Listening to the experiences of second generation Pakistani Muslim parents of children with special educational needs:

An Interpretative Analysis

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Abstract

The purpose of this study was to consider the lived experiences of second generation Pakistani Muslim parents, of children with special educational needs. The study aimed to understand how the mothers made sense of their experiences as parents including the influence of their identity, their understanding of disability and any arising key messages for professional practice.

This study was carried out by a trainee educational psychologist within a Local Authority setting. Semi structured interviews were conducted with seven mothers who were known by professionals from the Educational Psychology Service within the Local Authority. All the mothers identified themselves as second generation Pakistanis and as practising Muslims. Their children attended mainstream and specialist provisions in both primary and secondary schools. An additional focus group was also conducted with five of the mothers who were initially interviewed.

An interpretive approach was adopted for this study with Interpretative Phenomenological Analysis (IPA) applied to the generated data from the semi structured interviews and focus group. The themes emerging from the interpretative analysis of the mothers accounts highlighted religious responses to disability, complex family and community relationships, shared personal feelings and coping mechanisms. Issues relating to the perception and experience of working with service providers as both a parent and an ethnic minority were also identified.

Professionals should aim to examine the accessibility of systems and resources to parents from ethnic minority background with particular reference to cultural awareness and barriers that exist for parents for whom English is a second language. The need to listen to the individual experience of each family is stressed. Recommendations are provided for all agencies with the hope to lead to more effective inclusive practice.

Chapter 1: Introduction

The content of this thesis relates to the experiences of second generation Pakistani Muslim parents of children with special educational needs. The structure of the thesis will guide the reader as follows:

- a critical literature review reflecting the theoretical underpinnings of the research
- the rationale for the adopted methodological approaches
- the procedures followed for data collection
- the results that were obtained
- a discussion of the results
- future implications of the research for practice and research and the limitations of the research

The research comprises a number of areas of professional interest: identity, cultural awareness, religious perspectives, parent support and professional provisions. A number of factors have contributed to interest in this particular area of research. As a second generation Pakistani Muslim myself I am aware of the different perspectives that can exist within cultural, ethnic and religious identities. Within my previous career as a secondary school teacher of Religious Education, the need to promote cultural and religious awareness with an emphasis on diversity and individual differences was crucial to my role. My travel to countries such as Pakistan and working as teacher in an orphanage in Thailand, for children with disabilities, has allowed me to experience perceptions of disability that are not typically reflected in western thinking or provisions.

More recently, since undergoing doctorate training as an educational psychologist, I have become increasingly interested in partnerships with parents and the engagement of parents with service providers, particularly parents from ethnic minority backgrounds.

The aim of this research was to explore how understanding the experiences of second generation Pakistani parents with children with special educational needs may inform multi-agency professional practice.

This study recognises that the perspectives, experiences and position of the researcher are a crucial element of the research. As a second generation Pakistani Muslim trainee educational psychologist, with experience of teaching Religious Education and travel and working with individuals with disability in Asia, this research touches upon important aspects of both my personal and professional life.

An interpretative research method was therefore adopted for this study. Based on Interpretative Phenomenological Analysis (IPA), an interpretative account of the experiences of some mothers was sought. Semi structured interviews which were interactive and flexible in their approach were employed to generate shared understandings. A further focus group allowed the opportunity for the mothers to meet collectively. This contact allowed for a parent support group to emerge which was not an initial aim of this study.

The interpretative data analysis allowed for future professional considerations of the use of interpreters, the need to engage both carers of a child and issues centring on the cultural awareness of professionals.

The Research Journey

This research journey has been challenging and insightful, both professionally and personally. I felt extremely privileged by the relationships formed with the mothers and subsequently the incredibly rich data generated. In particular I felt conscious that some mothers sought great comfort in being able to relive their experiences to a professional of a similar ethnic and religious background, giving greater weight to the stories told. As a researcher this led to a strong desire to ensure that not only a considered and detailed account of their experiences was portrayed but also thorough consideration to professional implications was given.

However the restrictions of a doctoral thesis lead to a number of frustrations and dilemmas. IPA holds the role of the researcher and the reflections of the researcher as an integral aspect of the research process. The research journey has allowed me to reflect not only on the mother's religious beliefs and positions in society but also my own faith and what being a second generation Pakistani Muslim means to me. Furthermore I have been able to reflect upon similarities and differences between myself and the mothers as well as the feelings the mother's stories evoked in me. This research journey has also allowed me the opportunity to reflect on what it means to be a second-generation Pakistani Muslim in multi-cultural Britain as well as thoughts relating to integration and segregation in relation to 'inclusion.'

The decision was made to outline factors about myself that may have impacted upon on the research process rather than give detailed personal reflections. Additionally I decided to address the research aim of using the mother's experiences to inform multi-agency practice in as much detail as possible. I felt this gave greater weight to the mother's experiences allowing them to have a greater impact as well as highlighting the importance of their stories. Additionally my own personal reflections regarding my own identity and faith are on going and part of a life long journey and thus will continue after this particular research process has ended. However I wanted to draw the readers attention to the difficulties and frustrations experienced in the decision making process regarding the subject matter of this thesis and that further information has been omitted from the content rather than not being present in the research.

Chapter 2: Literature Review

Overview

The aim of this chapter is to provide the reader with an overview of the current literature pertaining to the subject of this study. The reader should be aware that in line with interpretative phenomenological analysis, the selected methodology, the literature review has been written before, during and after the analysis of the generated data. The first section of this review will address the concept of identity with a reference to migration and the issues relating to the second generation Pakistani Muslim identity with further references to ethnic, cultural and religious identity.

Section two will give consideration to issues centred around Islam and disability with specific reference to the Qur'an. Discussions will also focus on some perceived beliefs and practices of Muslims communities regarding disability as well as the religious accessibility of Muslims with disability. The concept of religious understandings of disability shall then be discussed in a broader context.

Section three will examine the experiences of families with disability. A summary of the experiences of parents of children with disability will be provided, with the exploration of ethnic minority families with disability in more detail followed by specific references to Pakistani families in the UK and in Pakistan.

Section four will examine barriers that exist for some ethnic minority parents in accessing services. Cultural awareness, stereotypes, language and issues relating to interpreters shall be explored. The concept of cultural brokers shall be introduced with particular reference to this study. The research aims of this study shall then be outlined.

Section 1: Identity

Migration

There have been a substantial number of ethnic minorities that have been present in Britain for a number of centuries. However, it has been since the Second World War that Britain has seen significant communities immigrate, settle and impact in a variety of ways upon the British public sphere (Vertovec 1997). In the post war years the expansion of industry and change in economic structure in Britain, as well as death and injury in war, resulted in a demand for cheap labour for undesirable jobs. Active recruitment campaigns were undertaken particularly from the Caribbean, India, Bangladesh and Pakistan in which chain migration patterns emerged. London Transport sent out recruiting officers to Jamaica, Bradford mill owners sent officers to Kashmir, Pakistan and India (Shah 1992).

Second Generation Pakistani Muslims

Pakistani second generation Muslims have been described as *The Half way Generation, The In-between Generation* and as having *The Best of Both Worlds* (Ghunman 1999). Ghunman argues that for many second generation Pakistani individuals, their primary nurturing has been based on traditional beliefs from parents whilst their education within British schools has also provided alternative values and beliefs. Whilst this may be an overgeneralization, it certainly highlights how many second generation Pakistani individuals may be presented with a variety of beliefs and values when growing up in multi-cultural Britain.

Ethnic Cultural and Religious Identity

Stopes-Roe and Cochrane (1990) found interesting perceptions of both first and second generation Pakistani individuals in regards to how identity is perceived. From a sample of one hundred and twenty, they found that fifty nine percent of first generation Pakistani's perceive Britain as their home, which had seemed to have emerged depending on the longer the individual had spent in Britain. For some individuals a greater amount of time had been spent in Britain than in Pakistan. However, an overwhelming majority regarded their identity as Pakistani rather than opting for a British identity. This shows a discrepancy between the country in which one lives and the identity to which they feel they belong. Stopes-Roe and Cochrane argue that whilst Britain may have been perceived as home *"the customs and culture of the natives and their attitudes towards himself and his people may preclude a personal feeling of being one of them."* (1990 p154).

A sharp contrast was noted with second generation Pakistani individuals, in which seventy four percent regarded Britain as their home, with a further fifty seven percent perceiving their identity as being British. This shows a significant difference to the beliefs of first generation individuals within this study.

Dosanjh and Ghuman (1996) argue that second generation individuals from the south Indian subcontinent have different socialising practice to their parents. This includes less salience of religion, reduced rituals surrounding pregnancy and child birth, as well as reduced family sizes. The second generation are also more likely to be bilingual, with British born individuals increasingly using English as their first language.

The concept of identity, values and beliefs of second generation individuals is complex. Hussain (2005) argues that academic, policy and lay discussions can often over emphasise cultural conflicts between parents and young peoples. Instead, Hussain proposes that the experience of second generation individuals is a dynamic process with outright rejection of parents' ethnic and religious identities as rare and partial, with reinterpretation of some values occurring.

However it is important to observe that whilst changes in socialisation have been noted, a strong religious Muslim identity may still exist for many, which Sharif (2001) argues may override any cultural solidarity:

"For many British Asians, being Muslim forms an essential part of their identity. For many it is the foremost aspect of their identity, often overriding any cultural solidarity they might have with other people from the Indian subcontinent sharing the same language or regional affiliations." (p24).

This is an interesting notion particularly in today's current political climate consisting of issues relating to the war on terror, Islamaphobia and terrorism. Such issues can not be explored in detail but it is important to acknowledge their existence. Bywaters et al (2003) argue that the perception of certain minority groups and their religious beliefs can be negative and often based on stereotypes:

"The current focus on religious 'fundamentalism' or 'fanaticism'-terms rarely applied to white European religious believers-may well provide a context which can reinforce inaccurate negative or racist attitudes towards minority ethnic communities." (p508).

This notion of singular identities or hierarchies of identifications can be disputed and may offer a simplistic understanding (Hussain 2005). It is therefore important not to make generalisations and to understand the religious, ethnic and cultural identity and beliefs particularly in relation to how they impact on the experience of disability and special educational needs. This stance will be taken in this study in which the complex nature of identity is recognised as well as the diversity of beliefs and practices that exist within a shared identity.

Section 2: Islam and Disability

Whilst diversity of belief is recognised it is worth considering Islamic teachings on disability. Summarising various religious responses to disability within any faith is difficult and *"even less can one summarise confidently how the major eastern religions of Hinduism, Buddhism or Islam have addressed disability"* (Miles 1995 p50). Hasnain et al (2008) highlight this gap in publication and argue that it can often result in misrepresentation:

"*As disability service providers are increasingly called upon to work with persons from Islamic backgrounds, knowledge of these perspectives may enable them to provide more effective services.*" (p. I)

When understanding Islamic perspectives on disability, it is important to highlight that Islam is a religion rather than a specific culture and spans across many regions of the world and many cultures. The term "Muslim" refers to a worldwide community, who adhere to Islam as their religion in varying and diverse ways. The understanding of the population's perspectives, experiences, and practice of Islam in their habituated country is a challenge to service providers given the diversity that exists (Hasnain et al 2008). However it is crucial that misrepresentations do not exist in order to provide effective services. This study aims to understand the experiences of Muslim parents who were born in the UK but whose parents were born in Pakistan.

In understanding Islamic perspectives on disability, it is important to remember that over generalisations can lead to stereotyping, which can lead to discrimination. Therefore an understanding of an individual's culture is useful for initial interactions, but it is important to keep at the forefront of ones mind that two individuals with similar backgrounds may hold different life views and opinions. Service providers must therefore be aware of the potential range of differences of opinion within the Muslim population in order to provide effective services.

The Qur'an and Disability

The nature of disability in the Qur'an shall be examined. It is important to note that it is not intended to state a definite account of disability in the Qur'an. Rather an examination of some perceived understandings will be explored. The Qur'an is the source of divine revelation or scripture for Muslims and is believed to have been revealed to the Prophet Muhammad. The Qur'an is perceived as Allah's direct personal account to mankind and for many Muslims is *"the true word of God"* (Asad, 1980, p 2).

The Qur'an makes few references to disability. On examination of the primary source of Islamic teachings, the Qur'an and the life examples of the Prophet Muhammad as reflected in his sayings and teachings (Hadith), Bazna and Hatab (2005) conclude that the term "disability" is not found in the conventional sense. Instead there is an emphasis on the disadvantage that is created by society and upon individuals who may not possess social, economic, or physical attributes that society may value at a certain time and place. Bazna and Hatab further argue that the Qur'an places the responsibility upon Muslims to recognise the disadvantage and discrimination and to make attempts to rectify it.

Bazna and Hatab argue that the Qur'an portrays physical disabilities as being *"morally neutral,"* as the Qur'an states that *"every person is potentially perfect so long as they work on developing their innate and individual qualities to the limit of individual differentiation."* (p25). Physical conditions are perceived as a part of the human condition that exists as a part of human life, thus neither a curse nor a blessing. Therefore it is arguable that the Qur'an removes any stigma to the full inclusion of individuals with any physical condition. Islam offers relief from certain religious duties in order to address any difficulties that may arise from any condition. However, it is argued that there is an expectation that one must exert themselves spiritually to the best of their ability.

Secondly, The Qur'an refers to the notion that some individuals may be discriminated against, as they do not meet certain standards that are valued in society, for example social and economic status. The Qur'an states that Muslims should stand up for the rights of those that are disadvantaged against in society, as well as seek to improve their conditions. This notion of free will and fate was addressed from the Hadith literature on the teachings of the Prophet Muhammad who advised Muslims to *"Trust in God, but tie up your camel."* This suggests that Muslims are expected to be active participants in the world but ultimately the outcomes of their efforts lie with Allah (Hasnain et al 2008).

Scripture and Practice

However in spite of this moral neutrality, Muslims with disabilities can often feel stigmatised and even perceive physical conditions as a result of previous sin.

> *"Asian parents of disabled children usually do not have a positive or encouraging attitude; rather it is mostly one of shame or fear of social scorn and stigmatisation, coupled with an almost religious or superstitious view of disability as a manifestation of the will of God-and even in some instances, of the wrath of God for their own prior sins."* (Shah, 1992)

In reference to this, Hasnain et al (2008) argue that many Muslims perceive disability in the context of *kismat* or fate, in that that was meant to be will be and what was not meant to be will not happen.

Bywaters et al (2003) found a variety of beliefs expressed by Muslim parents in terms of explanations of disability. Disability as a punishment from God, illness of the mother during pregnancy, early illness of the child and consanguinity were all expressed. Similarly it is important to be aware of the range of complex views that may be held. Within this study a number of parents expressed a belief in both religious and scientific explanations simultaneously. Equally some parents also rejected a religious explanation and differences in opinion were also expressed between parents.

