their marriage mainly depends on elders, who sometimes do not consider a family with a person with an intellectual disability as a suitable family. Some reasons for concerns displayed by the community included fears of a negative genetic impact on future generations, worries about possible aggressive behaviour from the person with intellectual disabilities or dependence on siblings for future care.

> *I think no one wants to marry into the family with a disabled person either because it could have an impact on genes and linking it with causes, but also because I think, particularly girls, she would have to look after him as well as the parents (P07).*

> *If it is just one child (with intellectual disabilities in the family) I think the chances of the marriage going ahead is probably quite high, but if it is with two or three children then the chances are probably quite low. I think they would be worried about, yeah again genetics and probability. You know, people are not that tolerant, I do not think (P15).*

3.4. Community responses

Participants recounted instances of stigma, exclusion and negative attitudes as well as instances of sympathy and kindness displayed by the community towards individuals with intellectual disabilities and their families.

3.4.1. Stigma and negative attitudes

A lack of understanding, stigma and negative attitudes within the community was a common theme.

> *Yeah, I think a lot of it might come down to reputation within the community and they are being seen as not esteemed as a family as much as another family (P08).*

> *There is still that little bit of stigma … a lot of hypocrisy as well (P15).*

> *So when it's known, people who are near to the family can only sympathise. The ones who are negative will only taunt. And even in taunting, there are two things. One is that they are jealous anyway because of personal clashes and the second thing is from the government there is a very reasonable support for such families. People are also jealous because of*

that, that these people on this basis are getting a lot of benefits … Some people start saying that they got lottery if they have a child with disability (P09).

Stigma and negative attitudes were said to result in parents being cautious and, in some instances, ashamed of their child's disability. They avoided taking their children to social occasions such as weddings or parties, as they feared that if their child did not behave according to cultural norms or displayed challenging behaviour, they or their child would face judgement or criticism from community members. They also worried about their child being perceived as a burden on and inconvenience for the community. All these fears were perceived to lead to isolation for the person's family members.

There is a lot of isolation, not shame … People are not ashamed that they have got a disabled person. There is a lot of isolation because people do not want to take them out in a manner, which could expose them to show some embarrassment for their loved one … they feel the shame rather than the other people there (P04).

Seven participants reflected on the possible reasons for stigma in the Pakistani community. These included a lack of understanding regarding intellectual disabilities, a lack of education and a perception of intellectual disabilities as an embarrassment to the family. Parents' inability to answer relatives' and acquaintances' questions regarding their child's disability was also thought to promote stigma. Some participants considered differences in attitudes towards mental health problems and intellectual disabilities. Two participants felt that the community is more accepting of individuals with intellectual disabilities. However, another two participants disagreed and thought that acceptance was greater towards people with mild to moderate mental health problems as these were not seen as permanent and were less visible than intellectual disabilities.

I think when I talk about there is a lot of stigma attached and lack of awareness, I would say that is probably more first generation and second generation Pakistanis and people who

come from the more rural backgrounds, have less education and less integration with other parts of society, I reckon that is the only kind of things to be aware of (P11).

They would not go around telling you have got a child with learning disability. You know, they will hide it … because it is a sort of embarrassment, cultural embarrassment, to have somebody born with a disability because you know when you go to the subcontinent or any part of the Asian continent in that sense or to some part of Africa, you know anybody with the disabilities is left on the street to go and beg (P04).

3.4.2. Sympathy and politeness

Despite the above mentioned negative attitudes, the Pakistani community was also reported to be polite, sympathetic and understanding towards individuals with intellectual disabilities and their families. It was reported though that sympathy and politeness was not usually accompanied by offers of practical support.

I think that people admire them, they also feel sorry for them, so like 'Toba' [God forbid] hopefully like this kind of thing will never happen to us (P06).

I think there is a lot of pity. Yes, like a lot of feeling sorry for the parents and a lot of assumptions that life must be very awful for them and really tough and you must feel sorry for them (P11).

People are very sympathetic, I must say. When a child is born or if they learn that child is blind or deaf or whatever people are sympathetic. They will get hundreds of phone calls from all the family and friends whatever "oh we heard this", "oh we are going to come round". They will come round and they will visit and everything, but everybody they will come around, they will do that, but nobody is really there to support the child and nobody is really there to support the mother because even when they do come round and the mother is busy trying to look after this disabled child. Still they will be sitting there and expecting a cup of tea and expected to be treated as a guest (P02).

Three participants felt that there was increased acceptance of intellectual disability in the second generation.

I mean people who are born or brought up here or living here, they are much more understanding (P05).

3.4.3. Inclusion versus exclusion

All participants could recount experiences where the Pakistani community integrated individuals with intellectual disabilities in conversations and social gatherings. Sometimes, this inclusion was triggered by feelings of sympathy and pity.

> *When I have been to the mosque and I have seen the children there … just walking about engaging as much as they can, so they might have small group of friends and just chatting to them and I generally think that they fit in. I think they are fine. They are not on the sidelines or anything like that. They are just doing their own thing (P01).*

> *So whenever there is like a 'Majlis' or like a kind of religious gathering at someone's house, or like I would say 'Quran Khuwani' [reading of Quran] then they always invite and they always come because I think that is their like main social outlet. It is their main opportunity to go out, so yes they are always invited on these kinds of things and weddings and stuff like that, so they are never really excluded (P06).*

> *People generally have good intentions, from my experience and they may well say "yes you know I am fine about my child having friendship with that child" simply because they want to feel they have done some good, so they might feel sorry for that person or that family (P01).*

All participants could also reflect on a number of incidences when the community excluded individuals with intellectual disabilities by avoiding or ignoring them or excluding them from normal life altogether. Friendships with individuals with intellectual disabilities were also generally avoided and thus they were not invited to activities shared by groups of friends such as cricket matches or nights out.

> *I mean if somebody unfortunately was less able, he will be treated like 'Jhalla Talla' [simple and stupid] … They shut them up from normal life, oh! you know he is mentally ill, so no matter, whatever scale of the difficulty is, they do not care, they just say he is not a normal person (P05).*

> *I went somewhere when everyone was kind of greeting each other and the child was just sitting in there like while everyone else was playing, was sitting with head down and it just felt like people were missing her out [interviewer: excluding her] yes excluding her because "oh she would not understand" (P13).*

> *I do know actually know of that scenario and I would say that the general belief is not, it is discouraging and when I have spoken to different families about why, they would say that*

the child who has got the different learning difficulties/ disability is not a good influence (P15).

A number of factors pertinent to the inclusion or exclusion of individuals with intellectual disabilities were identified. Family relationships, regular exposure to, or growing up with, an individual with intellectual disabilities, the level of awareness and understanding in the community were all seen as affecting integration. The severity of the disabilities and presence/absence of challenging behaviours were other factors relevant to inclusion. Participants however had differing views regarding the impact of severity of disability on inclusion. Three participants said that the Pakistani community was more tolerant and accepting towards people with mild intellectual disabilities. However, another three mentioned that people were more compassionate and understanding towards people with severe intellectual disabilities and/or with physical disabilities.

> *On the whole, no [friendships are not encouraged], but again I think it depends on the parents' relationships and family and again that kind of level of awareness and understanding, so yes I think if they are closely related, or they are good friends i.e. parents are good friends, then I think yes they will be encouraged, but if they do not know each other then I do not think they would like to encourage that kind of interaction between their children (P11).*

> *I think they will accept someone, you know a child sitting in a wheelchair or a child physically that you are able to see that is unable to move, but a lot of the time if the child has got learning difficulties not apparent … that is probably quite difficult for them to understand you know like why she is not understanding at this age or why she is behaving in a certain manner (P13).*

> *The thing I have seen is a kind of tendency to stay away, not really acknowledging and I think there might be a few reasons for that and it might be just because of our own incompetence and our own sort of worry, apprehension about approaching the mother or speaking to them about it because we might not want to hurt her ... I would say that generally the people I have seen have good intentions and they are really feeling for them, but they do not know what to do (P01).*

Another factor important to exclusion, mentioned by ten participants, was that individuals with intellectual disabilities were not always taken out to social occasions by their family even if they were invited. This was due to embarrassment or lack of practical support. Moreover, individuals who have severe intellectual disabilities and/or physical disabilities were rarely taken to social occasions or for a 'day out', thus leading them to be 'hidden away' from the community.

> *I know a couple of families that would tend not to take the child in to social occasions, depending what the occasion is. So you know they feel that it is not appropriate for every occasion to be able to take their child (P01).*

> *People with the severe disability probably would not bring them with them … They will be invited anyhow and if they did turn up, you know, no body will mind but no body will have enough of that, the family would feel embarrassed because they are going to spill things, they are going to do things (P04).*

3.4.4. Views on independence

Twelve participants mentioned that in some instances the Pakistani community encouraged independence in individuals with intellectual disabilities, for instance by encouraging them to work. However, they were only expected to work as unskilled labourers and were usually given jobs by family and friends.

> *Again, thinking about the people I know professionally and personally, they are encouraged to work, but there is a lot of sensitivity around that, so they are encouraged maybe to work in places where there is not that much interaction with other people, so there is less likelihood of interpersonal difficulties arising … they are doing like a routine task … may be shorter hours, may be part time … in a very, very safe environment (P11).*

All participants agreed that most members of the Pakistani community do not encourage independence.

> *Majority of the ones I have seen is that there is not that much scope for independence particularly for girls, there is none. I think it is really, really minimal. May be with the boy, if*

he was to go out with siblings. If he was to go out with friends or something then may be that will be allowed, but with the girls I do not think there is much of that (P02).

Independent accommodation for individuals with intellectual disabilities was said also not to be encouraged by family members and the community and. In cases where independent accommodation was sought, it was as a last resort.

I think most people think that she can carry on living at home with her parents and her brothers and sisters will grow up, have families of their own, may be the brothers will stay in the home situation supporting the parents and she would carry own staying as an aunt in that family situation. Yeah, and I have seen cases like that so that is why I think that that would be the case (P01).

The expectation is that they would kind of stay within the family environment, say, whether it's siblings or aunts, uncles, you know, someone in the extended family (P11).

Cultural and religious factors, gender, the level of disability and support and worries about the person with intellectual disabilities were believed to have an impact on the encouragement of independence.

I think may be it just comes down to that unity within the Pakistani community and I think it comes maybe from religion as well as well as from culture … how the family should look after one another … I think it is exactly like when our parents get old, we do not want to put them in a care home, whereas it is the norm maybe within other communities, it is norm to put them in a care home, but within the Pakistani community I think it would be seen as a bad thing and may be more just as much, so that looking after someone, letting someone else do it, is not seen as the right thing to do. So it is simply may be because of that (P08).

3.5. Sources of help

The most common source of help for individuals with intellectual disabilities and their families, mentioned by seven participants, was support from immediate family members and acquaintances. Other sources of help cited were: GP and health visitors, gaining financial security, sending individuals with intellectual disabilities to Pakistan or marrying them off, religious help such as going to 'imams' for 'taveez' (amulet) and praying to

saints, home food remedies such as almonds, semolina soup, behavioural interventions

such as punishment, and physical interventions such as exercise, medication,

physiotherapy and ECT. Two participants also described support from local charities and

voluntary services as valuable. There was a lack of appreciation of the value of any

psychological interventions. Interestingly, participants felt that there was a lot of similarity

between intellectual disabilities and mental health problems regarding which sources of

help were considered to be helpful by the community.

> *Yes, immediate family, yes. Brothers and sisters and that sort of thing, but extend families not really* (*P02).*

> *There might be practical help in terms of maybe looking after the other children [from family and neighbours], but there would not be any emotional, psychological or any of that kind of help and it would not be necessarily knowledge based (P07).*

> *I would not say it is a large number, it is a very small number, but in percentage we are talking about 3-4% of the Pakistani community who would believe in that [evil eye and teeka]. The larger number would be those that believe in these 'peer' or saints, they will be 30-40% (P04).*

> *Maybe speaking to the Mullah and see if there is any possibility of like black magic or something and may be gave him like a 'Taveez' ... Lots of people just do lots of prayers for them and they get them involved in prayers as well. I think that seems to keep everyone going, gives them some hope and I think there is some belief. Some people pray for full recovery and some people just pray for patience (P06).*

> *They are kind of like, you know, the whole culture of Pakistan, is not really sort of, in to counselling and talking and sort of geared towards that because I think most of the talking and counselling is done through friends and family …and that what the other way they see, or a local authority may be, local 'Imam' or community head, a community person, who is reputable, you know. But the thing is that, you know, talking to a psychologist or they are kind of like, they are not really sort of, they do not really see that much point in that really (P02).*

4. DISCUSSION

This study aimed to explore beliefs and attitudes towards intellectual disabilities in the

Pakistani community. A key finding is that the concept of intellectual disabilities is not well

understood within the Pakistani community. A widespread confusion about Western terminology to refer to intellectual disabilities was common. Moreover, terms used by the Pakistani community to explain intellectual disabilities mostly have negative connotations. This aspect was also identified by Miles (1992). This suggests that over time and despite migration to the UK, there has been little adoption of Western terminologies among the Pakistani community. To date research has not examined whether confusion about terminology may be greater among Pakistanis than the indigenous population. A national survey by Mencap (2008) found widespread confusion among the UK population, in that 3 in 4 people could not give an accurate example of an intellectual disability. However, Sheridan (2008) and Coles and Scior (in press) compared South Asians to white British sixth form students and found increased lack of awareness and confusion regarding intellectual disabilities amongst South Asians. Previous literature has indicated that language barriers (Ahmad & Atkin, 2000; Azmi, Hatton, Caine & Emerson, 1996; Chamba et al., 1999) and socio-economic deprivation (Nazroo, 1997) could also affect awareness.