Religious Accessibility to Individuals with Disability

Whilst there is available discourse on Islamic perspectives on disability, Khedr (2006) argues that issues surrounding disability need to be addressed within the Muslim community. Speaking as the spokesperson for The Canadian Association of Muslims with Disabilities (CAMD), she stated that whilst inclusion may be an ever-increasing agenda within mainstream society, it is still an area where barriers exist within faith-based communities. Little support is argued to be available from religious communities, in which individuals are excluded from participating and engaging in spiritual and social activities.

Research examining the views of young South Asian women growing up with physical impairments found that all had a good working knowledge of ethnic traditions and religious teachings and were attached in some way to their parent's ethnic, religious and cultural traditions. For many their religious beliefs also played an important role in their lives (Hussain 2005). However their religious knowledge was based on discussions with family members and reciting the Qur'an at home. Hussain (2005) argues that young disabled people, irrespective of gender, do not have the same access to religious and cultural socialisations as their non-disabled siblings. Attending places of religious worship can be problematic. This is emphasised in Amin's (2000) account of the difficulties she encountered on completing the religious pilgrimage of Hajj in a wheel chair. An individual's disability may impact on their religious socialisations and subsequently their overall religious experiences.

Western Perceptions of Religious Responses to Disability

Miles (1995) raises some important issues in regards to the notion of professionals working with the religious beliefs parents may hold regarding their child's disability. Miles raises the crucial point that many western professionals may not share the same perspectives as individuals holding eastern religious perspectives:

"The quiet, continuing undercurrent of this religious heritage may surprise many western debaters who do not consciously think in religious terms." (Miles. 1995 p 49).

However Miles (1995) points out that approximately seventy percent of global disability is experienced in countries in which western beliefs and philosophy impact only peripherally. The vital point is made that individuals that many westerners have most contact with, are individuals who can *"accommodate western thinking,"* for example, by learning European languages. However essentially, a significant amount of disability in the global population is understood in very different terms. However such alternative perspectives are unfamiliar to many western professionals and can unfortunately be reared as *"eastern fatalism, outdated and barbaric"* (p50). The imperative point is made by Miles that:

"..the existence of concepts and belief systems that differ radically from those conventional in western debate cannot continue to be ignored; nor, on the other hand, too hastily swallowed" (p 50).

It is however essential to remember that within any religion, a variety of beliefs can exist. Such theological debates cannot be explored in detail but Thompson (1997) points out that it is also important to remember that *"religion is a total experience, not just a set of propositions"* (p5). As a professional it is important to understand the religious experiences of others in relation to disability to allow for appropriate interventions:

"To devise suitable resources, one should study people's cultures and their concepts of disability, in order to communicate appropriately" (Miles, 1995 p51).

Although a somewhat crude example, Miles (2000) describes a situation in which a Pakistani Muslim family living in Britain offered an alterative explanation to their son's epilepsy, which resulted in respite not being sought:

"Mr Ahmed explained that at night a spirit often cane to Imran. When this happened, all the family had to rush to his bed and pray and read the Qur'an until the spirit went away. If Imran were to spend the night away from his family, nobody would be able to help him when the spirit came, and it would be dangerous for him." (p2).

Miles response to this was crucial in engaging the family with service providers leading to the subsequent uptake of respite care and medication to control Imran's epileptic seizures:

"There was no point in arguing about this, as the existence of djinn is a well-attested part of Muslim belief. Instead I decided to try another approach" (p2).

Miles accredits the engagement of the family to respecting their beliefs. The parent's religious views were respected, incorporated into her approach and coupled with a western-based intervention (Hasnain et al 2008).

Furthermore there is an acknowledgement that religious faith may act as an important coping mechanism for parents and this should not be disregarded by professionals:

"Religious or spiritual beliefs may be an important element in the coping mechanism of some families with a disabled child, and therefore, should not be off limits for professionals who may and may not share those beliefs." (Bywaters et al 2003, p508).

Atkin (1991) argues that no communities' views regarding disability should be considered as inferior to another's. Miles' (2000) case clearly demonstrates the importance of accepting and working with alternative understandings of disability. The impact of not doing so has the potential to result in ineffective and inappropriate interventions and responses for families (Westbrooke 1993).

To prevent such inappropriate response, Bywaters et al (2003) argue that it is essential that service providers are not Euro-centric, by responding to the knowledge and attitudes of families, as the parents are not only the prime carers of the child but key workers whom professionals must engage with. However Bywater et al argue that:

"acknowledging and dealing with religious or spiritual beliefs is an area in which few health care professionals are likely to have effective training during the past twenty years." (p508).

Bywaters et al conclude that:

"Families could hold religious explanations alongside medical ones, and although they might believe that their child's life was in God's hands, this did not usually mean that they did not want and seek assistance or strive to provide the best care they could themselves." (p508).

This highlights how the belief systems for some families can be different to those of service providers but that similarities can also exist. This however is not a new or radical concept and the notion that service users and service providers do not always hold the same health beliefs, understandings, objectives and priorities has been previously argued (Ali et al, 2001).

Section 3: Family experiences of children with disabilities

In understanding the experiences of second generation Pakistani Muslims parents of children with special educational needs, it is important to first consider literature relating to the experiences of parents of children with disabilities. Due to the constraints of the study a detailed exploration cannot be provided, but below is a summary of some pertaining issues:

- Research suggests that parents' responses to understanding their child's disability is similar to stages involved in bereavement. For example, feelings of initial shock, denial, sadness, anger, anxiety followed by adaptation and reorganisation (Drotar 1975).

- Parents of children with disabilities are generally more likely than other parents to suffer from stress, anxiety and depression. Marital strains can also increase. (Sloper and Turner 1993)

- Many parents can find themselves socially isolated due to fears of rejection, in which the focus can often shift inwards towards the core of the family (Intaglio and Doyle, 1984).

- Many parents may be resistant and reluctant to work with professionals (Blamires, Robertson and Blamires, 1997).

- The diagnostic process is an *'emotionally difficult'* process in which parents can grow frustrated by waiting lists, experience family rejection and perceive professional blame (Gray 1993).

Wall (2003) argues that within current literature there tends to be a focus on the experiences of mothers, as they tend to be the main carer, but the neglect of fathers' views may lead to marginalisation. Fazil et al (2002) argue that it is not only the individual but also their family that can find themselves *'disabled'* in that they too can experience stigma, discrimination and marginalisation. What further compounds this is that *'disabled families'* are likely to experience many barriers in obtaining access to beneficial information and services which therefore impinges upon their ability to *"exercise their rights and responsibilities as citizens."* (p238).

The need to engage and work in partnerships with parents is highlighted although Todd (2003) argues authentic partnerships between professionals and parents are rare. Willis (2007) advocates the benefits of support groups but argues a parent's desires to attend support groups will depend on the extent to which they want to *"enter the world of disability."* However families that have low support in and out of the home may benefit from attending such groups and it may be helpful for professionals to facilitate with this (Dale 1996). Literature suggests there are clearly additional stresses placed on families living with disability as well as there being a need for professionals to work in partnership with parents to provide support to reduce such anxieties.

Ethnic minority families with disability

Fazil et al (2002) argue that ethnic minority parents with children with disabilities experience additional disadvantages in comparison to the white majority: Ali et al (2001) state" *Disabled individuals from ethnic minority backgrounds may experience differential treatment due to one or more aspects of their perceived identity.*" (p950).

The experience of ethnic minority individuals living with disability is therefore unique to their white counterparts as racism remains an issue and can impact upon an individual's engagement with society (Hussain 2005).

However it is important to note that whilst some experiences are unique to ethnic minorities, similarities also exist between all parents of children with disabilities. Shah (1992) argues that differences between racial groups can be highlighted, which can often be based on stereotypes. She argues that all parents *"regardless of race"* may experience feelings of profound guilt, confusion and disbelief. It is crucial to acknowledge the experiences which are unique to ethnic minority parents of children with disabilities, but also recognise shared experiences of all parents.

Pakistani families with disability in UK

On examination of the experience of Pakistani and Bangladeshi parents of disabled children in the UK, a number of interesting findings have emerged. Raghavan and Waseem (2006) found that families and young people with learning difficulties from Pakistani and Bangladeshi communities in Bradford were experiencing significant difficulties in accessing services. This was highlighted as arising from a reluctance to obtain help and perceptions held about the importance of the caring role within the family. Interestingly families that were allocated a liaison worker, had more access and contact to a wider range of services with more positive outcomes than those that had not, suggesting communication as key to accessing services.

Fazil et al (2002) found some families reported only visiting their child's school on a needs basis as they often felt distressed or uncomfortable on seeing other children with disabilities. Attendance at annual reviews was also found to be very low.

Only two mothers out of twenty reported having any support from their families in looking after their child. None of the parents within the study had access to any parent support group with only two parents having contact with another parent with a disabled child. However the desire to meet with other mothers with disabilities was expressed.

A quarter of all mothers expressed having little support from their partners, leading to increased tensions between husband and wife as well increased tiredness for the mothers. Fazil et al argue that energy levels are an important coping resource and therefore reduced energy levels can increase the stress and anxiety for carers of individuals with disabilities. Further to this, it was found that mothers within this study were more likely to report feelings of anxiety and insomnia and severe depression than fathers. Twenty eight percent of parents within this study also have a diagnosis of severe depression. Interestingly the level of the parent's depression was found to be significantly correlated with their perceived satisfaction of their social support. Increased marital strains were expressed in which one mother reported leaving her husband. Six other mothers reported that their marital relationship had been directly influenced as a result of having a disabled child. For example some mothers have been blamed for their child's disability as well as some mothers feeling that their husband's would not accept their child's disability.

However in spite of such difficulties, Fazil et al argue that the families demonstrate resilience, and in spite of difficult practical and emotional circumstances the parents, especially the mothers, were continuing to care for their children.

This study highlights the need for the families' circumstances to be catered for holistically. It also highlights that language, whilst not the only barrier is a significant barrier and despite over three decades after the main contemporary period of immigration from the South Asian subcontinent, effective means of providing services to individuals who are non-English speaking are still not fully effective (Fazil et al 2002). Further to this diversity between families that share religious ethnic and cultural identities were also identified between families. Fazil et al argue that service providers should therefore not make assumptions about the families or what type of services they may or may not value.

Fazil et al conclude that disadvantage and institutional discrimination were found and that:

"the widespread disadvantage and discrimination experienced routinely by families with a disabled child in the UK in the twenty-first century is compounded for the

families who talked to us by everyday institutional and individual racism that is the backdrop to their lives" (p252).

It would appear that such factors can increase difficulties experiences by Pakistani families with disability living in the UK. The purpose of this study is to explore such issues in further detail.

Disability in Pakistan

As the views of second generation Pakistani individuals are being sought, it is useful to examine some views that may exist towards disability in Pakistan. It is worthy of note that there is little published work in this area. Miles (1995) found a range of responses towards disability in Peshawar. This included:

a) Mocking, playing tricks, fear and rejection
b) Pity mixed with fear: pity overcoming fear
c) Alms-giving as a religious duty
d) Idea of society's duty
e) Ascription of caste status and social needs
f) Should be enabled to live their own lives as far as possible
g) Should have access to rights and services available to anyone else
h) Positive action to make rights and services
i) Should have the right to be different. (p53)

This range of responses reflects the diversity of beliefs regarding disability in Pakistan and thus the difficulty in being able to summarise perspectives of disability in Pakistan. Miles argues that it is important to remember that in countries such as Pakistan *"great material inequalities exist: millions live in crushing poverty or in the fear of it, with little hope of future improvements"* (p62).

The reality of living in a country where absolute poverty is a reality, can impact on both the perceptions and care given to individuals with disability:

"*Ordinary families can be rather pragmatic about whether or not they give the necessary care for a severely disabled infant. If they see little prospect of success, the infant soon finds it death and the parents start another one*" (Miles 1995 p62).

The focus may then fall on the individual's disability rather than ability (Hasnain al 2008).

Consideration should be given to alternative ethical dilemmas that may exist for parents living in third world countries where absolute poverty is a daily reality. Many individuals migrating from homelands, in which there is limited support for disability, may know little about systems of care or resources available to individuals with disability (Hasnain et al 2008). This may be the case for the parents of many second generation Pakistani parents who migrated to the UK in the post war years, as well as individuals who continue to migrate to the UK today. This may also impact on the experiences of second generation Pakistani Muslim parents who have married first generation partners from Pakistan.

Section 4: Barriers

The literature examined suggests additional barriers exist for ethnic minority families with disability living in the UK. These shall be explored in further detail with specific reference to the Pakistani Muslim community.

Cultural Insensitivity

A lack of cultural awareness and cultural sensitivity has been highlighted as a barrier to effective relationships between Pakistani families and service providers. Ali et al (2001) outline how some Pakistani parents were unwilling to send their children to day centres or for respite care, as they feared their cultural needs would not be addressed for example male members of staff may look after their daughters and halal food may not be available.

Inappropriate responses from service providers can additionally lead to ineffective relationships. Fazil et al (2002) highlight a case where a housing officer advised a family that their twenty year old daughter should move out and get a place of her own. This angered the family who explained to the researcher that this would not be common practise within Pakistani families. Additionally Bywaters et al (2003) reported that some families were told by professionals that consanguinity may be an explanation for their child's disability. This lack of cultural awareness, sensitivity and understanding can lead to parents feeling misunderstood and alienated (Ali et al 2001).

Stereotypes

Preconceived ideas about the Pakistani Muslim community may impact upon services provided by professionals. Bywaters el al (2003) argues that there are a number of stereotypes held around Pakistani parents who have children with disabilities. Firstly there can be an assumption of religious adherence within Muslim communities, leading to the assumption of theological based explanations of disability with disability as an act of God.

A second assumption is that Pakistani parents may feel a greater sense of shame about having a child with disabilities than a White majority family. The assumption of shame can be further used to explain the low uptake of services by ethnic minority families with disabled children. A subsequent assumption that everything in life is in control of God with the knowledge of professionals as incomparable can often be made. In addition to this there is a perceived desire to maintain the care of the child within the privacy of the family.

Crabtree (2007) found that families from Pakistan and Bangladesh living in the UK reported feeling anxious and concerned about how other members within their community would perceive family members with a disability. This notion of stigma leading to Pakistani families in the UK feeling socially isolated was reinforced by Bywaters et al (2003). Feeling embarrassed of their child's actions in front of other members of the community was expressed, which some families stated could make them feel reluctant to take their children out to other people's houses and to public places. In particular a lack of a diagnostic label was found to be unhelpful when addressing the perceived negative attitudes of others.

Bywaters et al (2003) argues however that there was little evidence to suggest that any of the parents within their study had failed to seek professional help despite feelings of shame and stigma. The notion that Pakistani Muslim families are unwilling to access services is not a sufficient explanation for low uptake of services. In addition to this, it was found that being from an extended family did not always equate to family support and additionally being part of an extended family did not mean that respite care was not wanted. Also it is worthy of note that it is not clear whether informal support from family members from Pakistani families is either a cause or result of the absence or inaccessibility of formal professional support (Fazil 2002).