Lack of understanding regarding intellectual disabilities also seemed to create difficulties in their identification, especially when the disability was not severe or physically apparent. During the interviews, participants referred to this issue as well while vignettes were being discussed. Difficulties in identification of intellectual disabilities have also been reported in the past whereby it has resulted in delayed diagnosis and lack of service utilisation in the Pakistani community (Bywaters et al., 2003; Mir et al., 2001; Mirza et al., 2009). It is possible that such difficulties relate particularly to mild intellectual disability, perhaps because these individuals are integrated more in the community and are considered as on

the "lower end of a normal continuum", as mentioned by participants in this study. Alternatively one might suggest that the Pakistani community marginalises these individuals so much that they are absent from the community and thus the community cannot identify their difficulties due to a lack of exposure and direct contact. No matter what the reason of this lack of awareness is, it has implications for service providers as it results in lack of access to services.

In the current study, lack of knowledge was also reported to be one of the factors giving rise to prejudice and stigma. Since no previous study has examined the general Pakistani population in particular, these findings cannot be evaluated further. However, South Asian parents in previous studies have complained of stigma and prejudice from their communities, sometimes mainly as a result of lack of awareness and knowledge (Bywaters et al., 2003; Croot et al., 2008; Edwardraj et al., 2010).

Explanations provided by the community regarding intellectual disabilities and/or associated challenging behaviours were vital in increasing or decreasing experiences of shame and stigma. For instance, where challenging behaviours in individuals with intellectual disabilities were viewed as a result of poor parenting or pretence, it resulted in increased stigma, blame and exclusion. Whereas, if supernatural or theological explanations were provided where the locus of control was not the person with intellectual disability or his/her family, more inclusive, accepting and sympathetic attitudes were noticed. Previous studies on parents have suggested that reliance on a fatalistic approach can increase acceptance of a disability as it is then considered a duty, pious act or an act

of salvation to look after such a person (Bywaters et al., 2003; Croot et al., 2003; Mirza et al., 2009). One can argue that fatalistic approach to some extent can promote one of the current policy aims namely social inclusion. However, to what extent this is applicable can only be determined through further research. Moreover, whether fatalistic beliefs promote other policy aims such as choice, independence and rights of people with intellectual disabilities is highly debatable.

With regards to interventions, results from the current study suggest that for the Pakistani community, prayer, saints, amulets etc. were considered more helpful than psychological and social services. A contributory factor for this may be the above mentioned belief in fate, encouraging the community to suppose that apart from God, no one else can help (Miles, 2002). There have also been suggestions that other factors such as feelings of shame and stigma, negative stereotypical views held by some professionals and service providers about minority ethnic communities could also affect service uptake (Butt & Mirza, 1996; Bywaters et al., 2003; Chamba et al., 1999; Katbamna et al., 2000; Mir, Nocon, Ahmad & Jones, 2001).

The current study suggests that lack of understanding regarding intellectual disabilities increases exclusion of such individuals. Previous studies suggest similar findings whereby individuals with intellectual disabilities were reported to be excluded, e.g. from conversations and social interactions, it was assumed that they would not be able to understand or follow the conversation (Bywaters et al., 2003; Edwardraj et al., 2010). Moreover, the confidence level of the community in interacting with individuals with

intellectual disabilities had a direct influence on inclusion or exclusion of these individuals (Edwardraj et al., 2010; Mirza et al., 2008). All of these factors can lead to experiences of shame and stigma for people with intellectual disabilities and their families' unwillingness to take them out of the safety of their home (Bywaters et al., 2003; Croot et al., 2008), ultimately resulting in them being 'hidden away' from the community as noted by a few participants in this study.

The study highlighted that, in the Pakistani community, marriage was considered a priority for everyone, including individuals with intellectual disabilities. However, it was not sought as a means to increase or prove the person's independence as in Western societies (Miles, 1992), rather it was considered as a way of securing the future of the person and to release their family from the burden of care. Miles (1992) mentioned that in Pakistan, for a person with intellectual disabilities, marriage was normally arranged with a person from a lower social class. A similar aspect was highlighted by the participants in this study. These people were not considered desirable for marriage and thus a person from a lower socio-economic status in Pakistan was sought, who would be more likely to agree to marry them mostly because of secondary gains (such as entry to the UK and financial security). Marriage was not a guarantee for a secure future though, as instances were reported where once the partner had arrived from Pakistan and got settled in the UK, they left their spouse. Reliance on marriage instead of formal sources of support can be attributed to a number of factors. Current findings suggest that in addition to a lack of awareness of services available, perception of marriage as a safe and culturally accepted transition also played a role. Hepper (1999), in a single case study on a Bangladeshi

woman, reported similar emphasis on marriage where it was believed by the woman's immediate and extended family that marriage could not only provide her with social support but could also strengthen her social identity, thus diminishing the significance of her disability. Of note, in Pakistani society where discussion of sexuality is surrounded by taboos, people with intellectual disabilities may have little access to relevant and necessary information (Mir et al., 2001). This raises the issue of capacity to consent in cases where marriage is sought and has implications for service providers.

Another key finding is that on the whole, independence and individuality are not culturally encouraged values, even within a UK context. However, as also highlighted by Miles (1992; 2002), these are further discouraged in individuals with intellectual disabilities because of fears of possible harm, especially to females. It was also noted that in cases where independence was encouraged, this was mostly in terms of gender specific roles. For instance, the key role for a girl was considered to be a good wife in the future and thus girls are encouraged to learn household chores. This also facilitated prospects of marriage which, as mentioned above, was considered a priority. Thus, it is vital to take into account cultural differences while negotiating the independence and individuality of people with intellectual disabilities (Mir et al., 2001).

Other than merely a lack of awareness of different services, the cultural belief that families should look after their own' appears to be an important influence on service access. Given that it has been recognised that 'independence' in the form of leaving the family home to live in residential provision does in many cases not equate to social

inclusion and better quality of life (Bond & Hurst, 2009; Cummins & Lau, 2003), encouraging this form of independence for individuals with intellectual disabilities from the Pakistani community should be considered with caution. Furthermore, the very meaning of key policy values, how these fit with different cultural values and practices, and how they perhaps can be implemented in ways that respect both individual and cultural priorities clearly needs to be the subject of careful negotiation.

4.1. Strengths and Limitations

The major strength of this study is its generation of a fairly comprehensive picture from the reflections of key members of the Pakistani community. They were able to draw on a range of experiences and by being asked to talk about the community, rather than themselves, were not preoccupied with presenting themselves in a positive light, thus reducing a potential source of bias. However, to what extent they were able to be neutral in their reflections is not known. It is possible that their own views and experiences influenced what information they remembered or discussed in the interviews. For instance, they could have selected information which was in line with their pre-existing values and ideas. Similarly, they might have been more sensitive to information with which they disagreed.

It is also worth noting that about half of the participants had a health or social services background. This could have created a bias in terms of what sort of information was brought up in the interviews. However, as the remainder of the participants belonged to

different professions, it is hoped that a relatively accurate and broader picture about the attitudes and beliefs of the Pakistani community has emerged.

Major difficulties were also encountered in recruiting participants with whom I did not have personal contact. Participants recruited through personal or professional contacts were mostly from mental health backgrounds. This raises the question of the representativeness of the sample. Although it was difficult to select a more representative sample because of the recruitment criteria, different results may have been found had there been more participants from varying professional backgrounds (for instance, more teachers, special education needs co-ordinators, key workers etc).

The results of the study are however in line with previous studies on Pakistani parents complaining of stigma from their communities thus increasing the reliability of the findings. Although this study has identified a range of attitudes and beliefs prevalent in the Pakistani community, which could be used as a foundation for future research, caution needs to be exercised in generalising the findings. The main reason for this caution is that the validity and reliability of each theme cannot be fully established unless it is tested on a representative section of the general Pakistani population in the UK.

The positioning of the researcher is an important aspect worth discussing. Being from a Pakistani background not only helped me as the researcher in recruitment but also in the interview process. I shared a common language with the participants, which facilitated the discussion without them needing to explain difficult concepts in detail. Participants were

perhaps also less worried about being judged personally and as a member of the community under investigation as I belong to the same community. Thus they were able to discuss some very complex topics with ease. However, as with participants, my views and personal experiences might have influenced the data generation in the interviews. It is possible that I ended up focusing more on certain topics because of my personal interest in them.

The use of vignettes to facilitate interviews merits some discussion. In these vignettes no diagnostic label was given. Although the vignettes facilitated interesting discussions about attitudes and beliefs towards the types of difficulties presented, for some participants they elicited confusion. This was especially pertinent for professionals from non health or social work backgrounds as they were less likely to identify the vignettes as depicting symptoms of intellectual disabilities. In those cases, I had to explicitly mention the difficulties characters in the scenario were facing. Moreover, sometimes the difficulties faced by the characters in the vignettes were totally attributed to social factors (such as in the vignette about Sarah, which noted an expectation that she would study) and environmental factors (such as in the vignette about Faizan, which noted migration from Pakistan and loss of the grandmother) thus ignoring the influence of intellectual disabilities. Different information may have emerged if the vignettes were more specific.

Credibility checks were regularly undertaken throughout the research. However, participants' validation was not sought (Barker & Pistrang, 2005), mainly because of the

time constraints of the study. Seeking their validation could have been very useful in generating further insights into the subject.

4.2. Implications

The findings of this study have important implications for government policies and service delivery. Firstly, there is a need to tackle an overall lack of understanding regarding intellectual disabilities. Taking a proactive approach in educating the Pakistani community about various aspects of intellectual disabilities is vital to bring about change in attitudes and beliefs within the community. This can be achieved through different methods. For instance, by educating key community members and encouraging them to educate their community in turn. Places frequently visited by the Pakistani community such as mosques, Islamic and community centres can be targeted for such efforts. Local media are also an important tool to increase the awareness of the community and to spread understanding of current policies. However, this needs to be done in a culturally sensitive manner.

The results also suggest the importance of cultural values in shaping attitudes towards individuals with intellectual disabilities. Freedom and independent living are not encouraged in the Pakistani community and taking care of a family member with intellectual disabilities is considered a moral duty. Similarly, arranged marriage is considered to be very important. These findings have implications for service delivery and suggest that perhaps service providers need to consider how current policy aims can be applied more flexibly. For instance, for a girl with intellectual disabilities from a Pakistani

background, learning household chores may be considered more important than learning skills for independent living, taught in many schools and specialist further education courses. Where marriage is considered by the person's family, it is vital to assess the capacity of the individual to consent to a relationship in a culturally sensitive manner.

Lastly, it is important to bear in mind cost implications of increasing awareness of the Pakistani community regarding intellectual disabilities or attempts to implement policy aims. For instance, increasing awareness campaigns can require a substantial amount of funds. Similarly, if the Pakistani community becomes more accepting of the idea of independent living, overall cost of care of these individuals will increase. Moreover, increased access to services by individuals with intellectual disabilities and their families may mean increased need for more culturally appropriate services.

4.3. Future research

This study has focused on the reflections of key Pakistani community members. It can be built on by future researchers who can explore themes that emerged from this study in a wider context. They can either conduct a large scale qualitative study on the general Pakistani population or carry out a quantitative study which ensures an accurate representation of the Pakistani community from different backgrounds and socio-economic status. A triangulation of both methods can also be done in order to increase the reliability and validity of findings (Patton, 2002).

5. REFERENCES

Ahmad, W., & Atkin, K. (1996) *'Race' and Community Care*. Buckingham: Open University Press.

Ali, A., Strydom, A., & Williams, R. (2008). A measure of perceived stigma in people with intellectual disability. *British Journal of Psychiatry, 193*, 410-415.

Azmi, S., Hatton, C., Caine, A., & Emerson, E. (1996). *Improving Services for Asian People with Learning Disabilities: The Views of Users and Carers*. Manchester: Hester Adrian Research Centre/ Mental Health Foundation.

Barker, C., Pistrang, N., & Elliot, R. (2003). *Research methods in clinical psychology: An introduction for students and practitioners*. Chichester: John Wiley & Sons.

Barker, C., & Pistrang, N. (2005). Quality criteria under methodological pluralism: Implications for conducting and evaluating study. *American Journal of Community Psychology, 35*(3/4), 201-212.

Baxter, C., Poonia, K., & Ward, L. (1990). *Double Discrimination. Issues and Services for People with Learning Difficulties from Black and Ethnic Minority Communities*. London: King's Fund Centre.