Gender, Hasnain et al (2008) argue, is one of the most misunderstood aspects of Islam. Stereotypes held portray women as *"oppressed, secluded, vulnerable, considered inferior and denied basic human rights"* (p46). Stereotypes held by professionals may emerge as some may find it difficult to *"navigate between competing world views"* combined with blurred boundaries between cultural and religious practise and political agenda, as well as religious concepts being taken out of context (Hasnain et al 2008).

Bywaters et al conclude that the difficulties for this particular community of parents results from institutionalised racism which impacts on low access to appropriate services. Parents are often poorly informed about the medical understanding of their child's condition, rather than them rejecting a medical model of explanation. Thus, a lack of access to service provision is more likely to be a result of socially created barriers rather than the attitudes of the parents.

English Language and Interpreters

The rights of ethnic minority families can be further inhibited depending on their own confidence and familiarity with the use of the English language and service providers being unable to work equally effectively in languages other than English. Ineffective communication between professionals and families has been argued to be a crucial factor in the individual needs of families not being met:

"…….those families most likely to be facing material deprivation and disadvantage (Pakistani and Bangladeshi families) are least likely to be receiving services, least

likely to be able to understand professionals' information or processes, and least able to express their own requirements effectively in a language service providers will understand." (Fazil et al 2002 p240).

The reliability and inconsistent use of interpreters has been much questioned. Shah (1992) argues strongly that individuals who are unable to speak English, have the right to access information and it is the duty of the services involved to ensure this. However in reality Shah argues, interpreters are often considered a luxury for the client and can be used ineffectively.

Whilst the dissemination of information through an interpreter may be effective, responding to and conveying emotional responses can be problematic. There can also be a number of other issues that may arise such as the interpreter may feel it inappropriate to interpret certain language and the limited involvement with the client may result in a mechanical interview. The interpreter and professional may vary in their levels of empathy for the client. There may also be barriers between the client and the interpreter such as social class or gender. Shah therefore concludes that:

"*Interpretation may be considered useful for obtaining background information; but counselling and emotional relationships in general are difficult or impossible to carry out through the medium of interpreters."* (p54).

Shah suggests that to help promote effective working relationships with interpreters, briefing sessions should occur before the interview followed by a debriefing session after the interview. It is also crucial that the interpreter is provided with any relevant information before the interview. To promote effective working Shah also believes that professionals should receive training on how to prepare, speak through and discuss events with interpreters.

It may also be worth giving consideration to the practice and guidelines associated with using an interpreter for hearing impaired individuals. For example, the requirement of using the first person when voicing information as well as both the professional and the client sitting opposite each other (Communication Limited, 2008).

English is thus not only a means of communication but essential for accessing crucial information and services deemed beneficial for their child, which is not accessible for all ethnic minority families. This can lead to some parents being depended upon to relay information to partners who may not be able to speak English. Fazil et al (2002) found that the parent with the better spoken English was more likely to be the parent who had the most contact with the service provider. In addition Bywaters et al (2003) found if one parent was able to speak very little English, it was assumed that they would relay information to the parent for whom English is limited. This was not always the case, resulting in one parent being more informed in regards to professional opinion. This highlights the need for greater consistency and availability in the use of interpreters as well as the inaccessibility of services for individuals who speak English as an additional language.

Ethnicity of Professionals

Bywaters et al argue to address the aforementioned barriers it is essential that professionals are more representative of the communities they work with. Bywaters et al argue *"at this basic level, much still remains to be done to make these elements of good practice a reality."* (p508).

Fazil et al (2002) reported that many Pakistani parents with disabled children felt the ethnicity of professionals was important with a strong desire being expressed for professionals of a similar ethnicity. The main reason provided was to address the issue of language barriers but some parents expressed the reassurance they would feel by consulting with someone of their own ethnicity. However this was not a unanimous perspective as some parents felt that having an Asian professional could be a hindrance. This suggests that both the skill set and ethnicity of a professional can be influential factors as well as the perceptions of the parents.

Cultural Brokers

The concept of cultural brokering is a term given to a perspective that can lead to individual differences being celebrated and is a helpful concept when considering meeting the needs of Pakistani Muslim families with disability. This term was initially coined by anthropologists and later employed by health care professionals. Cultural brokering can be applied as a theoretical concept or as an actual role. For the purpose of this study, cultural brokering will be addressed as a theoretical perspective which can help professionals and families work together more effectively. The theoretical framework of "cultural brokering" is defined by Jezewski and Sotnik (2005) as the "*act of bridging, linking or mediating between groups or persons of differing cultural backgrounds for the purpose of reducing conflict or producing change.*" (p37).

Cultural Brokering with Pakistani Muslims with Disabilities

Hasnain et al (2008) propose five steps for action for service providers based on the culture brokering frame work. This shall be adapted to make reference to Pakistani community in Britain:

1. Increased understanding of the demography of Pakistani Muslims
2. Identify barriers, challenges and successes that face Pakistani Muslims with disabilities
3. Obtain the participation of Pakistani Muslims with disabilities in aspects of service planning and delivery
4. Promote collaborative research
5. Promote a broader cultural understanding and mutual respect through partnerships and collaborations with Muslims and non-Muslims

Ultimately cultural brokering reflects how service providers respond to diversity and hear the minority voice. The steps for action highlight the importance of not only hearing the voice of minority families, but incorporating views into service delivery and increased intercultural skills of professionals.

Cultural brokering is a two way process. It is essential for providers to understand issues within the Pakistani Muslim community but also the variables that are part of the service systems (Hasnain et al 2008). Individuals from the Muslim population with members with disabilities can act as their own cultural brokers. Many families will make adjustments to accommodate community norms and expectations, without sacrificing or compromising their own culture or beliefs.

Essential to cultural brokering, is cultural awareness. However Hasnain et al (2008) argue that:

"*....even specialists who are knowledgeable about a given ethnic background, language and culture, and religion admit the complexities and varieties are hard to describe or comprehend*" (p12).

Therefore attending courses such as Islam Awareness are not sufficient and the stance should be taken that one cannot comprehend the understanding of a community, but that it is an ongoing process.

Cultural Brokering should therefore be perceived as a perspective leading to appropriate engagement, in which professionals are encouraged to pay close attention, skilfully listen, respectfully question and find effective ways forward based on mutual respect (Hasnain et al 2008). The critical skill of a cultural broker is therefore not to master the complexities of a community but to know what questions to ask, being open to asking such questions and truly listening (Hasnain et al 2008).

Section 5

Research Aims

The above literature leads to the research aim of this study which hopes to gain some insight into issues relating to identity, religious beliefs, understanding of disability and relationships with and accessibility to service providers and the subsequent influence this has on the lived experiences of second generation Pakistani Muslim parents. The notion that a diverse set of beliefs can be held within a community will be held as a central belief within this study with the stance of a cultural broker being taken. For this reason the below single broad research question has emerged which also reflects the theoretical underpinnings of interpretative phenomenological analysis, which shall be discussed in later chapters:

Research Question:

What are the experiences of second generation Pakistani Muslim parents of children with special educational needs?

Chapter 3: Methodology

Introduction

This chapter is concerned with justifying the selection of the Interpretative Phenomenological Analysis (IPA) as a methodological approach for this research. This chapter will seek to demonstrate that the research question *"What are the experiences of second generation Pakistani parents with children with special education needs?"* is appropriately matched with the methodological approaches.

Section one will address issue relating to the selection of methodology and the epistemological position of the researcher as well as addressing issues relating to what makes research 'good.' Section 2 will examine phenomenological research with specific reference to IPA. Following this the rationale for rejecting narrative approaches will be explored. Section three will address issues concerning semi structured interviews and focus groups which are to be used within this study. Lastly section four examines the methodological issues of ethical considerations, reliability and validity.

Section 1: Selecting Methodologies: Recognising Good Research

Research within the field of psychology is scrutinised not only for the results that are generated but also for the methodology used. The epistemology of "methodologism" refers to criteria for judging whether research has been conducted according to certain methods. For example, were the groups randomly selected or was the sample size large enough? Methodologism has been traditionally used within the quantitative field of psychology and more recently is beginning to influence qualitative psychology (Salmon, 2003). However there are limitations in doing so:

"Unfortunately, methodologism is a limited epistemology. It is a forlorn belief that quality can be guaranteed simply by following procedures." (Salmon 2003, p24).

Therefore approaches such as IPA should be considered as "epistemological perspectives" rather than techniques that can be "used."

Salmon further raises an interesting point that researchers may state an epistemological position, in order to justify a selected methodology and that this may indeed be necessary in order for researchers to be more explicit about the basis of their work. It has been argued that researchers should be aware of ones epistemological stance as this will determine the research methods selected. Opie (2004) argued that how knowledge is perceived will subsequently determine the type of research conducted.

> *"Your views of research will be dependent on a number of factors but perhaps the most significant is your epistemology. By this we mean your view of how knowledge is acquired and how it can be communicated to others. How you align yourself profoundly affects how you go about uncovering knowledge of social behavior." (Opie, 2004, p.13)*

A researcher is constrained by the epistemological stance that they take, as this will determine the research methods that are selected. However this may be somewhat difficult at times as a qualitative researcher may consider that research can discover underlying reality whereas another researcher may perceive that it is their interaction with the participant which allows reality to be constructed. Therefore merely stating an epistemological position may not provide a great insight into the researcher's perspective. In addition to this, Salmon boldly states that positions are often *"post-hoc rationalisations"* (p25) as methods are often selected for practical, historical or ideological reasons, including methods that the researcher is comfortable in using.

However this is somewhat of a conundrum. It may be argued that a researcher is attracted to particular approaches due to their epistemological stance, which may be become more explicit on consideration of one's epistemological position after the selection of a methodological approach.

Research should therefore not rigidly follow methodological rules. Instead scientific progress can emerge from creativity, imagination and common sense (Rennie, 2000). Therefore good research should look at the approach used and whether it "fits" the phenomena being studied. In addition to this, a researcher should be aware of the impact that they have on the research and not act as an observer in the process (Potter, 1996). IPA addresses this point and shall be discussed later in this chapter.

This research shall address some of the above points. Methodological rules shall not be slavishly followed, but considered and creativity and common sense applied. A thorough analysis of data will be undertaken, in which results will be presented coherently, and thus empowering the reader (Salmon, 2003). This should allow readers to judge whether a more elaborate understanding about the experiences of second generation Pakistani parents, of children with special educational needs, has been obtained.

Taking into consideration that social phenomenon can often be context-bound and therefore generalisation debatable, it would be hoped that the reader of this thesis would be invited to produce and develop their own ideas in regards to this topic area. In order to gain a broader understanding of the quality of this research, it would be beneficial to present any conclusions drawn to the intended audience e.g. service providers. However, within the restricted time scales of this research project, this would not be possible, but is certainly a consideration for future implications and practice.

Overview

IPA will be adopted as the selected methodological approach for this research. Semi-structured interviews will initially be used to ascertain the views of parents. To help obtain a richer understanding of the experiences of the parents, an additional focus group will be conducted. The parents will be invited to take part in the focus group, in which the key themes/concepts generated from the individual interviews will be further explored. The research process will be cyclical and non-linear. Data collection and analysis will not be perceived as separate processes. Analysis and data collection will occur cyclically, so that initial attempts of data analysis will inform protocols and procedures for further data collection.

Section 2: Phenomenological Approaches

IPA takes a phenomenological approach. Moustakas (1994) describes Edmund Husserl (1900-1970) as a pioneer of phenomenology as a philosophy. Phenomenology is concerned with how individuals gain knowledge of the world around them and argues that certain ways of knowing may be more constructive. Phenomenology, as a philosophical framework, does not constitute a unified or closed system of propositions or practices (Willig, 2001).

Phenomenology is concerned with how, within particular contexts and at certain times, the world is experiences by individuals. The world of objects and subjects are not considered to be separate from ones experience of it. Therefore "reality" is presented as how objects and subjects portray themselves to an individual.

However it is intentionality which allows objects and subjects to appear as phenomena that appear in our consciousness, as we engage within the world that is presented to us. Therefore the perception of phenomena is dependant upon an individual's location, context, angle of perception and mental orientation (Willig, 2001). *"Knowledge of intentionality requires that we be present to ourselves and to things in the world, that we recognise that self and world are inseparable components of meaning"* (Moustakas, 1994, p.28).

This perception can however be influenced by ideas, values and judgements. What is it that individuals bring to this perception? An individual will think, feel, remember and judge. The phenomenological method can therefore be used to derive knowledge, which is the aim of this study.

Phenomenological Research: Interpretative Phenomenology Analysis

IPA has been commonly used in health psychology and aims to examine how participants make sense of their personal and social world. Moustakas (1994) described the primary target of phenomenological knowledge as:

"The understanding of meaningful concrete relations implicit in the original description of experience in the context of a particular situation." (p14)

Phenomenological research allows experience to be examined as well as the basis for reflective analysis:

"The (empirical) phenomenological approach involves a return to experience in order to obtain comprehensive descriptions that provide the basis for reflective structural analysis that portrays the essence of the experience." (Moustakas,1994, p.13).

The researcher is able to establish the underlying structures of an experience through interpretation of the original descriptions given of a situation, in which the experience occurs (Moustakas, 1994).

This understanding of experience occurs at two levels. Firstly, naïve descriptions are obtained from participants through the means of open-ended questions and dialogue. Secondly, through reflective analysis and interpretation of the participant's story, underlying structures of the experience are explained (Giorgi, 1985).

Thus, phenomenological research aims to capture what an experience means for an individual so that universal meanings are gained, in order to capture the essence or the structures of that experience (Moustakas, 1994).

IPA is an inductive approach in that it does not test a hypothesis and avoids prior assumptions. The participants are perceived as the experts to their own experiences and when provided with the opportunity to tell their story, their thoughts, commitments and feelings can be understood (Reid et al 2005).

The analysis process depends firstly upon the participants making sense of their world followed by the researcher being able to make sense of it. IPA recognises the research process as dynamic and Smith (1997) states that an interpretative engagement with transcripts *"is facilitated by a series of steps that allows the researcher to identify themes and integrate them into meaningful clusters, first within and then across cases."* (p46).

Thus the analysis should be both rigorous and systematic with a focus on shared experiences as well as distinct experiences. As the analysis is interpretative, IPA does not aim to state facts. Instead Reid et al (2005) state that a successful interpretative analysis is *"interpretative (and thus subjective) so the results are not given the status of facts; transparent (grounded in example from the data) and plausible (to participants, co-analysts, supervisors, and the general readers)"* (p20).