Berry, J., & Dalal, A. (1996). *Disability attitudes, beliefs and behaviours: Report on an international project in community based rehabilitation*. Report submitted to International Centre for the Advancement of Community Based Rehabilitation.

Bond, R. J., & Hurst, J. (2009). How adults with learning disabilities view living independently. *British Journal of Learning Disabilities, 38*, 286–292.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3, 77-101.

Butt, J., & Mirza, K. (1996). *Social Care and Black Communities.* London:HMSO.

Bywaters, P., Ali, Z., Fazil, Q., Wallace, L., & Singh, G. (2003). Attitudes towards learning disability amongst Pakistani and Bangladeshi parents of disabled children in the UK: considerations for service providers and the disability movement. *Health Soc Care Community, 11,* 502-509.

Chamba, R., Ahmad, W., Hirst, M., Lawton, D., & Beresford, B. (1999). *On the edge: minority ethnic families caring for a severely disabled child.* Bristol: Policy Press.

Cinnirella, M., & Loewenthal, K. M. (1999). Religious and ethnic group influences on beliefs about mental illness: A qualitative interview study. *British Journal of Medical Psychology, 72*, 505-524.

Coles, S., & Scior, K. (in press). Public attitudes towards people with intellectual disabilities: a qualitative comparison of white British & South Asian people. *Journal of Applied Research in Intellectual Disabilities.*

Croot, E. J., Grant, G., & Cooper, C. L. (2008). Perceptions of the causes of childhood disability among Pakistani families living in the UK. *Health and Social Care in the Community, 16*(6), 606-613.

Cummins, R. A., & Lau, A. L. D. (2003). Community Integration or Community Exposure? A Review and Discussion in Relation to People with an Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities, 16*, 145-157.

Department of Health. (2001). Valuing People: A new strategy for learning disability for the 21st century. London: HMSO.

Department of Health. (2007). Valuing People Now: From progress to transformation. London: Department of Health.

Department of Health. (2009). Valuing People Now: The Delivery Plan. London: Department of Health.

Edwardraj, S., Muntaj, K., Prasad, J. H., & Jacob, K. S. (2010). Perceptions about intellectual disabilities: a qualitative study from Vellore, South India. *Journal of Intellectual disabilities Research, 54*, 736-748.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and research fields, *British Journal of Clinical Psychology, 38*, 215-229.

Emerson, E., Azmi, S., Hatton, C., Caine, A., Parrott, J., & Wolstenholme, J. (1997). Is there an increased prevalence of severe learning disabilities among British Asians? *Ethnicity & Health, 2*, 317-321.

Emerson, E., & Hatton, C. (2004). Response to McGrother et al. regarding 'The prevalence of intellectual disability among South Asian communities in the UK'. *Journal of Intellectual Disability Research, 48*(2), 201-202.

Fatimilehin, I., & Nadirshaw, Z. (1994). A Cross-cultural study of parental attitudes and beliefs about learning disability. *Mental Handicap Research, 7*(3), 202-227.

Goodman, H., Gottlieb, J. & Harrison, R. (1972). Social acceptance of EMR's integrated into non-graded elementary school. *American Journal of Mental Deficiency, 76,* 412–417.

Gottlieb, J. & Budoff, M. (1973). Social acceptability of retarded children in non-graded schools differing in architecture. *American Journal of Mental Deficiency, 78,* 15–19.

Graffi, S., & Minnes, P. M. (1988). Attitudes of primary school children toward physical appearance and labels associated with Down syndrome. *American Journal on Mental Retardation, 93,* 28–35.

Greig, R. (2005). Valuing people: The story so far. London: Department of Health.

Hagen, B., Powell, C., & Adams, R. (1983). Influence of personal and academic experience on formation of attitudes toward mentally retarded adults. *Perceptual and Motor Skills, 57,* 835–838.

Hatton, C., Azmi, S., Caine, A., & Emerson, E. (1998). Informal cares of adolescents and adults with learning difficulties from the South Asian communities: family circumstances, service support and carer stress. *British Journal of Social Work, 28*, 821–837.

Henry, D., Duvdevany, I., Keys, C. B., & Balcazar, F. E. (2004). Attitudes of American and Israeli staff toward people with intellectual disabilities. *Mental Retardation, 42*(1), 26-36.

Hepper, F. (1999). 'A woman's heaven is at her husband's feet'? The dilemmas for a community learning disability team posed by the arranged marriage of a Bangladeshi client with intellectual disability. *Journal of Intellectual Disability Research 43*(6), 558-561.

Katbamna, S., Bhakta, P., & Parker, G. (2000). Perceptions of disability and care-giving relationships in South Asian communities. In W. I. U. Ahmad (Eds.), *Ethnicity, Disability and Chronic Illness*, pp. 123–138. Buckingham: Open University Press.

Kobe, F. H., & Mulick, J. A. (1995). Attitudes Toward Mental Retardation and Eugenics: The Role of Formal Education and Experience. *Journal of Developmental and Physical Disabilities, 7*(1), 1-9.

Lee, B., Syed, Q., & Bellis, M. (1998). *Improving the Health of Black and Ethnic Minority Communities: A North West of England Perspective*. Liverpool: Sexual Health and Environmental Epidemiology Unit.

Lindesay, J., Jagger, C., Hibbert, M. J., Peet, S. M., & Moledina, F. (1997). Knowledge, uptake and availability of health and social services among Asian Gujurati and white elderly persons. *Ethnicity and Health, 2,* 59-69.

Madood, T., Berthoud, R., Lakey, J., Nazroo, J., Smith, P., Virdee, S., & Beishon, S. (1997). Ethnic Minorities in Britian: Diversity and Disadvantages. London: Policy Studies Institute.

Markova, I., & Jahoda, A. (1992). The language of special needs. In S. R. Baron & J. D. Haldane (Eds.), *Community normality and difference.* Aberdeen, Scotland: Aberdeen University Press.

McGrother, C. W., Bhaumik, S., Thorp., C. F., Watson, J. M., & Taub, N. A. (2002). Prevalence, morbidity and service need among South Asian and White adults with intellectual disability in Leicestershire, UK. *Journal of Intellectual Disability Research, 46*, 299-309.

MENCAP. *Lack of Knowledge of learning disability revealed*. Article downloaded from
the World Wide Web on 25/09/11: www.mencap.org.uk/news.asp

Miles, M. (1992). Concepts of mental retardation in Pakistan: Toward cross-cultural and
historical perspectives. *Disability, Handicap & Society, 7*(3), 235-254.

Miles, M. (1995). Disability in an eastern religious context: historical perspectives.
Disability & Society, 10(1), 49-69.

Miles, C. (2002). On Working in Peshawar with Disabled Children and Families. *Journal of
Religion, Disability & Health, 6* (2), 145-148.

Mir, G., Nocon, A., Ahmad, W., & Jones, L. (2001). *Learning Difficulties & Ethnicity*.
London: Department of Health.

Mirza, I., Tareen, A., Davidson, L. L., & Rahman, A. (2009). Community management of
intellectual disabilities in Pakistan: A mixed methods study. *Journal of Intellectual
Disability Research,,53*, 559-570.

Morad, M., Nasri, Y., & Merrick, J. (2001). Islam and the person with intellectual disability.
Journal of religion, disability and health, 5(2), 65-71.

Nazroo, J. (1997). *The Health of Britain's Ethnic Minorities*. London: Policy Studies
Institute.

Office for National Statistics (2001). *2001 National Census*. London: ONS.

Parsons, G., Elkins, J., & Sigafoos, J. (2000). Are people with intellectual disabilities just
another customer? Interviews with business owners and staff. *Mental Retardation,
38,* 244–252.

Patton, M. Q. (2002). Qualitative study and evaluation methods (3rd edn). Thoudand Oaks,
CA: Sage.

Ryan, G. W., & Bernard, H. R. (2000). Data management and analysis methods. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.) (pp. 769-802).

Rees, L., Spreen, O., & Harnadek, M. (1991). Do attitudes towards persons with handicaps really shift over time? Comparison between 1975 and 1988. *Mental Retardation, 29,* 81–86.

Scior, K., Kan, K., McLoughlin, A., & Sheridan, J. (2010). Public Attitudes Toward People With Intellectual Disabilities: A Cross-Cultural Study. *Intellectual and Developmental Disabilities, 48*(4), 278-289.

Sheridan, J. (2008). Attitudes to People with Intellectual Disabilities: a cross cultural study. Unpublished doctoral research. Sub-dep. of Clinical Psychology, University College London.

Sinson, J. (1993). *Group homes and community integration of developmentally disabled people.* London: Jessica Kingsley.

Tak-fai Lau, J., & Cheung, C. (1999). Discriminatory attitudes to people with intellectual disability or mental health difficulty. *International Social Work, 42,* 431–444.

Westbrook, M.T., Legge, V., & Pennay, M. (1993). Attitudes towards disabilities in a multi-cultural society. *Social Science and Medicine, 36*(5), 615–623.

World Health Organisation. (1990). International Classification of Diseases (ICD)- 10. Geneva: World Health Organisation.

Yousafzai, A. K., Farrukh, Z., & Khan, K. (2011). A source of strength and empowerment? An exploration of the influence of disabled children on the lives of their mothers in Karachi, Pakistan. *Disability and Rehabilitation, 33*(12), 989-998.

Yuker, H., & Block, J. (1986). *Research with the Attitude Toward Disabled People Scales: 1960–1985.* Hampstead, NY: Holstra University Center for the Study of Attitudes Toward People with Disabilities.

PART 3: CRITICAL APPRAISAL

INTRODUCTION

This critical review consists of three main sections. The first section focuses on my reflections on my experiences of conducting this study. The second section addresses the methodological issues pertinent to this study. The last section reflects on the clinical and research implications of this study and offers a direction for future research.

1.   PERSONAL REFLECTIONS ON THE STUDY PROCESS

1.1. Development of the study

The dearth of literature on the attitudes and beliefs of specific ethnic minority communities in the UK regarding intellectual disabilities, my pre-existing interest in this area and my ethnic background encouraged me to study the Pakistani community.

1.2. Being a researcher from a Pakistani background

As the study progressed, some salient aspects emerged as a result of my Pakistani background. Firstly, it was beneficial for me in terms of recruitment to be Pakistani as I recruited six of the fifteen participants through personal contacts. This is especially relevant as I faced difficulties in recruitment of those participants I did not have personal or professional contact with. The six participants with whom I did not have any previous contact were recruited through telephone or email. All the participants were very interested in the research area and agreed enthusiastically to participate. It is hard to ascertain how these participants would have reacted if I was a researcher from a different background. Their initial response was very welcoming and some directly asked about my background and appreciated my efforts in doing something "for the benefit of the

Pakistani community''. They also appreciated that I was studying the Pakistani community separately instead of subsuming Pakistanis in the category of South Asians. These responses were very encouraging, as they suggested that participants recognised the importance of this study, through a communicated desire to improve both their practice and the interaction with the community. However, sometimes I wonder if their cooperation was in large part prompted by respect for me in that I was making an effort to understand more about the Pakistani community or whether they perhaps they felt a sense of duty to help someone from their own community.

Another aspect worth mentioning is that sometimes participants did not have to explain a relevant concept in detail as I also understood that concept, for instance, the issue of independence and family values in Pakistani society. This was useful as research participants have reported feeling more comfortable when they know that the researcher is aware of the language used by them and understands the issues being discussed (Hinton, Guo, Hillygus & Levkoff, 2000). Moreover, it allowed more time to discuss other topics in detail. However, one potential disadvantage of a shared cultural background between researcher and participants is some important aspects were perhaps not questioned adequately as I assumed a shared understanding.

1.3. The interview process

This was my first experience of conducting qualitative research. The experience of conducting interviews was very interesting and rewarding. Most of the participants needed little prompting and enthusiastically talked about a range of issues in some depth. All of

them seemed very comfortable in discussing quite sensitive issues. I felt that one of the benefits of asking participants about community views instead of their own opinions was that one potential source of bias was hopefully reduced, namely the need to present themselves in a positive light (Podsakoff, MacKenzie & Lee, 2003). However, it is hard to ascertain how much of their responses were affected by their own beliefs and attitudes. There is a possibility that they selected only that information which seemed relevant to them or was synonymous to their pre-existing beliefs and values. As mentioned briefly in the empirical paper, about half of the participants belonged to health or social services background. This could also have created a bias in terms of what sort of information was brought up in the interviews. These participants were more likely to be in a professional contact with those members of the Pakistani community who seek mental health services. Beliefs and attitudes of individuals seeking services might be different from the ones not seeking services.

It was intriguing to see how different participants came across in the interviews. Almost all of the participants referred to personal experiences in addition to professional experiences and observations, while reflecting on the understanding and attitudes of members of their community. The ability to refer to both professional and personal experiences was useful as it increased their confidence in reflecting on a wide range of attitudes and beliefs prevalent in the Pakistani community. However, it is also likely that as a result of personal reflections, some bias was created in the information gained. Most of the participants were highly qualified. One might argue that these participants were more likely to come from families where education was common or more valued. Similarly, it is also more

likely that these participants had more personal contact with those individuals who were highly qualified. Education is known to make a difference in the attitudes and beliefs regarding intellectual disabilities with highly educated having more positive attitudes and beliefs (Murphy, Bernadette, Black, Duffy & Kieran, 1993; Rees, Spreen & Harnadek, 1991; Tak-fai Lau & Cheung, 1999). Thus, this issue needs to be taken into consideration while generalising the results.

1.4. Analysis and write-up of study findings

Asking my supervisor to conduct audits of the analysis reassured a novice qualitative researcher like me about the rigor of my study. I found the process of presenting the study's findings in the empirical paper quite challenging. There was a lot of very interesting information which emerged during interviews and I wondered how to do justice to it, as I was concerned about losing the idiographic richness of individual accounts or themes. Maybe the situation would have been different if I had a smaller sample. However, at the same time, I realise that it was quite useful to have a bigger sample size as the results which are produced become more valid and generalisable. For instance; if certain themes are repeated over and over again, that signifies their commonality and importance.

1.5. Impact of research on me

My impression about the Pakistani community in the UK before starting this study was that they were generally unaware of and did not understand mental health difficulties. I had also observed a lot of prejudice against people with mental health difficulties.

However, I could not generalise these impressions to intellectual disabilities as I had not observed many people commenting about them.

After conducting this study, my understanding of the attitudes and beliefs amongst the Pakistani community in the UK regarding intellectual disabilities has increased a lot. I am much clearer on specific issues pertinent to the Pakistani community, such as lack of awareness, cultural perspectives on independence and the importance of marriage and how they interact with the encouragement of choice, inclusion and independence of individuals with intellectual disabilities. As one would expect, more traditional views were reported by participants to be increasingly prevalent among first generation immigrants. It was interesting to realise how similar the attitudes and beliefs of the Pakistani community here were to my experiences of Pakistanis living both in the UK and Pakistan. If I compare my attitudes and beliefs before studying psychology, I have to admit that they were very similar to the present findings. All I knew about mental health problems and intellectual disabilities was through the media, which in my experience did not portray an accurate image. This makes me wonder how much of a difference general education alone can make without specific education about mental health problems and disabilities.

2. METHODOLOGICAL ISSUES

2.1. Understanding of participants regarding intellectual disabilities

With all participants, in order to avoid any confusion, I checked their understanding of different terms used to refer to intellectual disabilities and explained, where necessary, what these mean before progressing with the interview. This was helpful in avoiding

confusion during the interview process and reassuring me that data gathered in the interview process was valid. Most of the participants either worked with individuals with intellectual disabilities or had direct contact with them and thus were aware of terms like 'learning disabilities'. However, I found that three of the participants (two councillors and one teacher) were confused about different terms. The teacher and one of the councillors, who were second generation Pakistanis, confused 'learning disabilities' with 'specific learning difficulties' such as dyslexia. However, the other participant, who was first generation, was not very aware of terms used in the UK to refer to intellectual disabilities. He used terms like 'mental retardation' for people with severe intellectual disabilities and 'mentally ill' for people with mild to moderate intellectual disabilities and found it very difficult to divert from these terms. It could purely be a coincidence that the two participants from the second generation had one type of difficulty in understanding these terms and the first generation participant had a different sort of difficulty. However, as reflected by almost all the participants in the study, it can also be an indication that different terms are used among first generation Pakistanis to explain intellectual disabilities.

I conducted one interview in Urdu and it was difficult to translate 'intellectual disabilities' into Urdu. I nonetheless mentioned the terms 'intellectual disability' and 'learning disability' to him in English anyway. However, during the interview, the term 'zehni mazoori' ('mental handicap') was mostly used by both of us as it is a proximate translation. Thus although the terminology used was different, the same concept was discussed.

2.2. Interview schedule

The interview schedule used in this study was developed to facilitate the interview process and to ensure that pertinent topics identified by the previous research on families of individuals with intellectual disabilities were discussed. This section will consider each item of the interview schedule (see Appendix C1 & C2) in detail and reflect on how each facilitated the interview process.

The first two items focused on collating background information of the participants and accessing information about the sections of the Pakistani community they were most in touch with. These items were vital in situating the sample (Elliott, Fischer & Rennie, 1999) and assessing the generalisability of the findings.

The third item related to two vignettes presented in the interview. Vignettes facilitated a conversation about different understandings of intellectual disabilities, the community's attitudes regarding individuals with intellectual disabilities and the language used within the community to talk about this. These vignettes were referred to later on in the discussion as well, as they proved to be beneficial in grounding the examples participants provided. Moreover, they helped participants to identify how their experiences were similar or different to those of the individuals presented in the vignettes and thus a wide range of information was gained.

The fourth item focused on the terms used to identify intellectual disabilities. This item also facilitated the discussion about beliefs and attitudes of the community regarding

intellectual disabilities. For instance, the use of terms with negative connotations such as 'pagal', lazy, spoiled and pretending also gave an opportunity to discuss the reasons for their use and underlying attitudes of the community.

The fifth item focused on beliefs about the causes of intellectual disability. This helped to identify a wide range of explanations used by the Pakistani community to explain the origin of intellectual disabilities. However, similar to the previous item, this item led to in-depth discussions regarding the attitudes towards intellectual disability and how they interacted with the wider beliefs and attitudes of the community.

The next item explored the beliefs and attitude of the Pakistani community towards individuals with intellectual disabilities and their families. This was a vast area and thus was focused on more in the interviews. The prompts covered different aspects of this area and thus were helpful in getting a wider picture of prevalent beliefs and attitudes in the community.

The seventh item focused on help-seeking attitudes in the Pakistani community. In hindsight, I think that less emphasis was placed on this item in the interview. This might be because participants mentioned an overall tendency amongst the Pakistani community not to appreciate and seek services. Another reason could be that this item was touched upon earlier during discussion of other items in the interview schedule.

The last item compared intellectual disabilities with mental illnesses like depression and schizophrenia. This item was also not focused upon in detail. However, I am aware that this might be because I was cautious in not going into too much detail with the participants. This was because I was aware that detailed comparison of intellectual disabilities with mental illnesses could lead to another area of research and thus would lead us astray from the research questions.

In conclusion, the interview schedule helped to generate a wider picture about the attitudes and beliefs of the Pakistani community in the UK. However, the interview schedule was followed flexibly as the order of the questions was changed according to the flow of conversation. Moreover, prompts were used only as a guideline and did not restrict me asking other questions which were related to the participants' responses but were not mentioned in the prompts.

2.3. Quality of interview data

The quality of the obtained during interviews seemed to be dependent on a number of factors such as how well the interview schedule worked, my interviewing skills and the ability of participants to reflect on different issues.

The interview schedule and its role have been discussed in detail in the previous section and therefore this section will focus on the latter two factors. My training in Clinical Psychology was very helpful in interviewing as it had equipped me with the skills required for any interview. My supervisor listened to the first two interviews and provided feedback

on some specific skills which I could improve. For instance, I learnt that in research interviews summarising was not needed to the extent required in clinical interviews. Having interviews reviewed by my supervisor also increased my confidence in my interviewing skills.

The ability of participants to reflect on different issues was crucial in generating data. In order to achieve this aim, recruitment criteria required participants to be key members of the community with extensive contact with the Pakistani community and have a knowledge and understanding regarding cultural norms, beliefs and attitudes. In addition, at recruitment, the synopsis of the study was also given to make sure that participants felt comfortable and capable talking about the issues the study was interested in.

2.4. Impact of language used to conduct interviews

English was used to conduct all except one interview (P09). Of the fourteen interviews conducted in English, two participants (P04, P05) did not have English as their first language. However, they opted for being interviewed in English and seemed comfortable talking in this language. It can be argued that maybe they would have explained some issues with more comfort and in greater detail if they had opted for their first language. One of the participants (P05) however did revert to Urdu a couple of times when he found it difficult to express himself in English. Interestingly, the participants whose first language was English and thus opted to be interviewed in English sometimes reverted to Urdu words to emphasise a concept. For instance, the word 'pagal' (mad) was used by almost all the participants despite it being an Urdu word.

One participant opted for being interviewed in Urdu. As all the documents were translated into Urdu beforehand, this interview was conducted with ease. The participant was very able to reflect on the beliefs and attitudes of the Pakistani community in Urdu. However as mentioned earlier, we at times found it difficult to translate some of the concepts exactly into Urdu. In those circumstances a proximate translation was used and/or an English word was used as a replacement.

In my view, the ability of the participants to understand and speak two languages added to the strength of the study as it meant that participants were able to reflect on ideas prevalent in a wider Pakistani community. For instance, those whose first language was English were not restricted to reflect only on English speaking members of the community. In addition, being bilingual could very well have facilitated their understanding of cultural beliefs and norms.

2.5. Sampling and generalisability of findings

There are some key points which are worth mentioning regarding the representativeness of the sample used in this study and generalisability of the findings. The sampling of key members of the Pakistani community was based on the rationale that this would generate a fairly comprehensive picture of the beliefs and attitudes common within the UK Pakistani community, because key community members would have extensive contact and links within the Pakistani community and therefore would be able to observe a range of beliefs and attitudes present within it. A similarly comprehensive picture was unlikely to be gained

by recruiting a convenience sample of any member of the Pakistani community, unless one could recruit large numbers which was not possible within the constraints of a Doctorate in Clinical Psychology course.

To what extent I was successful in gaining a comprehensive picture was dependent firstly on successful recruitment and secondly on the quality of information gathered during the interviews. As mentioned in empirical paper, recruitment was partially successful. Participants had contact with Pakistanis from different backgrounds, generations, educational and economic status and thus were able to reflect on a range of experiences. Even the two participants who did not have a Pakistani background were in touch with the Pakistani community and had knowledge of prevalent attitudes, norms and cultural practices. Both of them could understand and speak Urdu and Punjabi and thus were aware of the terminologies used by the Pakistani community. However, as mentioned earlier, it is also worth noting that the majority of participants were from health or social work backgrounds. This raises the question of the representativeness of the sample. It is possible that the data generated from the interviews is biased in some ways as it is possible that responses of the participants were affected by their professional background and/or personal experiences. Thus, caution needs to be exercised in generalising these findings to the lay population of Pakistani origin in the UK.

2.6. Analytic framework

Guidelines suggested by Braun and Clarke (2006) about phases of thematic analysis made the whole process much easier and clearer for a researcher like me who was undertaking a qualitative analysis for the first time.

In the analysis, an inductive approach was used to identify themes in the data. The benefit of using this approach is that it is data driven instead of being driven by the researcher's preconceptions (Braun & Clarke, 2006). Although it was difficult for me to be free from preconceptions (Elliott et al., 1999), as it would for any researcher, deriving themes from the data and grounding them with examples were useful strategies assisting me to be as neutral as possible during the analysis.

2.7. Evaluation of the study in the light of good practice

Evaluating the quality of qualitative research is important to assess the ''trustworthiness'' of the findings (Barker & Pistrang, 2005; Elliott et., 1999). Therefore, the current study is evaluated in the light of Braun and Clarke's (2006) criteria for a ''good'' thematic analysis (see Table 1).

Table 1

A 15-point checklist of criteria for good thematic analysis (Braun & Clarke, 2006)

Process	*No.*	*Criteria*
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for each theme have been collated.
	5	Themes have been checked against each other and to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analysed, interpreted and made sense of rather than just paraphrased or described.
	8	Analysis and data match each other - the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organized story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do, and what you show you have done i.e. described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is positioned as active in the study process; themes do not just 'emerge'.

Braun and Clarke (2006) divided their criteria to evaluate a thematic analysis into five main areas. I will consider below how I addressed each of these areas in my study.

1. Transcription

I transcribed 1 interview myself, but hired a transcription service to transcribe 14 interviews for me, due to time constraints and the length of most of the interviews. The transcripts were verbatim and were checked by me against the audio-recordings for accuracy (Criterion 1).

2. Coding

The codes were generated by reading and re-reading each transcript in a lot of detail. Thereafter, I collated all the codes with their corresponding examples in a separate Word file (see Appendix G). All the codes were analysed in detail, collated in terms of common themes and then master and sub-themes were generated (see Appendix I). Themes were then checked against the transcripts and discussed with my supervisor in order to ensure that they were coherent and representative of the data. The discussions with my supervisor were very helpful in arriving at concise themes (Criteria 2 – 6)

3. Analysis

My supervisor conducted an audit of the analysis by looking in detail at my analysis of three interview transcripts (P02, P09, P15). She also reviewed all the codes and relevant examples which I had collated. This facilitated the rigor of my analysis. Moreover, this also ensured that extracts from the transcripts matched the codes and themes generated (Criteria 7 – 10).

4. Overall

I allocated time to each task and tried to adhere to it. However, it was difficult at times to predict how long each task would take, as it was my first experience of conducting a qualitative study. For instance, the whole process of transcribing, checking transcripts, coding, collating all the codes with their examples and generating themes took about 4 months. Although this was a long process, in my view it was very important not to rush this stage in order to ensure that the themes generated were coherent and accurately represented the data (Criterion 11).