Taking the above into consideration, IPA has been selected as an appropriate methodology for this study, as the research aim is to gain an understanding of the experiences of second-generation Pakistani Muslim parents of children with special educational needs. As a second generation Pakistani Muslim, I feel that I am able to gain an insight into these experiences as I may be perceived as an "insider." This may enable the parents to feel "safer" when asked about issues relating to their personal experiences, as they may take the stance that I too understand their cultural and religious backgrounds. Therefore the contexts of the situation in which the original descriptions are made are very important. Thus the phenomenological approaches allow the opportunity to understand the parents' experiences as well as reflect upon the researcher's role in the process of gaining the descriptions.

My role as a researcher

IPA stresses that the researcher has an integral role in analysing the data. The researcher has the potential to obtain both a different and new understandings of the participants discourse *'both stimulated by and grounded in her experience and sense making and offering deeper hermeneutic reading and indeed one which may be rather different from the one she might offer herself'* (Eatough and Smith, 2006, cited in Willig and Rodgers 2008 p.191).

IPA asks the researcher to be aware of one's own cultural, political, social and ideological understanding of their experience of the participant's voice as well as an attempt to understand the participant's experience itself (Mulveen and Hepworth, 2006). Due to the interpretive role in the analysis, it is important for the researchers involvement e.g. beliefs and preconceptions to be made clear prior to analysis (Brocki and Wearden 2006). These shall be outlined below:

Researcher Beliefs and Aims

As a second-generation Pakistani Muslim some similarities may exist with the mothers. This may have an impact on the interview process, as the participants may recognise such similarities and therefore feel more comfortable during the interview process. My role as a trainee educational psychologist may also impact the interview process, as the parents may assume that I have a good understanding and experience of working with children with special educational needs. The parents may therefore perceive my position as quite unique in that I too am a second generation Pakistani Muslim, who, like them, have experience of children with special educational needs. However I am aware that I am not a parent and do not have a child with special educational needs. Therefore there are some experiences of the parents that I may not be able to directly relate to.

As a researcher and a trainee educational psychologist, I have strong sympathies with the social constructionist paradigm. Social constructionism argues that the human experience is affected historically, culturally and linguistically. Some researchers also argue that our perception of the world cannot be free from subjective bias:

"There is no clear window into the inner life of a person, for any window is always filtered through the glaze of language, signs, and the process of signification. And language, in both its written and spoken forms, is always inherently unstable, in flux, and made up of the traces of other signs and symbolic statements. Hence there can never be a clear, unambiguous statement of anything, including intention or meaning." (Denzin, 1989, p.14)

In addition to this, as a trainee educational psychologist, through reflecting on my role and my own psychological perspectives, I have been attracted to some notions within community psychology and the concept that psychological praxis must be embedded within the lived experiences of individuals, especially those who may be marginalised (Kagan and Burton 2001). I also feel strongly that knowledge does not always equate to skill and that the unique contribution of an educational psychologist to professional practice is not merely their knowledge of psychology, but their ability to apply psychology, through understanding individual perspectives.

"Academic knowledge is partial. It can only be indirect knowledge, informative and explanatory. It lacks firm footing in raw reality that turns knowledge into a mobilising force capable of leading to action" (Wresinski 1980).

Kagan and Burton (2001) argue that through spending time understanding how individuals make sense of their social world, that one's practice should be *"experience near."* This joint participatory approach allows for working as near as possible with people which can help lead to social change. Understanding the experiences of individuals is therefore crucial, particularly as an educational psychologist, and this should be the basis of all interventions:

"To devise suitable resources, one should study people's cultures and their concepts of disability, in order to communicate appropriately" (Miles, 1995 p51).

This research does hold personal significance as it will also allow me the opportunity to reflect on my own practice, particularly with parents, and how I do engage with them on a day-to-day basis. Subsequently I hope to become a more effective practitioner.

Limitations of IPA

Whilst IPA has the advantage of being *"especially useful when one is concerned with complexity, process or novelty"* (Smith and Osborn, 2003 p.53), like all methods, there are some limitations of this methodological approach. Firstly the approach is dependent upon the participant in being able to articulate their thoughts and communicate the richness of their experiences (Brocki and Wearden, 2006). The approach would not be accessible to individuals who were unable to articulate their views. The approach is dependent on the participant's expressive language skills but also the researcher's ability to create an environment and atmosphere to facilitate open dialogue as well as having effective intervening skills. IPA is therefore dependent upon language which Willis (2007) argues can *"constructs rather than describes reality"* (p.80). Language can describe a *'particular version'* of an experience. However it is important to understand the *'particular version'* a parents chooses to articulate.

IPA also focuses on current perceptions of experiences and therefore does not give consideration to causes or origin. It is important to acknowledge that the generated understandings of phenomena do not give thought to past histories. Additionally IPA is further limited by the researcher's ability to reflect and analyse, as well as being further dependent on the researcher's subjectivity. The approach would be best adopted by researchers who value the importance of reflective practice and are skilled in doing so.

Rejected Approaches

Narrative Approach-The Free Association Interview

Narrative approaches were considered as alternatives to IPA but later rejected. Narrative research was considered as an approach in the term of the free association interview for this research project which is based upon the assumption that individuals will construct narratives or stories in their daily interaction with others:

"...people attempt to make sense of their lives by narrativising their experiences; people tell stories, both to others and to themselves, not merely through their words but also through their actions." (Billington, 2000 p37).

Therefore "critical realism" allows relationships between ambiguous representations and individual experience to be perceived. Holloway and Jefferson (2000) argue that there is a democratic reason for believing what an individual chooses to say in an interview. However in everyday informal dealings one will disagree, interpret, give counter examples and notice hidden agendas. This subtlety and complexity that is used in everyday encounters, Holloway and Jefferson argue, is often lost in research, which is perceived as a "more formalised and systematic" way of being able to know about people. In addition to this, they argue that traditional qualitative methods such as interviewing or observing, focus on uncovering consistent rationales rather than inconsistent or contradictory evidence (Holloway and Jefferson 2006).

Narrative approaches, based upon the psychoanalytical paradigm, is an interpretative method, that does not take the respondents account at face value, but also examines the use of absences and avoidances in the narrative and uses probes in order to identify areas of significance. In addition to this, it is argued that the respondent may not in fact understand their own actions, motives or feelings. Similarly the free association narrative interview take into consideration that whilst some individuals may be surprised by their own accounts, others may give coherent and perceived incoherent accounts of their behaviour and actions (Halloway and Jefferson, 2006). A number of interviews may be held, which will be examined critically. Attention will be given to a number of factors including any perceived changes of emotional tone, body language, inconsistencies, contradictions or avoidances. A narrative approach will use open questions, and will endeavour to avoid "why" questions as well as elicit stories and use the individuals' ordering and phrasing" (Holloway and Jefferson, 2000, p.3).

Thus, the goal of free association narrative interviewing is to reveal significant personal meanings. The analysis process of the generated data would aim to look contradictions and links, rather than specific codes.

I was initially attracted to this approach and I considered at great length whether to adapt a narrative approach to this research project. The interpretative element, as well as flexible nature of interviewing in particular appealed. I was also drawn to the honest, respectful, naturalistic and non-directive principles of the approach. This free association interview technique also allows for rich data to be collected by considering an individuals personal account.

The limitation of using this approach for this study is that in order to achieve this, a number of free association interviews would need to take place with an individual, in order to obtain a personal account of their narrative. This raises difficulties as I am interested in the relationships between stories given by individuals. Due to the time constraints of this research project, the collection of multiple free association interviews would not be able to take place with a number of individuals.

Therefore the interview technique was adopted to embody some of the principles of the free association narrative interview, for example using open questions and using the individuals ordering and phrasing. As a researcher I was interested in what impact I had upon the research process and was drawn to the interpretative element of the narrative approach. IPA allowed the researcher role to be interpretative and reflective, as well as examine the relationships between the stories of experiences. Thus, the free association interview was rejected but the principles of narrative approach adopted within the use of interpretative phenomenological analysis.

Section 3: Data Collection

Semi Structured Interviews

IPA approaches typically use semi structured interviews and small samples sizes, with Smith et al (1999) reporting that ten participants are at the higher end of recommendations for sample size. Semi-structured interviews provide a flexible data collection method allowing the researcher and participant to engage in conversation and dialogue. Questions can be modified in reply to the participant's responses. The researcher is also able to probe further any interesting and important issues that may arise. The researcher is therefore able to follow the participant's interests and concerns (Smith and Osborn 2003).

Semi structured interviews therefore allow the researcher to share, as far as possible, the psychological and social world of the participant. In addition to this, the flexible nature of the semi-structured interview allows the participant to introduce issues the researcher may not have thought of; thus complying with the principles of IPA, in attempting to understand how the individual makes sense of their world.

"In this relationship, the respondents can be perceived as the experiential expert on the subject and should therefore be allowed maximum opportunity to tell their own story." (Smith and Osborn 2003, p.59)

The style of questioning is non-directive and the researcher should also consider the effects of their own social identities such as gender, race and nationality on the interviewee (Willig, 2001).

Using a semi-structured interview can be difficult for the researcher as it can reduce the control one has over the interview, which is one difficulty when trying to obtain richer data. Therefore the researcher has to aim to find a balance between maintaining control over where the interview is going as well as allowing the participant to be able to re-define the topic under discussion. The production of an interview agenda would help assist with this.

The interview agenda outlines a number of open-ended questions, with a number of prompts for the researcher, in an appropriate sequence. For example, beginning with early experiences and introducing more sensitive questions later on, once rapport has been established, and the researcher feels the participant is at ease with the interview process.

General questions should be followed by more specific questions and when possible, it is important to restate the participant's comments, as well as attempting to incorporate the comments into further questions (Willig, 2001). It is also argued that taking a naïve stance or expressing ignorance can assist the researcher in obtaining a more detailed and comprehensive account from the participant, as well as asking for illustrations of events or experiences (Willig 2001). Within the role of a researcher, I am conscious of being perceived as an "insider." Therefore the naïve stance will have to be used with caution, so as not to portray a lack of understanding of the cultural background of the parents, which may result in more inhibited responses. However it is also important not to make assumptions about the cultural backgrounds of the parents and to ask for clarity where necessary.

Focus Groups

A focus group will be conducted to further explore the issues raised in the individual semi structured interviews. The use of focus groups with IPA has been contested with Smith (1999) arguing that IPA is *"committed to the detailed exploration of personal experience"* (p50). Focus groups have been used with IPA, although it does present challenges in applying experiential analyses to more complex social activities (Reid et al 2005). However it can allow for a multifaceted understanding of the experience:

"..the exploration of one phenomenon from multiple perspectives can help the IPA analyst to develop a more detailed and multifaceted account of that phenomenon." (Reid et al, 2005 p22).

IPA will further be used to analyse the data generated from the focus groups. A focus group promotes self-disclosure amongst participants, and uses the interaction between the participants as the source of the data. The role of the researcher will be adapted into a role of a moderator, in which group members will be introduced to one another, the focus of the group will be presented, and then where necessary, the discussion will be steered. This may involve encouraging group members, recalling the focus of the group as well as highlighting agreements or disagreements between group members (Willig, 2001).

The focus group aims to generate additional data to augment the data. This is achieved by allowing statements to be "*challenged, extended, developed, undermined, or qualified*" (Willig, 2001). The focus group is thus dependent on the participants responding and contributing to one another's contributions. The researchers role as a moderator is crucial in facilitating this, by establishing ground rules and ensuring confidentiality is stressed as well as making the participants feel relaxed and comfortable. To assist in this, the focus group will be kept to a small size, with a maximum number of six and minimum of four.

The strength of the focus group lies in looking at ways in which participants jointly construct meanings, but also where any differences of opinion lie. Through this, evidence is provided about how participants may justify their positions. A focus group is argued to be less artificial than a semi-structured so is further argued to have higher ecological validity (Willig, 2001).

Asking participants to meet and discuss issues they raised in a one to one interview, does present a number of challenges. Some participants may not feel comfortable discussing personal matters in front of other participants, and may not want to disclose further or elaborate, on issues that were raised in a one to one interview.

Section 4: Methodological Considerations

Ethical Considerations

This study may pose some challenges in regards to ethical issues. The issues raised in both the interviews and focus group may at times be sensitive in nature. I think it is important that I am aware of these at all times and respond accordingly. In accordance with the British Psychological Society' ethical code of practice, I will ensure that all parents involved in the study have consented to participate and are also aware of their right to withdraw at any stage. It is important to check with the parents if they do want to continue if they do become upset at any stage.

It will also need to be made explicit to parents what the implication of their involvement is i.e. to inform a research thesis for a doctorate student training to become an educational psychologist. Parents may feel that as a result of their involvement, some action may occur. Therefore, to avoid disappointment or false hope, the purpose and nature of the research needs to be made clear to parents from the onset. As a researcher it is also important to be aware that this may influence whether or not they want to partake in the research.

Confidentiality is a concern, particularly in regards to the focus group. The importance of confidentiality and the rules governing it will be stressed and made explicit at the beginning of the focus group. However it can be difficult for a researcher to ensure that the rules are followed subsequent to the research being conducted. To minimise the risk of breaching the confidentiality rules, a conversation will be held with the group before the focus group. A thank you letter will also be sent out to each individual in which there will be a reminder about the issues concerning confidentiality.

Maintaining professional boundaries between the research sample and the researcher is also important. After conducting the pilot study, I became aware that I was perceived as an "insider" i.e. part of the Pakistani community, which resulted in one mother making assumptions about myself and my way of life. I am keen not to engage in a dishonest relationship, particularly when parents are expected to disclose personal information themselves. Therefore it is important to maintain professional boundaries at all times.

When working with parents it is also important to consider any power differentials that may exist between an educational psychologist and a parent. This may be reduced somewhat within the focus group, although the balance of power will remain with the researcher. I endeavour to be flexible in my work with parents, particularly when conducting individual interviews e.g. venue and time. This may give more control to parents, and allow them to partake in the interview in a manner that is of most convenience to them. Any inconvenience will hopefully be offset by the value of the outcome of the project.

I have experience of working with parents in a variety of settings and will ensure a direct telephone number is given to parents should they wish to contact me during the research. I will also ensure that I make myself available after each interview and the focus group if parents want to further discuss any personal thoughts or feelings they may have in relation to the research.

Reliability

Reliability has been defined as *"the extent to which a test or procedure produces similar results under constant conditions on all occasions"* (Scaife, 2004 p66). Such considerations would suggest a tightly controlled positivist based experimental design would produce similar results on repeat designs and subsequent research. However such expectations do not match the aims of phenomenology which is concerned with how, within particular contexts and at certain times, the world is experienced by individuals. Holstein and Gubrium (2004) argue that within interpretive paradigms, one cannot expect such a replication:

"One cannot expect answers on one occasion to replicate those on another because they emerge from different circumstances of production" (p145).

IPA is highly subjective and no two researchers working with the same data are likely to generate a replication of each others analysis (Broki and Wearden 2006). Therefore within interpretative methodologies one cannot simply consider reliability in terms of the results produced but the whole data collection procedure (Scaife, 2004), which shall be outlined in the following chapter.

Validity

Scaife (2004) defines validity as *"the degrees to which a method, a test or a research tool actually measures what it is supposed to measure"* (p68) with considerations given to the intentions of the researcher, methodology applied and the results achieved. However Scaife further argues that good research should place an emphasis between research aims and the data gathering process concluding that if *"you believe that the data is saying what I claim it is saying-then you judge my claim to be valid" (p69).*

Therefore when taking adopting an interpretative approach, reliability and validity cannot be understood in their traditional terms. Instead Scaife argues the notion of 'credibility' may be more helpful. Sturman (1999), cited in Scaife (2004) generated the following list of considerations for credibility of qualitative research:

1. Data-gathering procedures are explained;
2. Data is presented transparently and in ways that enable ready reanalysis;
3. 'Negative instances' are reported. Data are included whether or not they fit the benefits or intentions of the researcher;
4. Biases are acknowledged;
5. Fieldwork analyses are explained;
6. The relationship between claims and supporting evidence are clearly expressed;
7. Primary data is distinguished from secondary data;
8. Interpretation is distinguished from description;
9. A diary or log is used to track what took place during the study;
10. Procedures are used to check the quality of the data.

Such considerations will be addressed within this research. Therefore validity checks in this study will not aim to examine "*the singular true account*" (Osborn and Smith 1998 p69) but rather the 'credibility' of the research. The reader will also be invited to form their own judgements on the 'credibility' of this study.

Chapter 4: Research Process

This chapter will outline both how the research developed but also how it was carried out. A factual account of the research process shall be given in which the participant selection procedure will be outlined as well as a profile given for each mother that was interviewed. The semi structured interview and focus group will be detailed as well as an examination to the process of analysis.

Embarking upon the Research

The previous chapters outline the reason of interest in this particular area as well as justification for selected methodologies. This chapter shall detail the specific nature of how the research was conducted. Due to the reflective nature of IPA a research diary has been used in which thoughts, anxieties, reflections and issues to discuss with my tutor have been noted. This diary has been kept from the onset of the research journey and has helped to clarify the reflective role of the researcher within the research process.

The main element of the research process has been the individual interviews that were conducted with all the mothers. These were followed by a single focus group. The wider context of such techniques has been outlined in the previous chapter with my positionality outlined.

Participant Selection

A list of ten parents was generated at a number of educational psychologist staff meetings. To some degree a convenience sample was obtained. The criteria required were second generation Pakistani Muslim parents of children with special educational needs. Due to the dependency of IPA on the ability for participants to be able to convey their experiences, the need to select parents who would be comfortable with the nature of the research was expressed. Gender initially was not an issue however all the names generated were those of mothers. Precision in participant selection is not crucial within IPA as generalisations are not made nor variables controlled (Smith, 1997). The loose criteria is thus fitting with the selected methodology.

Once a list of parents was generated a letter was sent out inviting all ten parents to take part (see Appendix 1a). The parents interviewed were the mothers who agreed to participate in the research following a subsequent phone call from myself. The participants detailed below agreed to take part in an initial interview. In total 7 mothers were interviewed individually. Following the individual interview a letter was sent inviting all the mothers to a focus group (see Appendix 1b). In total five mothers attended the focus group.

Participant Information

I shall outline some participant information to provide the reader with some individual information about each participant. The individual profiles are given in the order in which the individual interviews took place. All participants were mothers and second generation Pakistani Muslims. All mothers stated that they, their husbands and families were Sunni Muslims. The names of the parents are fictitious to maintain anonymity. Some mothers were known to me on a first name basis whereas other mothers were referred to using their titles.

Aneesa

Aneesa was born in Leeds, but later moved to Wakefield after getting married. Aneesa's husband was born in Pakistan and has been in England for 12 years. Aneesa has two boys, Zain who is 11 years old and Amir who is 7 years old. Zain has a diagnosis of Autistic spectrum disorder and a statement of special educational needs. He currently attends a secondary specialist autism resource. Aneesa works in a children's centre, and is very proactive in accessing support for her son, with a good understanding of the services available. Aneesa will often attend meetings on her own and feels she has a difference of opinion to her husband in regards to her child's special educational needs. Both Aneesa's family as well as her husband's family live in either Pakistan or in Leeds. Aneesa took part in both an individual interview and the focus group. Aneesa has also been the pioneer of the subsequent parent support group.

Niggat

Niggat and her husband were both born in Wakefield and have two children. She has one son Hussain, who is 9 years old who presents with physical disabilities and developmental delay. Niggat also has a 6 year old daughter who attends a mainstream primary school. Hussain has a statement of special educational needs and attends a specialist school for children with physical and learning disabilities. Niggat and her husband both attend meetings in regards to their son. Both Niggat and her husband's family live near by or in Pakistan. Niggat took part in the initial pilot study and later attended the focus group.

Naveen

Naveen was born in Wakefield and has three daughters. Her oldest daughter Ayesha, who is 12 years old, presents with developmental delay and attends a specialist secondary provision. Naveen's two younger daughters both attend a mainstream primary school. Ayesha attended a mainstream school up until the age of 9 years. Naveen's husband was born in Pakistan and has been in the UK for 13 years. Naveen's husband is not fluent in English and she will often attend meetings on her own. She has some family nearby and some in Pakistan.

Mrs K

Mrs K has two daughters who present with developmental delay. Saba is 4 years old and has a statement of special educational needs. Fatima is 2 and half years old. Mrs K was born in the UK and grew up in Wakefield. Her husband was born in Pakistan and has been in the UK for almost 5 years now. He is fluent in English and will attend meetings with Mrs K. Mrs K took part in an individual interview but was unable to attend the focus group.

Mrs Q

Mrs Q has a 14 year old daughter Razia who presents with developmental delay. She has a statement of special educational needs and attends a specialist provision. Mrs Q's husband was born in Pakistan and has been in the UK for 17 years. He works as a GP and will attend all meetings with Mrs Q. Mrs Q took part in both an individual interview and the focus group.

Mrs A

Mrs A has two boys. Both attend a mainstream primary school. Mrs A's oldest son has been referred to the educational psychology service due to concerns regarding his behaviour. He is also currently attending an ADHD clinic. Mrs A's husband was born in Pakistan. However they are currently separated and he is not involved in any capacity in her life or the life of her children. Mrs A has the support of some family who live nearby. Mrs A took part in an individual interview but was unable to attend the focus group.

Mrs H

Mrs H has two daughters who both have a diagnosis of Joubert Syndrome. Hina is 4 and half years old and has a statement of special educational needs and attends a children's centre. Yasmin is 3 and half years old, and is currently on the waiting list for Portage. Mrs H's husband was born in Pakistan and is reasonably fluent in English. They will both attend any meetings about their daughters. Mrs H's immediate family live very close by and will often help her look after her daughters. Mrs H took part in an individual interview and also attended the focus group.

Individual Interview

The interviews took place over a four month period. Before the individual interview took place, a participant consent form was signed (see appendix 2). A semi structured interview schedule, with prompts, was used (see appendix 3). The schedule was used as a guide and was also adapted to allow for a more naturalistic flow of conversation to occur. The participants were able to choose the location for the interview. All individual interviews took place in the homes of the mothers at a time of their convenience, and lasted between 40 minutes to an hour and a half. Within the phenomenological approach the interviews were recorded, with permission, and later transcribed. Notes were made and reflections entered into my research diary.

The Focus Group

Throughout individual interviews a desire to meet with other parents from similar backgrounds with children with special educational needs was expressed. This lead to the set up of the focus group allowing for issues expressed in the individual interviews to be explored in further detail.

All mothers were asked if they would be willing to attend an additional focus group to meet with other second generation Pakistani parents who have children with special educational needs, to explore the issues raised in individual interviews further. All mothers agreed to this; however it was difficult to set a date and time that all mothers could attend. Therefore the date and time selected was the one that the majority of mother could make.

The focus group took place a month after all the individual interviews had been conducted. The focus group was carried out in the Conference room at the Educational Psychology Service within the Local Authority. Aneesa, Mrs H, Mrs Q, Niggat and Naveen took part in the focus group. A small sample size was used for the focus group to allow for lengthy and intense discussions to take place and to minimise the possibility of individuals dominating the group discussions.

The focus group lasted for an hour and thirty minutes. There was an informal atmosphere, with food and drink provided. The focus group, chaired by myself, roughly followed a focus group schedule (see appendix 4) although a more informal conversational style was adopted to allow the mothers to feel more at ease in order to help promote self-disclosure. Therefore my role as a moderator was to *"ask questions, listen, keep the conversation on track and make sure everyone has a chance to share"* (Krueger and Casey 2000 p9).

The focus group was recorded and later transcribed. Notes were made and reflections entered into my research diary. The individual interviews were initially analysed, as detailed below. The generated themes were then examined against the data from the focus group, allowing for multiple perspectives to be provided to develop a more detailed and multifaceted account of the phenomenon (Reid et al 2005).

Processing and analysing the data

On reflection, I feel incredibly satisfied with the relationships that have been formed with the mothers interviewed for this study. I felt particularly moved by the stories of the two mothers, Aneesa and Naveen with whom I feel I developed closer relationships. Aneesa, a worker at a children's centre and Naveen, a school governor, highlight how parents can be very proactive and engaging with services. However in spite of this a number of "invisible" barriers exist which impact significantly on their experience as second generation Pakistani Muslim parents of children with special educational needs. Taking this into consideration as well as the flexible and interpretative nature of IPA, as a researcher I have chosen to predominantly focus on the interpretative accounts of these two mothers. Care has been taken to ensure that the shared perspectives of the other parents have also been represented, but this has been done through the interpretative accounts of Aneesa and Naveen. They reflect some of the shared experiences of the other mothers as well as tell a powerful and important story.

Analysis

The particular model of IPA used for analysis was that based on Smith and Osborn (2003). Whilst IPA is not a prescriptive method and lends itself to be adapted to personal ways of working, the following roughly outlines how the data were analysed in this study. The transcripts were placed into a table with identifiable units of data in each row. Two columns were placed to the left of the transcripts and one column to the right (see Appendix 5). A particular rich transcript was chosen as the first to be analyzed.

The transcripts were firstly read and re read a number of times in which thoughts and reflections were noted in the first left hand margin. With further re reading of the transcripts together with reflections, preliminary attempts were made at producing themes in the second left hand column.

The purpose of the preliminary themes was to attempt to capture the essence of the unit of transcript, which reflected my interpretative analysis. The text was then re-read to modify or change the themes where it did not appear to fully capture their essence, reflecting the cyclical nature of the analysis.

Subsequent texts and transcripts were analysed using the initial themes created in the first transcript. New emerging themes were added as well as existing themes being supported. After analysis of each of the transcripts the process of going back over the themes in the previous transcripts and modifying them in the light of greater reflection and familiarity was repeated.

Once all the themes had been created for all transcripts a colleague also familiar with IPA was invited to integrate the themes produced. This involved him scrutinizing the texts and asking for justifications for the themes leading to further modification of some of the themes.

In the final stage the themes were arranged into clusters of superordinate themes. The superordinate themes emerged from the process of looking for features, similar qualities and shared properties that the themes had in common. Again this was scrutinized by my colleague. The generated themes will be described and discussed in the following chapter.

Chapter 5: Interpretative Account of Research Findings

The following chapter outlines the themes that have emerged from the interpretative analysis. The following chapter will explore both shared experiences as well as allowing for unique individual experiences to also transpire. Analysis has allowed for five superordinate themes to emerge with a number of relating subordinate themes:

Table 1: Interpretative Superordinate and Relating Subordinate Themes

Superordinate Theme	**Subordinate Theme**
Religious Responses to Disability	Divine Intervention Belief in Allah Islamic Guidance and Teachings Muslim Identity
Family and Community Relationships	Support from family Lack of support from family Partnership with husband Competing Identities and Beliefs Insensitivity from Community Understanding and Awareness
Personal Feelings	Alone Accountable Struggling to cope Diagnosis Empowerment
Coping Mechanisms	Religious Comfort Friends Ignoring others Busy and Proactive Competing coping mechanisms
Perception and Experience of Service Providers	Frustration with professionals Professional support and good practise Services in Pakistan Language Barriers Stereotypes Inappropriate professional support Lack of cultural awareness and sensitivity

Due to the interpretative nature of this research both descriptions and interpretations will be provided in this chapter. This will be followed by a discussion chapter which further interprets and relates the data to the critical literature review, which has been composed before during and after the analysis process. Additionally interpretative analysis lends itself to lengthy extracts to assist in conveying the participant's lived experience. In order to give justice and the attention both required and deserved to the rich data generated, whilst still remaining within the criteria of a written doctoral thesis, quotations are placed in the appendix and are signposted for the reader. This allows abbreviations to be avoided, comprehensive quotations to be used and ultimately a more detailed portrayal of the interpreted experiences.

Religious Responses to Disability

This section will address the religious beliefs of the mothers with specific reference to how this impacts on both their understanding and experiences of disability.

Divine Intervention

Beliefs regarding the perceived impact of divine intervention were expressed in particular, the belief that visiting places of religious significance can impact upon both an individual's physical and mental health. Mrs H defined Durbars as a place where individuals of religious significance were buried and attendance and prayer at the location can impact upon health (Appendix 6:1)

The desire to visit durbars was expressed, with the hope that this could have some positive impact upon their child's disability. In particular, the husbands of all the mothers, (except Mrs A's husband) expressed a desire to go to Pakistan to visit Durbars. A mixed reaction to this emerged from the mothers. Both Mrs H and Mrs K expressed some hope and belief in visiting places of religious significance (Appendix 6:2).

However Naveen expressed some cynicism and felt that visiting Durbars may not have an impact on her daughter's needs (Appendix 6:3). Instead Naveen, inferred a belief in Allah's will, in that if Allah wished to intervene then He would, rather than visiting places of worship or holding significance to religious artefacts (Appendix 6:4 and 6:5). This further suggests differing views in beliefs about Allah, which shall be explored in greater detail:

Belief in Allah

A belief in Allah as being a supreme being was stated and acceptance of His will was expressed by Mrs Q (Appendix 6:6). Some mothers felt that their child's disability was part of Allah's will and as Muslims they should accept their child's disability as part of Allah's plan. For Mrs H this seems to contribute to the acceptance and understanding of her daughter's disability (Appendix 6:7).
For Mrs H, her children's disability appeared to also have strengthened her faith (Appendix 6:8), thus her faith being an important coping mechanism.

However for Aneesa, her child's disability initially made her doubt her faith in Allah due to the comments made by others who also inferred disability as an act of Allah (Appendix 6:9).