5. Written report

I explained how I conducted each step of the analysis in the empirical paper. Moreover, I tried to be very clear how I generated different codes and themes by providing examples in Appendix G & H (Criteria 12 & 13). The language and concepts used in the report are consistent with the epistemological position of the analysis which is exploratory but also guided by the previous literature (Criteria 14).

I have attempted to adhere to the last criterion by explaining my position as researcher, in terms of my preconceptions and understanding in the empirical paper. Thinking carefully about my own perspective was helpful in dealing with personal biases in the analysis (Criteria 15).

3. CONCLUSIONS

Current UK policies advocate social inclusion, greater choice, independence and the rights of people with intellectual disabilities (DoH, 2001; 2009). However, Greig (2005) noted that though these policies have brought positive changes for many people with intellectual disabilities, they have resulted in little change for some subgroups, including individuals from ethnic minorities. The current findings suggest that there is a lack of understanding in the Pakistani community about intellectual disabilities, especially among first generation Pakistanis. These people find it difficult to identify intellectual disabilities, are unaware of their causes and the interventions available to support individuals with intellectual disabilities and their families. In addition, cultural values and norms (such as 'families should look after their own', the encouragement of interdependence in the family as compared to the independence which is encouraged in Western societies, a pressure to conform with cultural standards and values of extended family systems, strong gender divisions and assigned roles) sometimes appear to clash with the values of UK policy. Thus, the very meaning of key policy values, how these fit with different cultural values and practices, and how they perhaps can be implemented in ways that respect both individual and cultural priorities clearly needs to be the subject of careful negotiation.

4. REFERENCES

Barker, C., & Pistrang, N. (2205). Quality criteria under methodological pluralism: Implications for conducting and evaluating study. *American Journal of Community Psychology, 35*(3/4), 201-212.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Study in Psychology, 3*, 77-101.

Department of Health. (2001). *Valuing People: A new strategy for learning disability for the 21st century.* London: HMSO.

Department of Health. (2009). *Valuing People Now: The Delivery Plan*. London: Department of Health.

Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative study studies in psychology and related fields. *British Journal of Clinical Psychology, 38*, 215-229.

Greig, R. (2005). *Valuing people: The story so far*. London: Department of Health.

Hinton, L., Guo, Z., Hillygus, J., & Levkoff, S. (2000). Working with culture: A qualitative analysis of barriers to the recruitment of Chinese–American family caregivers for dementia study. *Journal of Cross-Cultural Gerontology, 15,* 119–137.

Murphy., Bernadette, M., Patrick, B., Martin, D., & John, K. (1993). 'Attitudes towards the Mentally Ill in Ireland'. *Irish Journal of Psychological Medicine, 10*(2), 75–79.

Podsakoff, P. M., MacKenzie, S. B., & Lee, J. (2003). Common Method Biases in Behavioral Study: A Critical Review of the Literature and Recommended Remedies. *Journal of Applied Psychology, 88*(5), 879–903.

Rees, L., Spreen, O., & Harnadek, M. (1991). Do attitudes towards persons with handicaps really shift over time? Comparison between 1975 and 1988. *Mental Retardation, 29,* 81–86.

Tak-fai Lau, J., & Cheung, C. (1999). Discriminatory attitudes to people with intellectual disability or mental health difficulty. *International Social Work, 42,* 431–444.

APPENDIX A1

**RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL
AND HEALTH PSYCHOLOGY**
DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY

INFORMATION SHEET

1. Study Title: Beliefs and attitudes regarding learning disability among the UK Pakistani community

This study has been approved by the UCL Research Ethics Committee (Project ID: 0960/001)

2. Invitation to take part
You are invited to take part in this research study. Before you decide to take part, we would like to give you some information about the purpose of the research, and what your participation will involve. Please take time to read the following information, and ask if there is anything that is not clear, or if you would like more information.

3. What is the purpose of this study?
This study focuses on the Pakistani community's views about learning disability (also known as mental retardation or mental handicap). To date there has been little research in this area. There are some suggestions that service providers often do not have an accurate understanding of beliefs and attitudes amongst ethnic minority communities. This study aims to increase our understanding of the beliefs and attitudes prevalent in the Pakistani community regarding learning disability. To achieve this aim, we are interviewing key Pakistani community members (such as teachers, religious leaders, social workers, health professionals and politicians) who through their professional role have regular contact with any section of the Pakistani community in the UK; and thus are more able to reflect different views and practices prevalent in their community.

The information gained from the interviews will be used to inform policy makers and service providers to ensure that they have a more accurate picture of learning disability within the Pakistani community.

4. What is involved?
Taking part will involve one interview at your work place or at a place of your convenience at a mutually agreed time. The interview will take 45-60 minutes and will be audio taped. The tapes will be used for the purpose of transcribing the interviews only and will be destroyed after transcribing.

5. Confidentiality.
All information collected during the research project will be kept strictly private and confidential to the research team. Data will be presented in the form of a thesis and research journals and presented at conferences. However, in all circumstances any identifiable detail will be removed.

6. Contact details for further information.
If you are willing to take part or have further questions, please contact Amna either by e-mail: amna.malik1@ucl.ac.uk or telephone: 077-3783-2032.

Amna Malik   Dr Katrina Scior
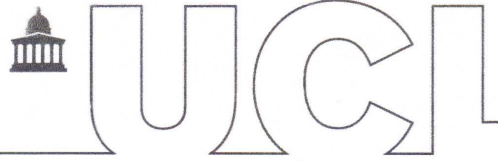Trainee Clinical Psychologist   Senior Lecturer

Doctorate in Clinical Psychology
Research Dept of Clinical, Educational and Health Psychology
University College London, 1-19 Torrington Place
London WC1E 7HB

**RESEARCH DEPARTMENT OF
CLINICAL, EDUCATIONAL AND
HEALTH PSYCHOLOGY**
DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY

🏛 UCL

معلوماتی صفحہ

1- **تحقیق کا عنوان :** برطانیہ میں رہنے والی پاکستانی برادری میں ذہنی معذوری کے متعلق اعتقادات اور رویے۔

یہ تحقیق UCL کی ریسرچ کی اخلاقیات کی کمیٹی سے منظور شدہ ہے (تحقیق ID: 0960/001) ۔

2- **حصہ لینے کی دعوت:** آپ کو اس تحقیق میں حصہ لینے کے لیے مدعو کیا جاتا ہے ۔ اس سے پہلے آپ اس میں حصہ لینے کا فیصلہ کریں ،

ہم آپ کو اس تحقیق کا مقصد اور اس میں حصہ لینے کے لیے کیا درکار ہو گا بتانا چاہیں گے۔ برائے مہربانی مندرجہ ذیل معلوماتی مواد کا مطالعہ

کریں۔ اگر کوئی بات واضح نہ ہو یا اگر آپ کو مزید معلومات درکار ہوں تو آپ ہم سے رابطہ کر سکتے ہیں۔

3- **اس تحقیق کا کیا مقصد ہے:** یہ تحقیق پاکستانی برادری کے دماغی معذوری کے بارے میں خیالات اور نظریات پر مبنی ہے ۔ ابھی تک اس

بارے میں بہت کم علم ہے ۔ کچھ رپورٹیں بتاتی ہیں کہ اکثر اوقات لوگوں کی خدمت کرنے والے اداروں اور پالیسی بنانے والوں کو اقلیتی برادریوں کے

اعتقادات اور رویوں کے بارے میں صحیح معلومات اور سمجھ نہیں ہوتی ۔

اس تحقیق کا مقصد یہ ہے کہ اس سمجھ میں اضافہ کیا جائے ۔ اس مقصد کو حاصل کرنے کے لیے ہم پاکستانی برادری کے اُن اہم

لوگوں (جیسے کہ اساتذہ ، مذہبی رہنما، سوشل ورکر، صحت سے منسلک اداروں میں کام کرنے والوں جیسے کہ جی پی ، سائکاٹرسٹ، ماہر نفسیات،

اور سیاست دان) سے انٹرویولے رہے ہیں۔ جن کا اپنے پیشے کی وجہ سے برطانیہ میں رہنے والے پاکستانیوں کی کسی برادری سے اکثر واسطہ پڑتا

ہے ۔ اسی تعلق کی وجہ سے یہ لوگ اس برادری کے مختلف نظریات اور رویات کے بارے میں بہتر رائے دے سکتے ہیں ۔

4۔ انٹرویو میں کیا شامل ہے ؟ حصہ لینے کے لیے ہم باہمی رضامندی سے آپ کی سہولت کے وقت اور جگہ پر ایک انٹرویو کریں گے ۔ انٹرویو 45 سے 60 منٹ کا ہو گا اور آڈیو ریکارڈ کیا جائے گا۔ اِس ٹیپ کو تحریر میں لا کر بعد میں ضائع کر دیا جائے گا۔

5۔ معلومات کو بصیغہ راز میں رکھنا: اِس تحقیق میں حاصل کی گئی تمام معلومات اِس تحقیق کی ٹیم کے پاس انتہائی خفیہ طریقہ سے رکھی جائیں گی ۔ اِس تحقیق سے حاصل کی گئی ہوئی معلومات تھیسس کی صورت میں رکھی جائیں گی ۔ اِس کے علاوہ یہ معلومات تحقیقاتی جریدوں اور کانفرنسوں میں بھی پیش کی جائیں گی ۔ بہر حال ہر صورت میں شناخت ہونے والی کوئی بھی تفصیل نکال دی جائے گی ۔

6۔ مزید معلومات حاصل کرنے کے لیے رابطہ :۔ اگر آپ حصہ لینے کے لیے رضامند ہیں تو برائے مہربانی آمنہ کو :۔

ای میل : amna.malik1@ucl.ac.uk

فون : 077-3783-2032

سے رابطہ کریں :

آمنہ ملک   ڈاکٹر کثرینہ سکائر
ٹرینی کلینکل سائیکالوجسٹ   سینئر لیکچرار

ڈاکٹریٹ اِن کلینکل سائیکالوجی
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19-1 ٹارینگٹن پلیس
لندن WC1E 7HB

APPENDIX B1

Participant Identification Number for this study:

CONSENT FORM

Title of Project: Beliefs and attitudes regarding learning disability among the UK Pakistani community

Name of Researcher: Amna Malik
Doctorate in Clinical Psychology (DClinPsy)
Research Dept of Clinical, Educational & Health Psychology
University College London, 1-19 Torrington Place
London WC1E 6BT
Contact no: 077-3783-2032

Participant's Statement

I …………………………………………………… agree that I have

- read the information sheet and/or the project has been explained to me orally

- had the opportunity to ask questions and discuss the study

- received satisfactory answers to all my questions or have been advised of an individual to contact for answers to pertinent questions about the research and my rights as a participant and whom to contact in the event of a research-related injury.

- I understand that my participation will be taped and I am aware of and consent to, any use you intend to make of the recordings after the end of the project.

- I understand that I am free to withdraw from the study without penalty if I so wish and I consent to the processing of my personal information for the purpose of this study only and that it will not be used for any other purpose. I understand that such information will be treated as strictly confidential and handled in accordance with the provision of the Data Protection Act 1998.

Signature: _____ Date: _____
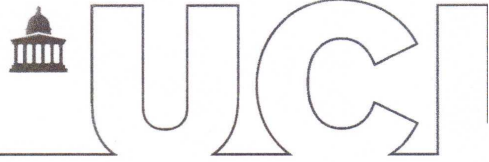
Investigator's Statement

I Amna Malik confirm that I have carefully explained the purpose of the study to the participant and outlined any reasonably foreseeable risks or benefits (where applicable).

Signature: _____ Date: _____

APPENDIX B2

RESEARCH DEPARTMENT OF
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DOCTORAL PROGRAMME IN CLINICAL PSYCHOLOGY

تحقیق میں شرکت کرنے والے کا شناختی نمبر : ....