The notion of their child's disability being the result of punishment from Allah is a belief that had been expressed to the mothers by various other individuals from either their family or the Pakistani Muslim community (Appendix 6:10).

This belief has been strongly refuted and dismissed by the mothers (Appendix 6:11). This suggests that there is an acceptance that their child's disability is part of Allah's will, but not as a punishment. Instead, a common belief of their child's disability as a test from Allah was expressed (Appendix 6:12).

In addition to this, Aneesa, after discussions with Mrs Q, likened this perceived test to being equivalent to completing the pilgrimage of Hajj, one of the five pillars of Islam (Appendix 6:13).

Overall a strong belief in their children's disability as part of Allah's will was expressed, but the ideas of it being a punishment from Allah was rejected in favour of the notion of their child's disability as a test from Allah.

Islamic Guidance and Teaching

As well as faith in Allah, belief and faith in the Islamic guidance of members of the mosque and Islamic scholars was expressed, in relation to their child's disability. For example, Aneesa took her concerns regarding her husband's lack of attention to her children to individuals at the mosque (Appendix 6:14).

Mrs H also took some advice from professionals to Islamic scholars, when advised to consider an abortion (Appendix 6:15). This suggests that religious perspectives can impact on decision making.

Muslim Identity

Whilst a variety of religious beliefs were expressed, a strong Muslim identity was communicated. Aneesa described whilst her faith was shaken, both her and her children are Muslims (Appendix 6:16).

However a distinction was made between religion and culture. For example, Mrs H stated that she felt some of the comments made by other Muslims were not necessarily a reflection of Islamic teaching (Appendix 6:17). Similarly Naveen stated that she felt there was a fine line between religion and cultural practice: (Appendix 6:18).

Therefore all mothers identified both themselves and their families as being Muslim, but within this, it was identified that that practice between Muslims can be varied and often it is hard to distinguish the difference between cultural and religious practice.

As well as the mothers identifying themselves as Muslim, they also identified the need to bring up their children as Muslims. However a number of concerns were raised about how they fulfil, what they perceive as their Islamic duty, the need to ensure their children have an understanding of Islam including being able to recite the Koran (Appendix 6:19).

A huge barrier perceived by the mothers was the inaccessibility of the mosque to individuals with disability and the lack of persistence in teaching their children the Qur'an. Mrs Q felt some members of the mosque showed no interest in children with disabilities (Appendix 6:20). Frustrations seem to exist in that there is a desire to educate their children about their religious identity, but the mosques attended did not seem to cater for children with additional needs.

Family and Community Relationships

This section explores experiences relating to both immediate family members and the Pakistani Muslim community.

Support from family

Some mothers expressed gratitude to the support they had received from their family. Mrs H outlined not only how supportive her family have been, but that she also has the advantage of an extended family living near by (Appendix 7:1). Similarly, Mrs K has the support of her family, who although live far away, are able to offer assistance (Appendix 7:2). In addition to this, Mrs H has also received support from family living in Pakistan as well as in the UK (Appendix 7:3).

However in spite of having the support of an extended family, there was an acknowledgement that their families do have their own lives and in spite of wanting to help as much as possible, family members have other commitments and their support can be limited. Mrs H stressed that her mother is unable to care for her daughters as much as she would like (Appendix 7:4). Mrs K also understands that although she does have a supportive family, they have their own lives (Appendix 7:5).

Support provided for by family members can also vary over time, and it can be hard to maintain high levels of support that were initially required when the family were in the early stages of understanding their child's needs, as expressed by Mrs H (Appendix 7:6).

Additionally, Niggat stressed that support from family does not substitute support and advice from service providers (Appendix 7:7).

Lack of Support from Family

Whilst Mrs K, Niggat and Mrs H stressed the support they receive from their family, Aneesa and Naveen conveyed a lack of support from their family, providing additional pressures upon them.

Aneesa describes herself as "unattached" in which she is unable to openly discuss her son's needs with her family (Appendix 7:8). Aneesa seemed frustrated by this lack of support, as attempts had been made to ensure her family understand autism, by providing them with literature in Urdu. However this literature has not enabled an understanding of autism that Aneesa would have hoped for (Appendix 7:9).

This lack of understanding has resulted in Aneesa giving up trying making them understand her sons needs, impacting on her relationship with certain family members (Appendix 7:10).

Due to the lack of family support, Aneesa has had to access additional professional support including child care facilities (Appendix 7:11). As well highlighting a lack of support, Naveen also stated that some family members have made hurtful insensitive comments about their child's disability making things more difficult for her (Appendix 7:12).

Partnership with husband

For some mothers, a strong partnership with their husbands was expressed, in which both mother and father appeared united in their beliefs about their child's needs as well as being united in meetings. Niggat expressed a unity with her husband, which she further accounted to him being born in the UK like herself, and therefore both having a similar identity and associated beliefs (Appendix 7:13). A unified stance with her husband was also portrayed by Mrs H when asked about support from her family (Appendix 7:14).

In discussions within the focus group Naveen commented on the benefits of having the support from your husband in a meeting, indicating that this would be something that she too would like: (Appendix 7:15).

However this notion of a partnership between mother and husband was not expressed by all mothers. A sharp contrast emerged in which competing identities and beliefs systems were expressed.

Competing Identities and Beliefs

Whilst a strong partnership with their husbands was expressed by Niggat and Mrs H, for some mothers a very different notion emerged. Aneesa and Naveen highlighted how as second generation Pakistani individuals, they perceived themselves to have a different identity to their husbands who were brought up in Pakistan. This was subsequently attributed to a contributing factor for different beliefs about their children and how best to meet their needs.

Aneesa acknowledged that growing up in Britain has had an influence on her beliefs (Appendix 7:16). Naveen also stated that as a second generation Pakistani parent she is more aware, than her husband, of her daughters needs. She also feels that as a second generation Pakistani she has different values and beliefs to her husband (Appendix 7:17).

Aneesa felt her different identity to her husband has also resulted in a different understanding of their son's needs. Aneesa feels that her husbands upbringing is one possible reason why he refuses to accept the advice and opinions of professionals (Appendix 7:18).

Aneesa expressed how both her and her husband have opposing views about what they feel is best for their son. Aneesa feels it is crucial to engage with services and seek professional advice, whereas her husband appears to be not only disengaged but opposed to this and feels that it is religious guidance and prayer will help their son (Appendix 7:19).

Aneesa herself acknowledges that her and her husband hold different beliefs but feels her understanding of her sons needs are superior to her husbands (Appendix 7:20). Aneesa and her husband not only appear to have different identities but also contrasting beliefs in which her husband seems strongly opposed to professional advice and involvement (Appendix 7:21)

This has led to Aneesa feeling unable to access certain support and interventions such as respite, which appears to increase her anxiety and stress. Aneesa also expressed that she is the main carer of her son (Appendix 7:22). The competing identities and beliefs have led to increased marital strains. Aneesa in particular stressed despair and a lack of agreement with her husbands approach (Appendix 7:23).

There also appears to be a lack of compassion and empathy between Aneesa and her husband, which has increased the strains on their relationship. Aneesa felt that even after attempting to commit suicide, her husband still failed to understand her perspective or needs (Appendix 7:24). Such conflicts have resulted in a breakdown of relationship in which Aneesa stated that she was exhausted and no longer had the energy to maintain their relationship (Appendix 7:25).

Insensitivity from community

A large number of responses were made by a number of mothers about the reaction of other members of the local community when they are out in public with their children (Appendix 7:26). This perceived insensitivity and being self conscious was also expressed by Aneesa (Appendix 7:27).

However it appeared that some mothers felt that this insensitivity was somewhat greater from the Pakistani Muslim community as stated by Naveen, who lives in a predominately Pakistani Muslim area (Appendix 7:28). This was also shared by Niggat who expressed that she felt members from the Pakistani Muslim community can be directly more insensitive with their comments (Appendix 7:29).

Mrs H expressed how comments particularly from the Pakistani Muslim community had upset her and also at times made her self conscious in public, impacting on her ability to manage her daughter (Appendix 7:30).

Mrs H's negative perceptions and experiences of living within the Pakistani community have resulted in her placing her daughter in a nursery that is out of the catchment area and therefore in a provision where there are not many Pakistani children (Appendix 7:31). However the notion that such insensitivities are solely from the Pakistani Muslim community was refuted by Aneesa who also reflected that she too has experienced negative experiences from the old coal mining community in which she lives (Appendix 7:32).

However in the focus group Aneesa acknowledged that in some respects living in an old coal mining community rather than a Pakistani Muslim area has its advantages as she can dismiss the negative comments more easily, without there being further consequences (Appendix 7:33).

Living in the Pakistani Muslim community appeared to increase stress and levels of anxiety for some of the mothers. As well as insensitive and negative experiences from different communities, a lack of understanding of their child's needs from the Pakistani Muslim community was expressed.

Understanding and awareness

Aneesa expressed that she felt that some members of the Pakistani Muslim community had low expectations of children with disabilities (Appendix 7:34).

As well as lower expectations, frustration was expressed with the lack of understanding of others about their children's needs. In particular frustrations about comments suggesting an expectance of a cure were expressed (Appendix 7:35). Similarly Naveen stated that she felt that members of the community feel that her daughter will simply get better, which does not match her own understanding of her child (Appendix 7:36).

As well as a lack of understanding, a lack of open discussions within the Pakistani community regarding disability was also stressed (Appendix 7:37). However, for Mrs H, this lack of open discussions with others was a conscious decision, in which she has chosen not to disclose her child's diagnosis to others (Appendix 7:38). This lack of open discussion about disabilities has led to some reservations in approaching other Pakistani parents with children with disabilities (Appendix 7:39).

Personal Feelings

This section shall examine the feelings that were revealed by the mothers, which impacts upon their experience as parents.

Alone

A number of personal and emotional feelings were expressed. There was an overwhelming feeling of being alone that was expressed by all the mothers emotionally, socially as well as when accessing professional support.

Aneesa expressed how emotionally she has detached herself from others (Appendix 8:1). Naveen also expressed concerns that despite having a husband she worries about the future as she feels she is alone in understanding and providing for her daughters needs (Appendix 8:2).

Mrs K also expressed that she is socially isolated and tends to spend most of her days at home alone with her children (appendix 8:3). Aneesa further expressed that she feels alone in accessing professional support and this can be very difficult at times, particularly when attending meetings alone (Appendix 8:4).

Struggling to cope

As well feelings of being alone, feelings of struggling to cope were also expressed. Mrs K stated how she tends to take each day as it comes (Appendix 8:5). This was echoed by Mrs H who said how on some days she can cope but on others she can find it very difficult just to keep to her daily household routines (Appendix 8:6).

Mrs H further stated that attending social events like weddings can be difficult as her main concerns is how she and her husband will be able to manage their daughters (Appendix 8:7).

Niggat additionally stated that looking after children with disabilities is very difficult and very difficult to comprehend unless you are in that situation yourself (Appendix 8:8). The mothers also expressed how their experience of being parents of children with additional needs has impacted on their emotional well being. Mrs H describes how often people do not acknowledge her hurt as a parent (Appendix 8:9).

Naveen also stressed how her experiences could have had a detrimental impact upon her emotional well being if she allowed them to (Appendix 8.10). Aneesa also described how her struggle to cope led her to attempting suicide. Aneesa states how both her husband and professionals were unaware of the extent at which she was struggling to cope, again reflecting how alone she is (Appendix 8:11).

Accountable

Naveen and Aneesa both expressed fears of being held accountable by their husbands for the decisions they make about their children, thus increasing their anxiety and stress levels, as well as making the decision making process more difficult (Appendix 8:12). Naveen therefore felt unable to make the decision of the appropriate secondary provision for her daughter on her own (Appendix 8:13). Aneesa also reflected on how she has been blamed for many difficulties that have arisen with her son (Appendix 8:14). This fear of being held accountable seemed unique to the experiences of Naveen and Aneesa, reflecting how the disengagement of one parent with professionals can lead to increased stresses for the other parent.

Diagnosis

A strong desire for a diagnosis or label for their child's difficulties was expressed by some mothers. For Mrs K, the desire for a diagnosis reflected a want to understand her daughter's needs, which she felt would be possible by her daughter being given a medical diagnosis. Mrs K also felt a diagnosis would also be able to indicate to her what her daughters needs may be in the future (Appendix 8:15).

Mrs H also expressed frustration when initially her daughter had not received a diagnosis, as she too perceived that a diagnosis would allow her to understand how to meet her daughters needs (Appendix 8:16).

For Naveen, her desire for a diagnosis reflected her need to be able to describe her child's difficulties to others, which she found difficult to do without a diagnosis (Appendix 8:17).

A number of feelings were expressed however on being given a diagnosis for their child. Mrs H describes how utterly devastated she felt on being given the diagnosis and the burden she subsequently felt (Appendix 8:18). Aneesa describes being given a diagnosis for her child as a life changing moment and one, despite understanding the multi-disciplinary assessment, she was unprepared for. She also acknowledges that the autism label given to her son impacts upon both her and her son's life (Appendix 8:19).

Empowerment

For some mothers, the issues discussed within the individual interviews and focus group seemed to have a real impact. Naveen stated how it provided her with the opportunity to reflect on issues that had always been at the back of her mind (Appendix 8:20). In particular Naveen valued being able to discuss such issues with a professional with a similar cultural background (Appendix 8:21).

Naveen was also very optimistic about the research and where it could lead to. In particular she was keen to establish a support group for parents and expressed a desire to meet with other parents with a similar background (Appendix 8:22).

Aneesa, as a worker at a children's centre, decided to take the step in setting up a support group for parents of children with disabilities, which is not dependant on the child having any specific disability or label (Appendix 8:23).

Coping Mechanisms

A number of coping mechanisms were identified.

Religious Comfort

Comfort in prayer was expressed. For example Mrs Q stated that she found that praying for her daughter helped her during difficult times (Appendix 9:1).
Similarly Mrs H expressed some comfort in prayer which helps give her a sense of hope for her daughter (Appendix 9:2). Mrs H also indicated that both praying and supporting charities of children with disabilities provide her with some reassurance (Appendix 9:3).

Friends

The importance of friends was highlighted and the support the mothers are able to provide to each other was stressed. When asked what helps her through difficult times, Aneesa stated her friends have been a better source of support than her family and even likened her friends to her family (Appendix 9:4).

This notion of friends as an important coping mechanism was also highlighted by Naveen, who too identified a closer bond with friends than with family (Appendix 9:5).

Not only was this stressed as being important for the mothers, but something that their children were also able to benefit from. Aneesa further stated that her son also enjoyed the company of her friends and also detected the closeness between some of the mothers (Appendix 9:6).

The benefit of meeting with other mothers, who too are Pakistani Muslim parents of children with special educational needs, was identified as being important coping mechanism, with benefits for both the mothers and their children. Within the focus group, Aneesa stated that having recently met with more Pakistani Muslim mothers of children with disabilities has been useful, particular as there has been a shared cultural understanding between the mothers (Appendix 9:7).

Ignoring others

Insensitive comments from members of the community were previously highlighted. However, as well as being identified as an additional stress, the ability to ignore other peoples lack of understanding of special needs was highlighted as a crucial coping mechanism for survival. Aneesa stated that she has learnt to ignore others in order to help her survive (Appendix 9:8).

Mrs H too stated that over time, the ability to block out other people and their insensitive comments transpires (Appendix 9:9). This too was echoed by Niggat (Appendix 9:10).

This "getting used to it" seems essential for the mothers and crucial in helping them to function on a day to day basis. It also infers the notion that the mothers have become stronger and more resilient over time.

Busy and Proactive

Keeping busy and proactive emerged as another important mechanism in helping the mothers cope with their child's disability. This has helped stop some mothers from dwelling on issues that may cause them further upset. Naveen stated that keeping herself busy has helped her tremendously and even prevented depression (Appendix 9:11).

This keeping busy and not focusing on the child's difficulties but also engaging with services, seemed essential for some mothers, particularly for Aneesa who expressed how engaging with services had not only given her more confidence but kept her sanity (Appendix 9:12).

Engaging with service providers for some mothers appears to assist with coping and managing with their child's difficulties. In addition to this, dealing with other responsibilities they have as parents allows them not to dwell too much on their child's difficulties (Appendix 9:13).

Competing coping mechanisms

As well as identifying coping mechanisms for the mothers, competing coping mechanisms for some mothers and their husbands emerged. A sense of conflict in beliefs has been identified. The need to be busy and proactive was highlighted, but Aneesa expressed that her husband responded in a different manner by spending time away from the family, thus his coping mechanism was to be alone (Appendix 9:14). Her husband's need to do this seemed to interfere with Aneesa's coping mechanism, resulting in conflict (Appendix 9:15).

Accessing support from service providers emerged as an important coping mechanism. However it also emerged that for some mothers there are barriers to accessing professional support due to the competing mechanism for both husband and wife. For example, Naveen attends meetings on her own, but will often need to discuss issues with her husband who will not attend meetings and as previously stated, has a fear of being accountable. Therefore barriers exist for Naveen in being able to access an important coping mechanism for her (Appendix 9:16). Similarly Aneesa's husband is opposed to her accessing services and therefore opposed to her accessing a coping mechanism she feels she needs to help maintain her sanity. Aneesa also seems frustrated by her husband's belief in divine intervention and singular focus on prayer

(Appendix 9:17). This can result in a further barrier to an important coping mechanism as well as additional pressures between husband and wife.

Perception and Experience of Service Providers

A variety of beliefs were expressed regarding the experience of engaging and working with service providers.

Professional support and good practice

Some mothers expressed their appreciation of the support they have received from the professionals working with their children. Mrs H expressed her gratitude towards the support that she has received from certain professionals including a speech and language therapist and the physiotherapist (Appendix 10:1).

Naveen also stated how she was very pleased with the support and reassurance she was given by an escort who worked with her daughter (Appendix 10:2). In addition to this, Naveen felt that this professional in particular understood her needs as a mother, and despite her no longer working with her daughter, they have remained in contact as friends. The professional also demonstrated an interest and understanding in Naveen's' cultural background which was much appreciated by Naveen (Appendix 10:3).

Within the focus group discussion, ideas about what makes a good professional were discussed in which a genuine interest by the professional was expressed as being crucial (Appendix 10:4). However some dissatisfaction was expressed in regards to the mother's experiences of service providers.

Frustration with professionals

Aneesa describes some of her experiences as a battle and the frustration she feels when trying to access services and resources for her son (10:5). This notion of battling for support was also echoed by Niggat within the focus group (Appendix 10:6). Additional frustrations were also stressed about waiting lists. Naveen stated how she felt frustrated being on a waiting list for over a year for art club (Appendix 10:7).

However this caused Naveen additional frustrations as initially it took her some time to convince her husband to agree to the art club for her daughter. Naveen believes a barrier exists between her home and professionals, making it harder for her to access professional support (Appendix 10:8).

Aneesa also expressed anger at an inappropriate response made by a professional (Appendix 10:9). Aneesa expresses her anger as she firstly trusted the professionals working with her son, but additionally as it led to increased strains between her and her husbands due to their different beliefs regarding their sons. It would appear that inappropriate responses from professionals can make it difficult for the mothers at times to justify their positions to their husbands.

However in spite of the frustrations and difficulties expressed in the UK, there was a unanimous agreement that there is a lack of services for individuals with disabilities in Pakistan.

Lack of services in Pakistan

Niggat stated that her son loves visiting Pakistan and if it were possible she would live there. However the lack of services for children with disabilities prevents her from doing so (Appendix 10:10).

As well as a lack of services, some of the mothers recall some negative experiences of the treatment of individuals with disabilities in Pakistan as well as a total lack of understanding (Appendix 10:11).

However Aneesa felt that the current situation in Pakistan is not dissimilar to how the UK had been in the past and makes reference to previous practice of institutionalisations (Appendix 10:12).

Mrs H acknowledges this too and expressed a gratitude to being born in the UK as this has allowed access to services for her daughters that would have not been available in Pakistan (Appendix 10:13). However in spite of this Mrs H made the decision to go to Pakistan and seek private medical advice due to the frustrations with waiting so long for professional advice in this country (Appendix 10:14). Whilst there was an overwhelming agreement in the lack of services in Pakistan for individuals with disability, some practices were highlighted as being superior.

Language Barriers

Language was identified by the mothers as barrier to access of services for their husbands. In particular it was expressed that, at times, their husbands may struggle to understand the language used in meetings by professionals as well as their husbands feeling intimidated and unconfident in voicing their opinions. Mrs K stated that as a result of the above, she prefers to go to meetings alone due to a fear her husband may confuse everyone (Appendix 10:15).

However Naveen reflected a desire for her husband to attend meetings with her, but feels that he chooses not to go as a result of not being able to understand all of the language spoken but also the jargon used by professionals. This is spite of Naveen being proactive and a school governor (Appendix 10:16).

Additionally, Naveen acknowledges that her husband feels intimidated and unconfident about attending meeting (Appendix 10:17). However, when considering sending their daughter to a specialist provision rather than a mainstream secondary school, Naveen insisted her husband attend the meeting and expressed how they both made a decision together, which she describes as the best decision she has ever made (Appendix 10:18).

This suggests Naveen was more confident when a joint decision was made. However the inaccessibility of services to her husband acts as a barrier to joint decisions being made.

There are acknowledgments that the systems surrounding service providers and resources to their children can be very intimidating and thus disengaging to individuals, like their husbands, who have not been brought up in this UK. This seems something that the mothers have a crucial insight into, as mothers of children with additional needs, being second generation Pakistani individuals and married to men who were brought up in Pakistan (Appendix 10:19).

Interpreters were discussed and described by Aneesa as an expensive resource that can not be made readily available to assist in making meetings more accessible for their husband (10:20).

Naveen expressed how often she will have to explain to her husband the outcomes of a meeting, which can impact on the decision making process at times as he can often disagree with the outcomes of a meeting (Appendix 10:21).

As a result some mothers are forced to take on a dual role. Not only do they have to respond as parents in the meeting, they also have to ensure their husbands understand the outcomes. This is necessary due to a fear of being held accountable particularly for some mothers where there are opposing views. This can act as a barrier to an essential coping mechanism for the mother, as well adding strains onto the relationship. Additionally the perception of interpreters as being expensive may result in the mothers not wanting to ask for an interpreter. There may also be times when they do and don't want their husbands present at meetings.

Stereotypes

Some mothers expressed how they believed a number of stereotypes were held by some professionals they have interacted with. Aneesa stated how she felt that some professionals had an expectation of Pakistani Muslim women as being quiet and timid and are surprised when they meet her (Appendix 10:22).

In addition to this, Aneesa expressed how some professionals have been shocked that she is going through a separation, as there is a stereotype that divorces do not happen within the Pakistani Muslim community. Frustration was expressed with a desire to be treated as an individual requested (Appendix 10:23).

An expectation that Pakistani women do not work was also shared by Aneesa in which she felt that a lot of professional assumed she was a housewife and did not work (Appendix 10:24).

The stereotype that Pakistani families have access to a support network of an extended family was also shared. This although not directly stated, was a stereotype Aneesa perceived that some professionals held (Appendix 10:25).

This, Aneesa felt, impacted on the support that she was offered, as many professionals were unaware of the lack of support that she has, due to their stereotypes. This has led to her feeling that she isn't believed by professionals and is keen to take someone with her to meetings. However having support at a meeting isn't always possible for her, again stressing how alone she feels (Appendix 10:26).

Inappropriate professional support

A perceived inappropriate service for ethnic minorities was highlighted in a number of individual interviews as well as discussed further in the focus group. A second generation Pakistani male has been employed to wok with Asian families who have a family member with a disability. Within focus group discussions it was felt that whilst his role was to engage with ethnic minority parents, the mothers felt they were unable to engage with him, as it was inappropriate to employ a male in that role who lives within the same community as them (Appendix 10:27). Due to the perceived inappropriate appointment, Naveen feels that the support that she needs has become inaccessible to her (Appendix 10:28).

Aneesa also challenged the notion that having a professional of the same race and religion is always advantageous. She described a situation where a Pakistani Muslim social worker assumed they had the similar views as they had a shared identity. However the social worker's response failed to acknowledged the diversity within the Pakistani Muslim identity and angered Aneesa (Appendix 10:29).

Aneesa highlights the distinction between religion and culture as well as the diversity that can exists within a shared identity. This assumption held by a Pakistani Muslim professional led to conflict and an inappropriate response being made allowing Aneesa to conclude that having a professional from the Pakistani Muslim community isn't always helpful (Appendix 10:30).

Lack of cultural awareness and sensitivity

A lack of cultural awareness and cultural sensitivity from a number of professionals was expressed by some of the mothers. Mrs K stated how a medical professional has expressed that her child's disabilities may be a result of Mrs K marrying her cousin, causing offence as well as being an opinion that Mrs K does not herself agree with (Appendix 10:31).

Aneesa also stated how some parent support groups were inaccessible to her as they chose to meet in a pub. As well as being a culturally inappropriate venue, Aneesa also felt that she could not attend as addressing this with her husband would be difficult (Appendix 10:32). This also prevented Aneesa from informing other Pakistani Muslim parents about the support group, as Aneesa was aware that they too would not want to attend a meeting in a pub (Appendix 10:33).

Similarly Naveen has also felt at times that some support put in place for her daughter has not been appropriate due to a lack of cultural awareness of professionals. For example, Naveen felt uncomfortable that her daughter had a male escort and also additionally knew that her husband would not be comfortable either. Naveen although not comfortable with it stated she would be prepared to let her daughter go, suggesting that at times she may feel culturally and religiously compromised. However as a consequence of having a male escort, Naveen resulted in taking her daughter to school herself to avoid any further difficulties (Appendix 10:34).

Such situations have left Naveen feel that she is unable to open up at other parent support groups she has attended, as she is conscious that other people may not necessarily understand her situation and perceive her as being difficult to please and fussy (Appendix 10:35).

Additional frustrations were expressed by Naveen, as she felt that she is often used by professionals as a tool to obtain information about the Pakistani Muslim culture and religion. At times she feels they often obtain more information from her than she gets from them (Appendix 10:36). The implications of this interpretative analysis shall be discussed in the following chapter.

Chapter 6: Discussion

This chapter shall examine how the research process has answered the research question, with reference to key points in the Literature Review chapter. Consideration will be given to the individual and joint experience of the mothers. Five superordinate themes emerged which were:

1. Religious Responses to Disability
2. Family and Community Relationships
3. Personal Feelings
4. Coping Mechanisms
5. Perception and Experience of Service Providers

Each theme shall now be discussed in relation to the literature review as well as further interpretations being made.

1. Religious Responses to Disability

The interpretative analysis suggests that religious beliefs impact upon the experience of second generation Pakistani Muslim parents of children with special educational needs. Religious beliefs were expressed as explanations of disability but faith also emerged as an important coping mechanism

Bywaters et al (2003) argued that there can be an assumption of religious adherence within Muslim communities, leading to the assumption of theological based understandings of disability with disability perceived as an act of God. Within this study it seemed that for most of the mothers their religious beliefs had some influence in their experience as parents although the specific nature of each mothers religious understandings of disability varied.

Differing views of divine intervention were expressed, with particular reference to visiting durbars, places of religious significance. Some mothers, such as Mrs K and Mrs H, reflected some optimism that visiting such places may have a positive influence on their children's health. Other mothers such as Naveen expressed some cynicism indicating differing beliefs in divine intervention and ultimately their beliefs in the nature of Allah and the subsequent relationship between Allah and disability. Naveen felt holding significance to particular artefacts or praying in particular places would not have an impact on her child's disability. However this did not lead to a rejection of a religious understanding but reflected a different religious perspective. Mrs H, Aneesa, Mrs Q, Naveen and Niggat all expressed that they felt their child's disability was part of Allah's will, supporting Hasnain et al (2008) argument that many Muslims perceive disability as Allah's kismat or fate. The supposition of disability as an act of God however is a simplistic assumption. This study demonstrates that differences in belief regarding the nature of Allah's will as an act of disability can exist within Muslim populations.

However the religious understanding of disability expressed was empowering for the mothers and was perceived as important in helping them cope as previously suggested by Bywaters et al (2003). The notion of disability as God's will is described as a test by Mrs H, Aneesa, Niggat and Mrs Q, with Mrs Q and Aneesa likening the test to the Islamic pilgrimage of Hajj. Such religious beliefs are not negative but encouraging and also help the mothers in understanding their child's disability through reference to Islam, an important aspect of their identity.

Shah (1995) argues that Pakistani Muslim parents often perceive that their child's disability is a manifestation of Allah's will and in some instances an act of punishment for previous sins. However this notion of disability as a result of previous sin was strongly refuted by the mothers, suggesting a belief in disability as a result of Allah's will is not necessarily negative or disempowering. However it is worthy of note that some mothers felt some members of the Pakistani Muslim community perceived their child's disability as a result of their own previous sin. Additionally Aneesa's husband was also portrayed as holding different religious beliefs suggesting at one point he felt his son had shatan, the devil, within him.

However it is important to note that for the mothers their religious beliefs were not held in isolation or instead of medical beliefs. For example on being given medical advice on terminations, Mrs H conferred with Islamic scholars to see what the Islamic guidance on such matters were. Mrs H's decision was based on considering both medical and religious guidance. Bywaters et al (2003) highlighted that religious explanations of disability do not necessarily mean that families do not want to engage with services as medical and religious explanations can exist together. This study supports this notion.