رضامندی نامہ

برطانیہ میں رہنے والی پاکستانی برادری میں ذہنی معذوری کے متعلق اعتقادات اور رویے

تحقیق کا عنوان:

آمنہ ملك

تحقیق کرنے والے کا نام :

ڈاکٹریٹ اِن کلینکل سائیکالوجی

ریسرچ ڈیپارٹمنٹ آف کلینیکل، ایجوکیشنل اینڈ ہیلتھ سائیکالوجی

یونیورسٹی کالج لندن

1-19ٹارینگٹن پیلس، لندنWC1E 7HB

ای میل : amna.malik1@ucl.ac.uk

فون نمبر 077-3783-2032

تحقیق میں شرکت کرنے والے کا حلفیہ بیان

میں ....متفق ہوں کہ :-

1- میں نے معلوماتی صفحہ پڑھ لیا ہے اور /یا مجھے زبانی طور پر اس تحقیق کے بارے میں بتایا گیا ہے۔

2- مجھے اس تحقیق کے بارے میں سوال پوچھنے اور بات چیت کرنے کے لیے موقع دیا گیا ہے ۔

3- مجھے اپنے سارے سوالات کا تسلی بخش جواب ملا ہے یا مجھے کسی ایسے شخص سے رابطہ کرنے کے لیے مشورہ دیا گیا ہے جو کہ اس

تحقیق سے متعلق میرے سوالات کا جواب دے سکے۔ اِس کے علاوہ بحیثیت شریک مجھے میرے حقوق سے آگاہ کیا گیا ہے اور یہ بھی بتایا

گیا ہے کہ تحقیق سے متعلق کسی بھی ممکنہ نقصان کی صورت میں کس سے رابطہ کیا جائے ۔

4۔ میں سمجھتا /سمجھتی ہوں کہ میرا انٹرویو ریکارڈ ہو گا اور میں باخبر ہوں اور اس بات کی رضامندی دیتا /دیتی ہوں کہ اس تحقیق کے اختتا

پر آپ جیسا چاہیں اِس ٹیپ کو استعمال کر سکتے ہیں ۔

5۔ یہ کہ سمجھتا /سمجھتی ہوں کہ میں جب بھی چاہوں بغیر کسی جرمانے کے اس تحقیق سے دستبردار ہو سکتا /سکتی ہوں ۔ میں اس بات

سے رضامند ہوں کہ میری ذاتی معلومات صرف اس تحقیق کے مقصد کے لیے استعمال ہوں گی ۔ میں سمجھتا /سمجھتی ہوں کہ ایسو

معلومات خفیہ رکھی جائیں گی اور Date Protection1998 کے قانون کے مطابق استعمال ہوں گی ۔

دستخط _____ مورخہ _____

تصدیق کرنے والے کا حلفیہ بیان

میں آمنہ ملک یہ تصدیق کرتی ہوں کہ میں نے اِس تحقیق میں شرکت کرے والے /والی کو احتیاط سے اس تحقیق کا مقصد او

کوئی بھی ممکنہ خطرے یا فائدے کے بارے میں آگاہ کر دیا ہے ۔

دستخط _____ مورخہ _____

INTERVIEW SCHEDULE

PROMPTS
- **Switch on tape recorder**
- **Give overview of study & answer questions**
- **Duration of the interview and what it would consist of. Explain in detail that we are interested in their community's point of view, that 'sometimes your community may hold different views than yours. In this interview, we are interested in you shedding a light on what you find your community's views to be'.**
- **Ask to sign consent form**

1) **Elaborate on the information (I may have gathered during recruitment) if needed:**
   Prompts:
   > *Ask them to tell a bit about themselves. Where were they born, where they grew up, were they in contact with Pakistani community then*
   > *Role within community (including work, how long worked there).*

2) **Can you tell me a bit about which section of the Pakistani community do you usually have contact with? Demographics (for instance; are they 1st generation, 2nd generation .....; rural vs urban; how religious & observant ; educational level)**
   Prompts:
   > *How often do you see them?*
   > *Their role (for instance; do they seek advice from you)?*

3) **Please read carefully this scenario and later on I will ask some questions regarding this: (give them the laminated sheets with scenario 1 and then repeat the procedure with scenario 2. Put scenario away after this question).**
   Prompts:
   > *What do you think might be going on in this scenario?*
   > *What would people in your community think is going on in this scenario?*
   > *Explore range of views – what else might they think. What would majority think?*

4) **Knowledge of the terms**
   Prompts:

   > *Have you heard of the terms learning disability, mental handicap or mental retardation?*
   > *How do you understand these terms?*
   > *Would most people in your community be familiar with these terms. Which ones are they most/least familiar with. What else might they say?*
   > *Do you know anyone with learning disability? How much contact do you have with them?*

5) **Beliefs regarding the causes of learning disability/ mental handicap/ mental retardation**
   Prompts: Use scenarios
   > *I am really interested what your community thinks about what might cause learning disabilities.*
   > *What are commonly held views in your community? Are their views similar or different to other Pakistanis? Any ideas perhaps only some people would hold?*
   > *How do they know about these beliefs about causes (have community members expressed them, do they have contact with someone whose family member has LD, someone with LD has told them of attitudes and beliefs they face by their community etc).*

6) Attitudes and beliefs regarding individuals with learning disability and their families

Prompts: Use scenarios

➢ *In your view how does your community feel about having people with learning disabilities around them? Comfortable, afraid, considered dangerous. Friendships with them.*

➢ *How are individuals with LD and their families **treated** in the community? (stigma, labelling etc)*

➢ *What do people think about **social contact** with them (for instance; at parties, family gatherings, weddings). Are such people invited and welcome at social events? At which events they are welcome and at which events are they not?*

➢ *People's feelings about the **birth** of a child with this?*

➢ *People's **views about parents** who have a child with this.*

➢ *People views about their **schooling**? Mainstream or special schools. Reasons.*

➢ ***Work.***

➢ *What do parents think about the **future** of their child with LD when they are no longer alive? Available **support systems**. Thoughts of wider community in this instance?*

➢ *How most people in their community would envisage Sara/ Faizan's adult life, i.e. where would they be living? Who would support them? What would they be doing? How different would this be from e.g. non-disables siblings and peers?*

➢ *How much independence would they give to their child with LD?*

➢ ***Marriage** and children of individuals with LD?*

➢ *What is impact on family of person with this, e.g. prospects for sibling's marriage etc?*

7) Help for individuals with LD?
Ask questions around different types of help and treatments: Physical care needs where applicable, support to access activities, mental health services, other health services etc)

Prompts:

➢ I would really like to know whether your community thinks that anything could be done for individuals with LD?

➢ If yes, what and what sort of help would people view as appropriate?

➢ Also explore what sort of help people seek.

➢ What would your community think could be done to support Sara? **(Give Sara's scenario)**

➢ What about Faizan? **(Give Faizan's scenario)**

8) Comparison to mental illness (like schizophrenia, depression)

Prompts:

➢ You have been very informative about your community's attitudes towards learning disability. In your view does your community have similar or dissimilar views about mental illnesses such as depressions and schizophrenia?

For instance (mentioned below are prompts only)

➢ What do they think about the causes of mental illness

➢ How do they feel about having an individual with mental illness around

● Schooling

● Work

● Stigma

● Prospects of marriage for them; prospects of marriage for their children or siblings

● Contact, friendships, having them in social events

● Help

انٹرویو کا طریقہ کار

یاد دہانیاں : -

☆   ٹیپ ریکارڈ کو آن کریں ۔

☆   اس تحقیق کے بارے میں بتائیں اور سوالات کے جواب دیں۔

☆   انٹرویو کی مدت اور اُس میں کیا ہو گا بتائیں۔ تفصیل سے بتائیں کہ ہم اُن کی برادری کے نقطہ نظر کو جاننے میں دلچسپی رکھتے
ہیں اور یہ بھی کہ بعض دفعہ ایسا بھی ہو سکتا ہے کہ اُن کا نقطہ نظر اُن کی برادری کے نقطہ نظر سے مختلف ہو۔ اس انٹرویو میں ہم اِس
بات میں دلچسپی رکھتے ہیں کہ آپ اپنی برادری کے لوگوں کے نظریات پر روشنی ڈالیں۔

☆   رضامندی نامہ دستخط کرنے کے لیے کہیں ۔

(1)   اگر ضرورت پڑے تو پہلے حاصل کی گئی معلومات پر وضاحت کرنے کے لیے کہیں ۔

مثلاً :

>   اُن سے درخواست کریں کہ اپنے بارے میں تھوڑا سا بتائیں۔ وہ کدھر پیدا ہوئے تھے۔ کدھر پلے بڑھے ، کیا اُن کا
پاکستانی برادری سے تعلق تھا؟

>   اُن کا اپنی برادری میں کیا کردار ہے (کام میں بھی ، کام کا عرصہ)

(2)   آپ کا کس پاکستانی برادری کے ساتھ عام طور پر ملنا ہوتا ہے ۔ اُن کی تفصیل (مثلاً کیا وہ ، پہلی یا دوسری
نسل ہیں۔ دیہی یا شہری آبادی سے تعلق تھا، مذہبی رحجان ،تعلیم)
مثلاً :

>   آپ اُن سے کتنا ملتے ہیں؟

>   اُن کا کردار (مثلاً کیا وہ آپ سے مشورہ لیتے ہیں)

(3)   مہربانی کر کے یہ مثال غور سے پڑھیں اور پھر میں اِس کے متعلق آپ سے کچھ سوال پوچھوں گی۔ (اُن کو مثال
نمبر 1 والا صفحہ دیں اور پھر یہی عمل مثال نمبر 2 کے ساتھ دہرائیں ۔ سوالات کے بعد دونوں مثالیں ہٹادیں)۔
مثلاً :

>   آپ کے خیال میں اِن مثالوں میں کیا ہو رہا ہے ؟

>   آپ کی برادری کے لوگوں کا کیا خیال ہو گا کہ اِن مثالوں میں کیا ہو رہا ہے؟

>   مختلف خیالات اور نظریات کو کھوجیں ۔ اِس کے علاوہ وہ کیا سوچتے ہیں ؟ زیادہ تر لوگوں کی کیا سوچ ہے؟

(4) استعمال کی جانے والی اصلاحات کا علم ۔

مثلاً :

◄ کیا آپ نے ذہنی معذوری Mental handicap, Leaning disability, Mental retardation جیسی اصطلاحات سُنی ہیں۔
ان اصلاحات سے آپ کے ذہن میں کیا آتا ہے ؟

◄ کیا آپ کی برادری کے اکثر لوگ اِن اصطلاحات سے واقف ہوں گے۔ کِن سے وہ سب سے زیادہ واقف ہوں گے۔ اور کِن سے
سب سے کم۔ ذہنی معذوری کو بیان کرنے کے لیے وہ اِس کے علاوہ کیا الفاظ استعمال کریں گے؟

◄ کیا آپ کسی شخص کو جس کو ذہنی معذوری ہو ،جانتے ہیں۔ آپ اُس سے کتنا ملتے ہیں؟

(5) ذہنی معذوری کی وجوہات کے بارے میں اعتقادات

مثلاً : مثالوں کو استعمال کریں ۔

◄ میں یہ جاننا چاہوں گی کہ آپ کی برادری کا ذہنی معذوری ہونے کی وجہ کے بارے میں کیا خیال ہے ۔

◄ آپ کی برادری میں کون سے نظریات عام طور پر پائے جاتے ہیں ؟ کیا یہ نظریات دوسرے پاکستانیوں کے نظریات سے ملتے ہیں
مختلف ہیں؟ کیا ایسے کچھ نظریات ہیں جو صرف کچھ لوگوں میں پائے جاتے ہیں؟

◄ اُن کو اِن نظریات کا کیسے پتہ چلا (اپنی برادری سے ، کیا اُن کا کسی اُس شخص سے تعلق ہے جس کے خاندان کے کسی فرد
ذہنی معذوری ہے ، جس فرد کو ذہنی معذوری ہے اُس نے لوگوں کے اعتقادات اور رویات کے بارے میں بتایا ہے وغیرہ وغیرہ)۔

(6) ذہنی طور پر معذور لوگوں اور اُن کے گھر والوں کے بارے میں اعتقادات اور رویات

مثلاً : مثالوں کو استعمال کریں۔

◄ آپ کے خیال میں اگر ذہنی طور پر معذور افراد آپ کی برادری کے لوگوں کے ساتھ اسامنے ہوں تو لوگوں کے کیا احساسات
ہوتے ہیں۔ مطمئن ، خوف، یا اُنھیں خطرناک سمجھا جاتا ہے ۔ کیا لوگ اُن سے دوستی کرتے ہیں۔

◄ ذہنی طور پر معذور افراد اور اُن کے گھر والوں کے ساتھ کیس سلوک کیا جاتا ہے ؟ (اچھا ، بُرا ، بہتان وغیرہ)

◄ لوگ اُن سے سماجی تعلق کے بارے میں کیا سوچتے ہیں (جیسے کہ پارٹیاں ، خاندانی دعوتوں،شادی ، تھوارات وغیرہ) ۔ کیا
ایسے لوگوں کو دعوتوں پر مدعو اور خوش آمدید کیا جاتا ہے ؟ کن مواقع پر اُن کو خوش آمدید کیا جاتا ہے اور کن پر نہیں۔

◄ ایسے بچوں کی پیدائش پر لوگوں کے کیا احساسات ہوتے ہیں۔

◄ ایسے بچوں کے والدین کے بارے میں لوگوں کے کیا نظریات ہوتے ہیں۔

◄ لوگوں کے اُن کی تعلیم کے بارے میں نظریات ؟ عام سکول یا اسپیشل سکول، وجوہات :

◄ کام

◄ ذہنی طور پر معذور بچوں کے والدین کیا سوچتے ہیں کہ جب وہ زندہ نہیں رہیں گے تو اُن کے بچوں کا مستقبل کیا ہو گا؟
مدد کا انتظام ، باقی برادری کے اِس معاملے میں کیا خیالات ہیں۔

◄ اُن کی برادری کے لوگوں کا سارہ افیضان کی جوانی کے بارے میں کیا خیال ہو گا؟ وہ کہاں رہ رہے ہوں گے؟ اُن کی مدد کون
کرے گا ؟وہ کیا کام کر رہے ہوں گے؟ اُن کی زندگی اپنے بہن بھائیوں اور ہم عمر لوگوں کے مقابلے میں کتنی مختلف ہو گی ؟

‹ ذہنی طور پر معذور لوگوں کی شادی اور بچے ۔

‹ ایسے لوگوں کے خاندان کے افراد پر اُن کی معذوری کا کیا اثر ہوتا ہے ۔ جیسا کہ اُن کے بھائی بہنوں کی شادی کے امکانات ۔

(7)   ذہنی طور پر معذور افراد کی مدد؟

مختلف مدد اور علاج معالجے کے بارے میں سوالات پوچھیں۔ انھیں اگر جسمانی طور پر مدد کی ضرورت ہے ، مختلف
سرگرمیوں میں جانے کے لیے مدد، ذہنی صحت کے لیے علاج، دوسرے صحت کے معاملوں میں مدد وغیرہ ۔
مثلاً:

‹ میں یہ جاننا چاہوں گی کہ آپ کی برادری کے لوگ کیا سوچتے ہیں کہ ذہنی طور پر معذور لوگوں کی مدد کے لیے کچھ کیا
جا سکتا ہے؟

‹ اگر ہاں ، تو کیا اور لوگ کسی قسم کی مدد کو مناسب سمجھتے ہیں؟

‹ لوگ کس قسم کی مدد لیتے ہیں؟

‹ آپ کی برادری کے لوگ کیا سوچتے ہیں کہ سارہ کی مدد کے لیے کیا کِیا جا سکتا ہے ۔ (سارہ کی مثال والا صفحہ دیں)

‹ فیضان کے بارے میں کیا خیال ہے ۔ (فیضان کی مثال والا صفحہ دیں)

(8)   دوسری ذہنی بیماریوں سے مقابلہ (جیسے کہ ڈپریشن ، Schizophrenia)

مثلاً:

‹ آپ نے اپنی برادری کے لوگوں کے ذہنی معذوری کے بارے میں کافی ضروری معلومات دی ہیں۔ آپ کے خیال میں آپ کی
برادری کے دوسری ذہنی بیماریوں جیسے کہ ڈپریشن اور Schizophrenia کے بارے میں وہی یا مختلف خیالات ہیں۔

جیسے کہ (نیچے دی ہوئی صرف مثالیں ہیں)

‹ آپ کے خیال میں ذہنی بیماریوں کی کیا وجہ ہے ؟

‹ لوگوں کے ذہنی بیماریوں میں مبتلا لوگوں سے ملنے کے بارے میں کیا خیالات ہیں۔

‹ تعلیم

‹ کام

‹ اُن کے بارے میں لوگوں کے تاثرات (بہتان وغیرہ)

‹ اُن کی شادی کے امکان ، اُن کے بچوں ، بہن ، بھائیوں کی شادی کے امکانات

‹ ملنا جلنا، دوستی ، محفلوں میں دعوت

‹ مدد

APPENDIX D1

Scenario 1:

Sara is 20 and lives with her parents and three siblings. She finds it difficult to learn new things. She also has difficulty in understanding what others expect of her and therefore often does not live up to other people's expectations. Throughout her schooling, she needed extra help to keep up with her school work. Despite extra support and effort she put in, she did not manage to pass her GCSEs. She has not been able to find any work and is in receipt of benefits. Her parents manage her money. She gets pocket money which she spends on makeup and jewellery. Currently her mother is teaching her how to cook but says Sara is finding it difficult to follow instructions.

(مثال نمبر 1)

سارہ کی عمر بیس سال ہے اور اپنے والدین اور تین بہن بھائیوں کے ساتھ رہتی ہے ۔

اُس کے لیے نئی باتیں سیکھنا مشکل ہے ۔ اُس کے لیے یہ بھی سمجھنا دشوار ہے کہ دوسرے لوگ

اُس سے کیا توقعات وابستہ رکھتے ہیں۔ اِسی لیے اکثر اوقات وہ لوگوں کی امیدوں پر پورا نہیں

اُترتی ۔ اُس کو اپنی سکول کی تعلیم کے دوران ہمیشہ اضافی مدد کی ضرورت رہی ۔ اضافی مدد

اور اُس کی محنت کے باوجود وہ GCSE کا امتحان پاس نہ کر سکی ۔ وہ کوئی کام ڈھونڈنے میں

کامیاب نہیں ہوسکی اور حکومت سے مدد لے رہی ہے ۔   اُس کے والدین اُس کے پیسوں کا خیال

رکھتے ہیں۔ اُس کو جیب خرچ ملتا ہے ۔ جو کہ وہ میک اپ اور زیورات خریدنے میں استعمال کرتی

ہے ۔ اِن دنوں سارہ کی والدہ اُسے کھانا بنانا سیکھا رہیں ہیں۔ لیکن سارہ کو اُن کی ہدایات پر عمل

کرنا مشکل ہو رہا ہے ۔

Scenario 2:

Faizan is 5. He recently moved from Pakistan to London with his parents and 3 year old brother. He did not attend any school or nursery in Pakistan. His speech and general development are well below other children of his age and his mother complains that he can do very few things for himself. Faizan is very close to his grandmother who was left behind in Pakistan. He sometimes becomes very angry and expresses his anger by throwing things and hitting his younger brother. His parents are quite worried about Faizan but do not know what to do.

(مثال نمبر 2)

فیضان کی عمر پانچ سال ہے۔ کچھ عرصہ پہلے وہ اپنے والدین اور تین سالہ بھائی کے ساتھ پاکستان سے لندن آیا ہے وہ پاکستان میں کسی سکول یا نرسری میں نہیں جاتا تھا۔ اُسکی بات کرنے کی صلاحیت اور عام نشو نما ء اپنے ہم عمر بچوں کے مقابلے میں کم ہے۔ اُس کی والدہ کو شکایت ہے کہ وہ اپنے بہت کم کام خود سے کرسکتا ہے۔

فیضان اپنی دادی جو کہ پاکستان میں ہے، سے بہت مانوس ہے۔ بعض اوقات فیضان بہت غصہ میں آجاتا ہے اور اپنا غصہ کا اظہار چیزیں پھینک کر اور اپنے چھوٹے بھائی کو مار کر کرتا ہے۔ فیضان کے والدین اُس کے لیے کافی فکر مند ہیں۔ مگر وہ نہیں جانتے کہ وہ کیا کریں۔

Phases of thematic analysis

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

APPENDIX G

Examples of data relevant to each code

God's punishment, curse	*P04: 14: 8 – 9 Even educated (Yes, but what they feel is that this is a God's punishment that they may have done something wrong in their lifetime)*
	P05: 10: 23 – 26 (Our people can be cruel sometimes. They think that mother or father might have been naughty and done something (Interviewer: sinned.) yeah, and there is curse on them, but that is not general, but I would say that mainly people can be unkind and say things like that)
	P06: 3: 2 – 6 (I think a lot of people might want to blame the parents, say it is something that the parents have done wrong, but then looking at his other siblings if may be they do not have as many issues then they might feel sorry for the parents, think this is may be a test for the parents)
	P06: 8: 23 – 25 (I think there always be some fringe members of the community that will say, you know, this is their punishment from God, but I think that is only in minority)
	P09: 8: 21 – 25 (Sometimes if there are family conflicts, we will also say that it is a curse from God on them. We will also say that it is a result of such and such thing they did. Because of this, after linking in some way, we not only torture the child but also the family)
	P09: 15: 1 – 11 (I have said earlier that the ones who are closer, with whom they have good relations, they obviously do not have any negative views about them but the ones who do not have good relations – they say that this happened because he/she did that bad thing to others. Look in our life you do get not get along with some sometimes, so anyone who has negative views about someone would link those events to them. Conflicts happen between mother and daughter in law. People say that she did that to her mother in law, so god has cursed her. So people who are negative would link it to some event. The ones who are positive would obviously have a sense of compassion. They do not link like that)
	P10: 8: 29 – 34 to 9: 1 – 2 (They would not see as failing of the parents necessarily. They would spare that. There may be old wives tales attached to, you know you have got this type of kid because you behaved very badly and you did this that is why you have got this child, there may be that element, which have come across, may be, but I am aware that only because I have heard a little story someone told me a while back, it is God punishment that is why you have this, this sort of, may be a stigma, but generally not)

	P12: 10: 34 to 11: 1 – 2 (you know the deformities because you know he did something wrong or did something bad or you know (interviewer says: and it is a punishment) yes somebody is punishing you)
	P13: 18: 7 – 15 (I do not know, I think blaming probably comes from internal, you know when you have like an internal grudge or internal problem then the blaming comes in. I think that probably may be in Pakistan or you know those kind of, back in Pakistan may be the general community will blame, but the blame here probably comes from you know in-laws or people who do not like the person and they have got a nerve, you know it is not nice to say grudge to say Oh yes we are not kind of, it is horrible thing to say even to repeat it but you know kind of serves them right, but they kind of make a conclusion as to what happened)
	P14: 4: 8 – 9 (They even blame the curse of Allah has come upon us)
Test from God	P06: 3: 2 – 6 (I think a lot of people might want to blame the parents, say it is something that the parents have done wrong, but then looking at his other siblings if may be they do not have as many issues then they might feel sorry for the parents, think this is may be a test for the parents)
	P06: 4: 29 – 33 (But then from there are like religious perspective, it is like you know this is a test, some people may be born blind, some people may be born with one arm and some people are just born with some more mental challenges and so that is one explanation)
	P06: 7: 17 – 23 (I certainly think that those people who see it more as a test find they have more strength, kind of emotional or spiritual strength to accept and deal with it, like they are not really looking for answers and those that may be do not see as much as a test from God. They seem to be less content, they seem to be more in a search of answers, so I do not know if that has built effect on their ability to cope)
	P13: 4: 1 – 4 (It is something that was given from God and I think that is their sense of security really and that is a system in maybe understanding what has happened as opposed to looking at a child's kind of disability that they look at from the you know it is a test from God)
	P13: 10: 29 – 33 to 11: 1 – 4 (Sometimes when something happens unfortunately if a child has got learning disability it is seen as a problem and sometimes they need a closure to a problem you know not to lay blame on something but to say this was the reason why it

happened and that is what they need, they just need a reason, they do not need to just accept that the child is like that so for them to say that it was from God or them to say you know this she must have done something maybe gives them that closure then actually dealing with the problem itself)

Integrated not sidelined	**Mostly interacting with family friends**

P01: 9: 9 – 12 (I have never seen them sort of pushed away or sort of ostracized or anything like that. I know that there are examples of cases like that, but I have never actually seen that in the personal experience I have had in the community)

P01: 10: 22 – 30 (when I have been to the mosque and I have seen the children there, I think the children themselves, I have seen a few of them walking around and sort of the children I know of, one has got a generalized learning disabilities from being diagnosed, couple of others Down's syndrome and they have actually just be walking about engaging as much as they can, so they might have small group of friends and just chatting to them and I generally think that they fitting in. I think they are fine. They are not on the sidelines or anything like that. They are just doing their own thing)

P01: 11: 2 – 5 (with their own friends or with their own family friends or the mother in the mosque might have a couple of friends that she is close to, so she is talking to them and the children getting over their kids, they are chatting and the others)

P01: 11: 14 – 22 (Yeah, people are comfortable for few reasons. One is because they have grown up seeing them come to the mosque. You know they are familiar with them. Also because those children are not displaying any particular negative or challenging behaviour or anything like that so those children may be having mild form of learning disability or moderate and they are able to attend the situation and behave appropriately according to the situation, that is why. For a start, I do think most people would not tend to bring children with severe learning difficulties in the first place)

P02: 13: 32 – 34 to 14: 1(The people who know that, the mother and the other people, they are very sympathetic and they all sort of try and help and talk to the person with learning disabilities)

P12: 16: 26 – 33 (What I have seen, where I have been to weddings, like people are like very affectionate with the ones that are in wheelchairs, all that you know. They are just sort of kind of included, I never saw them just left in the corner and just stay in there, I have not come across that. Yes, I think yes they do involve them. My sister's ex-husband, whose nephew is autistic, and he just sort of |

does his own thing, but you do try to get close to him and say, hello, you know you greet and my dad will try and go and shake hands, they are not disregarded)

Everyone

P03: 8: 29 – 35 to 9: 1 – 5 (I think they are comfortable. If you ever get to the local mosque, I mean, you will get people who bring their disabled kids to the mosque with them and you will see like the disabled child or disabled gentleman he is in the same line as everyone else and praying and the fact quite clearly shows that people do not have an issue with the fact that the other person is disabled and stuff like that because you know they are happily reading Namaz, standing in the same line as them in Ramadan time, you know you will get people come to the mosque with some of the learning disabled children and even learning disabled old people who eat and they are all sitting in a row and they are all eating together, so I believe these believes and stuff like that people do understand and they are quite comfortable in that)

P06: 6: 2 – 11 (I mean up until now there was nothing ever formal and just about two years ago this community just like someone became speech and language therapist and they just suggested that we should just have like a formal flat kind of friendship group, so like on the kind of natural basis they do not really have a friendship group, but now we have set something up so that every couple of weeks whenever someone is available, you might just kind of put them and go the cinema or something like that. So it is something new just taking off, but up until now there has not been anything, they just kind of stick with their dad)

P06: 6: 16 – 21 (So whenever there is like a Majlis or like a kind of religious gathering at someone's house, or like I would say Quran Khuwani then they always invite and they always come because I think that is their like main social outlet. It is their main opportunity to go out, so yes they are always invited on these kinds of things and weddings and stuff like that, so they are never really excluded)

P06: 13: 11 – 15 (Like just inviting them to everything, they are not celebrities, but they are the people whom you guarantee, you know they are going to be at this person's like, at their house for this function or whatever. So just keeping them included I think is just a help)

P06: 15: 7 – 15 (I think it would probably depend on like the threat they might perceive, so if you think someone is going to jump at you, but I do not think I have never sensed any fear in the Pakistani community of someone with mental health problems. It does not seem to be that much of a sense of a physical threat. It is just like

yeah that is cool, do not start screaming and shouting or like why is your face like "phittey munh", like why you are making such a face, but I do not think there would be that much of a problem, I do not think there would be a sense that you need to exclude them)

P13: 15: 15 – 23 (So I mean there are two extremes. There are people in the Luton Muslim or Pakistani community who are very open to it and are supporting I mean even how our charity runs is solely on volunteers. We have a large pool of volunteers and a lot of them come from the Asian community who want to pull together, who understand it, but those are volunteers from the kind of second generation, third generation. You know generation who are educated and who want to make a difference and who understand equal opportunities)

P15: 16: 19 – 28 (Yeah, I think they do generally speaking. I think the Pakistani community, and there is a lot of competition in the Pakistani community but it is quite close knit as well and I think if the faces are known so if there is, like you know during Ramadan there is Iftari, you have like Iftar parties and you are going to the mosque and you meet people and I think it is also inclusive, but I think it is limited. It is not like people do not live in each other's pockets, as it were, you know, they might have a function or Eid party whatever and then everybody would be together, so I do not think they would be excluded on that level, I think there would be support there, yes)

P07: 8: 7 – 19 (I think there will be a difference between the male and female response. I can imagine men just kind of chatting away and it would be quite clear even that they are physically sitting next to each other, there is a gap, quite clear distinction between those conversing and the person who is not and they might respond to that person, by saying go and get me a cup of tea, you know, go and shut the door and something like that. I think if women, you know, our community tends to separate men and women socially. I think the women I can imagine just kind of giving a very menial task to that person so including them but being very sort of, probably appropriately you know kind of basic about what they would necessarily get them to, I do not know, use a sharp knife but they will may be get them to shell some peas or something, you know that kind of thing)

Child with ID ignored during conversations	P09: 13: 7 – 17 (It depends if the people are talking about something important, they will ask him to keep quiet. But if there is some general discussion going on then they might responds. In our community, one thing which is rare that even if any common topic is being discussed, we discontinue that and give proper attention to that person with LD. Or answer him or make him understand something and make him satisfied. This is very rare. We normally would scold him by saying don't you know that we are talking. We will

keep him quiet by telling off or will say him to go out and play. So this will be the response of majority. And if people are sitting just like that, maybe someone will entertain that person's question)

P13: 15: 5 – 15 (I went somewhere when everyone was kind of greeting each other and the child was just sitting in there like while everyone else was playing, was sitting with head down and it just felt like people were missing her out (interviewer says: excluding her) yes excluding her because "oh she would not understand", you know, even a general greeting of, you know if you are Muslim to say Salaam to someone, you know you handshake someone just because you are in the room and you are saying Hi to someone. You know she was just sitting there because no one felt that she could understand. She can touch, she can feel touch, she can feel that someone is giving her a handshake and welcoming her, making her feel welcome)

P15: 7: 22 – 30 (They would not know what to do and so I think with autistic spectrum they are not educated enough to be tolerant and respectful actually. So often those children and I have seen a few will just get left to one side or they you know they are kind of doing this because it is sort of too much sensory stimulation so the child is doing this and everybody staring you know what is going on. So I do not think there is that much tolerance actually and that much acceptance and often I feel which is very sad is that those children get written off, they are disabled, so they are sort of almost half human and that goes along the spectrums)

P15: 8: 18 – 24 (I think the fact, there is one example I know of a child who gets taken everywhere and you could argue that those parents are not ashamed of that child and they are not worried about stigma. Yet, when that child is in that functioning, you know area or in a let us say wedding or I do not know mosque gathering or whatever there is not that much understanding of why that child is that way, so that child is not even get spoken to)

P15: 11: 8 – 14 (Yes I think so they are, they are ostracized quite a lot, which must not do a lot for their self-esteem and their confidence, you know. I think it does depend as well, if it is somebody who has got mild learning difficulty I think they would be better off if you see in relative terms than the ones who have the severe learning disability or even a physical disability, you know. They are not the children that you see interacting with others, I do not think)

Table of initial codes and sub themes

Sub themes	Codes
Some awareness	Awareness of term 'ID' and related terms
	No awareness unless professional help is sought
	Increasing awareness of intellectual disabilities
	Or
	More awareness about intellectual disabilities and related behaviours in 2nd generation
	(b/c they have grown in a British environment, educated more)
	ID severe and unchanging
	No Blame
	Some awareness of services
Lack of differentiated terms and awareness regarding intellectual disabilities	Awareness of term 'ID' and related terms
	Label of ID an explanation for everything
	Lack of terms for ID amongst Pakistanis
	''Pagal'' (mad), an umbrella term to define all the ''mental health disorders''
	Slow and Stupid
	Mental retardation as better understood term
	''Retard'' used to offend people
	Weak mindedness
	Idiot, Retard, spastic, mongol
	Saeen (simple minded)
	Deaf and dumb
	ID with challenging behaviours = mental, crazy, possessed
	Have to be severe to be classed as one with ID otherwise stupid
	Lack of awareness about intellectual disabilities
	ID without physical disability – difficult to understand
	People not bothered about knowing about ID
	Odd child
	Naughty
	(especially when disability is not visible)
	Being silly, spoiled
	Lazy, Do not want to learn, can't be bothered to learn

	Pretence
	or
	Has to be 100% disable to be classed as one with ID otherwise pretence
Lack of awareness and access of professional support	Lack of awareness of services and access of services 1st generation less help seeking attitudes than other generations Younger 1st generation different to older 1st generation Put off the problem as much as possible/brush it under the carpet Education, socio-economic status, language and explanation of services affecting help seeking Lack of trust in the system Shame in handing over their loved ones to the state - Will make internal arrangements Difference between Pakistanis and white British counterparts
Biological explanations	Genetic causes – consanguineous marriage, family genes Born with it / medical condition Problems with brain Medication taken by grandmother in pregnancy effecting mother's pregnancy
Environmental explanations	Cold shower Caesarean Early mistreatment, wrong diet, accidents Parents' fault, not bringing up their children properly Inconsistent schooling
Theological explanations	Not superstitious because of being Muslim Magic and evil eye Challenging behaviour + ID = Possessed by a Jinn God's punishment, curse Test from God Gift from God or Allah's will
Hope for normality and acceptance	Will automatically grow out of it Slight improvement giving false hope Looking for cure More hope for younger child Learning to live with the disability
Tragedy and bleak future	Suggestions of aborting or keeping the child Sense of tragedy in family vs. feeling sorry but no worry in general public Burden on parents

Worries about marriage	Worries about 'bleak' future
	Unable to focus on future
	Children with ID will not improve
	Assessed according to a general benchmark
	Only basic needs considered important
	No emphasis on routine or demanding/challenging tasks
	Marriage not encouraged
	Marriage as a priority and worries about it
	Arranged marriage and partner from Pakistan a preference
	Difficulties in marriage because of skills deficiency, physical symptoms and stigma
	Better marriage prospects for people with mild to moderate ID as compared to severe ID
	Difficulties after marriage
Stigma and negative attitudes	Effects on siblings' marriage prospects
	Community as patronizing and disrespectful
	People unkind to people with ID
	Lack of kindness and sympathy towards parents
	Community gossips, judgements and criticisms
	Jealousy
	Lack of understanding in Pakistanis
	Criticism if family does not care for the person with ID
	Lack of practical support and positive attitude
	Occasional resentment in parents
	Parents experiencing stigma, feeling that their child is burden and inconvenience on others, fear of criticism, feelings of embarrassment
	''My child is not mad''
	Putting blame on someone to help with stigma
	Intellectual disability an embarrassment in community
	Stigma because of explanation of causes
	Stigma because of lack of care
	Stigma because of parents' inability to understand and explain the problem, lack of openness
	Being a minority increasing shame
	Stigma because of lack of education
	High expectations
Sympathy and politeness	Increased awareness and acceptance in second generation
	Feeling sorry, pitying and polite, sympathising and kind
	Avoid commenting to be polite
	Understanding if supported accommodation sought
Inclusion versus exclusion	Integrated not sidelined
	Invited and taken to social occasions

	Accepted by people in social occasions
	Mainstream schooling as less stigma attached to it
	Friendships encouraged
	Sense of altruism in people helping in friendships with individuals with intellectual disabilities
	Inclusion of family of child with ID
	Shut them up from normal life
	Child with ID ignored during conversations
	Consistency in ID comforting, but overall avoidance
	Uncomfortable being around people with ID
	Ignored by family
	Individuals with ID hidden away
	Rarely taken out by parents / not a priority to take children out
	Not invited to specific activities
	Preference of special schools
	Friendships discouraged
	What is to be gained from friendship with someone with an intellectual disability?
	Ability to engage as a barrier in developing friendships
	Exposure/ Growing together helping in integration
	People with mild ID more accepted
	Tolerant after increase of understanding or education
	Attitudes affected by parent's position in the society
	ID + Physical disability = More compassionate, understanding
	Friendships and severity of ID
	Lack of knowledge and incompetence
	Practical difficulties in social integration and people's lack of understanding
	What's the point in taking the child to social occasions?
	Worries about community's response
Views on independence	Emphasis on schooling
	Independence encouraged
	Job encouraged but dependant on skill base, safe environment and right support
	Expected to work as labourers
	Family and friends help in giving them jobs
	Lack of independence and its relation to common cultural practice
	Work not encouraged
	(Not pushed to work if can't achieve highly / black and white thinking regarding jobs)
	What's the point in schooling/learning
	Sense of duty, our blood – our responsibility
	Expectation that will live in family home or with siblings

Sources of help	Independent living/supported accommodation as a last resort Independence dependant on level of disability Independence dependent on level of support Independence dependent on cultural and religious aspects Independence dependent on gender Worries about letting them go out on their own – always escorted Family (Immediate and extended) and community support Local GPs and health visitors as a source of information for parents Going to professionals to seek explanation of difficulties Financial security sought for Marriage as a solution Going to saints/peers Going to Imams, taveez (amulet) and prayer Home food remedies (Drinking soft dough, eating semolina) Sending back to Pakistan Hitting Exercise for physical health ECT as solution Medication and physical interventions valued Events held by charity Pakistanis accessing voluntary services Counselling/ Psychological not encouraged/valued People seeking advice from friends, family, community leaders, imams

APPENDIX I

Master and sub themes

1. Awareness of intellectual disabilities

1.1. Lack of differentiated terms and awareness regarding intellectual disabilities

1.2. Lack of awareness and access of professional support

2. Range of explanatory models

2.1. Biological explanations

2.2. Environmental explanations

2.3. Theological explanations

3. Beliefs about prognosis

3.1. Hope for normality and acceptance

3.2. Tragedy and bleak future

3.3. Worries about marriage

4. Community responses

4.1. Stigma and negative attitudes

4.2. Sympathy and politeness

4.3. Inclusion versus exclusion

4.4. Views on independence

5. Sources of help

UCL RESEARCH ETHICS COMMITTEE

Amendment Approval Request Form

1	**ID Number:** 0960/001	**Name and Address of Principal Investigator:** Dr Katrina Scior Research Dept of Clinical, Educational & Health Psychology UCL
2	**Project Title: Public knowledge and attitudes towards intellectual disability: a cross-cultural and cross-religion study**	
3	**Information about the amendment:** (a) Is the amendment purely administrative?　☐ Yes　☒ No　☐ N/A (b) Has the Participant Information Sheet/Consent Form been changed as a result of the amendment? 　If yes, please enclose a copy.　☐ Yes　☒ No　☐ N/A	
4	**Summarise the issues contained in the amendment:** 1) One strand has been added to the approved project: We are looking to extend this study to examine knowledge and attitudes to learning disability in more depth, using a qualitative approach. Following a media analysis looking at the portrayal of people with learning disabilities within different cultures, in-depth interviews will be completed with members of the general public in order to ascertain their views and understanding of disability from their personal and cultural perspective. Participants will be fully informed about the purpose of the research and ask to give written consent.	
5	**Please give any other information you feel may be necessary:** N/A	
	Signature of Principal Investigator: *K. Scd*	**Date of Submission:** 3/6/09