This study highlights the differences that can exist between religious teachings and cultural practices. Interestingly the concept of disability as being morally neutral did not emerge (Bazna and Hatab, 2005). Rather than based on specific teachings in the Qur'an, the religious responses from the mothers may have emerged from their own personal lived experiences as Muslims. When asked, in the focus group, what the understandings were of teachings on disability in the Qur'an, the mothers stated they were unsure. However each parent had their own personal religious understanding of disability. Thus there was a personal individualised religious experience of disability that was reflected by the mothers, not based specifically on religious scriptures but their own understandings of Islam.

Additionally, it is important to note that the mothers, who are second generation Pakistani parents, valued religious explanations for disability and yet were proactive in seeking professional support for their children. Whilst Islam reflects what Miles (1995) described as an "*eastern religion,*" this study acknowledges that religious perspectives are held by individuals who have lived in Britain all their lives. This further highlights the importance of professionals to acknowledge and engage with such beliefs.

Miles (1995) argues that such perceptions of disability can be a challenge to western thinking but this study demonstrates that such thinking can play an important part in the experience of second generation Pakistani parents i.e. British citizens. Such perspectives can also impact upon decision making, for example Mrs H made the decision not to terminate her pregnancy following the guidance from an Islamic scholar. Additionally, it should not come as a surprise that an individual who identifies themselves as a practising member of a faith may hold religious explanations particularly centred on their children. Miles (2000) demonstrates the advantage that can be gained by engaging with such beliefs allowing for effective working relationships to be formed based on an acknowledgement of the families beliefs.

As well as identifying themselves as Muslims, some mothers expressed concerns about the religious identity of their child with disabilities. Concerns were raised in regards to the inaccessibility of mosques for children with disability as well their children being unable to recite the Qu'ran. Such concerns were acknowledged by Khedr (2006) who stated that barriers still exist within faith-based communities and the inaccessibility of places of religious worship can change the religious and cultural socialisations for the individual with disabilities.

This was raised in discussions in the focus group in which Niggat felt that when it came to teaching the Qur'an to individuals with additional needs there was little persistence or interest. This creates frustrations and anxieties as whilst the mothers clearly identify themselves as Muslims they perceive a religious duty to teach their children about Islam. However there are barriers to the religious education of children with disabilities, leaving some mothers feeling they are not fulfilling a religious duty as well as future concerns about the religious understanding and identity of their children.

It is crucial to engage with religious leaders to examine effective ways to support the inclusion and accessibility of public religious experiences to individuals with disability. The religious identity of being Muslims clearly plays a vital role in the daily lives of these mothers. The importance of religious identity has been contended by Sharif (2001), although rather than suggesting a hierarchy of identity exists, this study supports the notion that rather than making generalisations of religious adherence, understanding the religious, ethnic and cultural identity and beliefs in relation to how they impact on the experience of disability is crucial (Hussain 2005). This study suggests that for some parents religious, ethnic and cultural beliefs can impact on their understanding of disability, coping with a child's disability, decision making as well as creating concerns about the religious understanding of their child.

2. Family and Community Relationships

Different experiences emerged in regards to relationships with family and community members. The term' community'' will refer to the Pakistani (both first and second generation) Muslim community.

Different responses were made in regards to family support available. Both Mrs H and Niggat expressed their gratitude for the support they had received from their family. This support from family also extended to Pakistan. However even though gratitude was expressed there was an acknowledgment that in spite of being supportive, their families do have their own lives to lead and therefore their support can be limited at times. Additionally Niggat stated that support from family did not mean she would not access professional support.

A contrast was expressed by Aneesa, Naveen and Mrs Q. who reflected that they did not have family living in the local area and subsequently did not receive much support. In addition to this, family relationships for Aneeas and Naveen appeared to be a source of additional anxieties. There appeared to be a disengagement of their partners and some family members with professional support and advice.

The assumption therefore cannot be made that Pakistani Muslim families have the benefit of an extended family (Bywaters et al 2003). Whilst support may be available some of the mothers within this study did not want to impose upon their extended family.

This interpretation does not support Raghavan and Waseem's (2006) finding that Pakistani and Bangladeshi communities experience significant difficulties in accessing services due to beliefs held around the importance of the caring role within the family. Different findings may be a result of the mothers being second generation Pakistani parents and therefore fluent in English and able to act as their child's advocate. The allocation of a liaison worker within Raghavan and Waseem's study increased accessibility to services suggesting there was a language issue and may reflect the inaccessibility of services to individuals whose first language isn't English, such as Aneesa's and Naveen's husbands. Additionally the assumption cannot be made without understanding what support the specific extended family can provide or what their circumstances are. For example Mrs H described her mother's severe arthritis which impacts on the support she is able to offer her and her daughters. This again reinforces the importance of listening to the lived experience of families to ensure appropriate interventions are implemented

The notion that Pakistani Muslim families have access to support from an extended family also makes the additional assumption that the extended family have accepted and come to terms with the child's disability. Gray (1993) highlighted that many families of children with disabilities often experience family rejection. Naveen, Aneesa, Mrs H, Mrs K and Mrs Q all expressed that some members of their extended family having difficulty in accepting their child's disability. For example, Mrs H recalled how her mother in law felt she had been punished by having grandchildren with disabilities. Aneesa also expressed that despite providing information in Urdu from the National Autistic Society, her family still did not fully accept the diagnosis.

The assumption of an individual having support from an extended family should never be made nor should it be assumed that it will replace professional support. Instead time should be taken to ascertain the families' needs and provide appropriate support based on individual need. Again this highlights the importance of professionals taking the stance of a cultural broker and maintaining a genuine curiosity when working with families. This also reinforces the researcher's belief in interventions being 'experience near' (Kagan and Burton 2001).

As with family, different levels of support provided by partners was expressed. For some mothers such as Niggat and Mrs H , a strong partnership was expressed, in which both couples were perceived as working together to meet their child's needs. For some mothers such as Mrs Q and Mrs K it was difficult to ascertain the level of support they received from their husbands. However for mothers such as Aneesa and Naveen conflicting approaches in understanding their child's needs was expressed. Interestingly within the focus group and in individual discussions with Naveen, Aneesa and Niggat, the upbringing and identity of their husbands was contributed to the views their husbands held regarding their children.

Naveen and Aneesa both highlighted that being born in this country has had an impact on the understanding of their child's needs. Both expressed how they have a more western perception and expressed a frustration in their husbands' belief in divine intervention.

Whilst both Aneesa and Naveen identified themselves as practising Muslims, both reflected frustrations at their husbands' belief and focus on divine intervention. Their focus on divine intervention was attributed to their upbringing in Pakistan by both Aneesa and Naveen, therefore suggesting further that identity can impact on perceptions and experience of disability.

Frustrations appear to exist between both couples as their different perceptions, as well as identities seem to lead to different ideas about the type of support their child needs. The experience of being parents of children with special needs has been the cause of conflict for Aneeas and Naveen as it has highlighted differences in identity and religious beliefs between both parents.

It is however important to recognise that Mrs H, Mrs K and Mrs Q did attribute upbringing of their husbands as an influence in their understanding of their child's needs. This suggests that being a parent of a child with special needs can highlight both differences and act as a source of conflict between parents as well as being an important factor in strengthening the partnership between parents. Such conflicts however reflect the need to understand the father's perspectives of being parents of children with disabilities. This is a under represented area of research and highlights that fathers experiences in general need more attention as well as fathers from the Pakistani Muslim community (Wall 2003).

Naveen expressed some reluctance from her husband in engaging with professionals, which Naveen identified as an additional barrier, impinging upon decision making process. Aneesa and her husband appear to strongly oppose one another's beliefs, leading to marital strains as well disengagement with the others approach to their child. For example, Aneesa opposed the notion of hanging onions in the house to remove the perceived djinnn and her husband refused to attend any meetings arguing that Aneesa needed to pray instead. Therefore both parents appeared to be responding in isolation to their child, increasing frustrations certainly for Aneesa and possibly her husband too.

It is important to consider why such resistance exists as not only can it increase conflict between parents; it can also increase the anxiety and stresses that exist for parents with children with disabilities. Language was highlighted as a barrier for both Aneesa and

Naveen's husbands. This may contribute to such disengagement as both reported their husbands often lacked the confidence to voice their opinions in meetings.

Additionally it is important to consider the argument proposed by Hasnain et al (2008) that poverty is a reality for many individuals in Pakistan which can lead to a focus on disability rather than ability. This can further result in individuals, who migrate to the UK from homelands where there is limited support for disability, being unaware of systems of care or resources available. This may contribute to some of the resistance from the father's coupled with the inaccessibility of the systems centred around the care of their children. This could leave the fathers feeling very intimated, alienated and disempowered. Therefore the fathers are not only unable to "enter the world of disability" (Willis, 2007) but such marginalisation and inaccessibility of services, impinge on their rights as citizens (Fazil et al 2002). This has the subsequent effect of increased tensions for the mothers including increased tiredness due to a lack of support, thus impacting on their ability top cope (Fazil et al 2002). The inaccessibility of services coupled with competing coping mechanisms appears to create a cycle of marginalisation, disengagements and reduced coping resources.

It is important to be mindful that professional advice and support can be the source of conflict for a family. Additionally the inaccessibility and disempowering nature of systems to individuals whose first language isn't English, and whose beliefs around disability may be surprising to many professionals, can cause increased conflicts and strains for parents who are trying to engage with professional support.

Aneesa and Naveens' stories highlight hidden barriers that professionals may not be aware of as both mothers are proactive and engaging. For example Naveen is a governor at her children's school and Aneesa a worker at a children's centre. It is crucial to elicit the views of both carers of the child and to make enquiries about greater accessibility if both contact and attendance at meetings is dominated by one parent, particularly if they are the parent who is most fluent in English.

Complex relationships with the Pakistani Muslim community were also identified. Aneesa, Naveen, Niggat and Mrs H seemed to feel that the Pakistani Muslim community demonstrated more insensitivity than non Muslim Pakistani communities.

For example Mrs H chose a provision out of the catchement area to ensure her daughter did not attend at school with a high majority of Pakistani Muslim children.

There seemed to be an agreement within the focus group that living in a Pakistani Muslim community was stressful. Aneesa highlighted that insensitivities exist in the coal mining town she lives in but she can choose to ignore them, which would be more difficult in a Pakistani Muslim Community. Some mothers also felt that within the Pakistani Muslim community they live in, there was also a lack of understanding and awareness of disability. This resulted in some mothers such as Mrs H not wanting to disclose the child's diagnosis with others. However rather than feelings of embarrassment, shame or stigma (Crabtree 2007, Bywaters et al 2003), a frustration with the Pakistani Muslim community was expressed.

This reflects the complex nature of religious, cultural and ethnic identities in relation to disability. All appear to have an impact in some capacity in terms of understanding their child's disability. However as Hussain (2005) argued, it is crucial not to make generalisations or allude to a hierarchy of identifies but to understand the interplay of each for a particular individual, particularly in reference to disability. For example all mothers identified themselves as Pakistani Muslims although also expressed some disengagement with the Pakistani Muslim community.

Overall the complex nature of family and community relationships appears to have impacted on the parents experiences within this study. Having a child with special needs has impacted upon family relationships in which some relationships have been tested and others strengthened. Various levels of support were available to the mothers, although support from family was not perceived to replace professional support. Disconnections with some beliefs within the Pakistani Muslim community were expressed by some mothers reflecting the complex nature of what it means to 'belong' to a community.

3. Personal Feelings

This study shows that whilst some of the experiences of second generation Pakistani Muslim parents are distinct, a number of emotions that are typical of parents with children with disabilities were also expressed. Sloper and Turner (1993) argue there is considerable evidence that parents of children with disabilities are generally more likely than other parents to suffer from stress, anxiety and depression. Additionally many parents can find themselves socially isolated due to fears of rejection, in which the focus can often shift inwards towards the core of the family (Intaglio and Doyle, 1984).

There was an overwhelming sense that the mothers felt alone or socially isolated. Also there were frustrations expressed regarding diagnosis of their children. Mrs H described how difficult it was to receive the diagnosis of Joubert syndrome and Aneesa describes herself as being unprepared when her son was diagnosed with autism. The mothers also highlight at times that it has been difficult to cope resulting in Mrs K taking each day as it comes and Aneesa attempting to take her own life. Mrs H also stated how it can be difficult to attend just day to day routines and chores.

The difficulty of day to day life was highlighted. A real struggle to cope was expressed as well as high levels of stress combined with some mothers feeling socially isolated. An additional burden was that mothers such as Aneesa and Naveen felt additional pressures that they may be held accountable by their husbands. The pressure of attending meetings alone and making decisions alone increased the anxiety and stress levels for Naveen and Aneesa. This shows how for some mothers the disengagement of one parent can increase their already high levels of stress. It important to be mindful, as professionals, the burdens that can be felt by parents, particularly those that attend meetings alone and the stress they may feel.

The focus group itself felt like an empowering experience for some of the mothers. The mothers seemed to find reassurance in sharing their experiences in a groups setting and appeared more confident in the focus group than in the their individual interview. For example Aneesa chose to make jokes about her husband, which lightened the mood whilst maintaining a supportive atmosphere. Additionally it seemed that the focus group allowed for some mothers to reflect upon their own experiences when hearing the accounts of the others mothers. For example Niggat commented on how on hearing the other mothers stories made her realise that her husband was much more supportive in comparison.

It seems that for second generation Pakistani Muslim parents additional stresses can exist such as family and community relationships, inaccessible services to individuals whose first language isn't English, a lack of acknowledgment of different perspectives on disability, as well as cultural insensitivities and lack of cultural awareness. Such variables can further compound the difficult emotions that may be experienced as a parent of a chid with a disability. Thus supporting the notion that ethnic minority families with disability may experience 'double discrimination' (Fazil et al 2002). Further to this, not only are systems still inaccessible to individuals who are non-English speaking, despite over three decades after the main contemporary period of immigration from the South Asian subcontinent, there is a significant impact of this upon the experiences of second generation parents for whom language isn't a barrier.

4. Coping Mechanisms

A number of coping mechanisms were identified. Firstly many mothers expressed that their faith helped them. Whilst the nature of their religious beliefs may have varied, there was an overwhelming feeling that faith was an important coping mechanism for some of the mothers. Equally it should be noted that faith also seemed to be an important coping mechanism for some of the fathers including Aneesa and Naveen's husbands.

Additionally engaging with services also emerged as a coping mechanism, questioning the stereotype that Pakistani Muslim families may not engage with professional support as they may rely on family support. Clearly for some of the mothers in this study, being busy and proactive was a crucial aspect of their experiences as parents of children with special educational needs. Parents can vary to the extent to which they want to "enter the world of disability" (Willis 2007) however for some mothers within this study, entering the world of disability was crucial in their ability to cope and function on a daily basis with their child's disability.

However as previously discussed, competing coping mechanisms appeared to emerge for some families. It is important as service providers to examine how both the coping mechanisms of each parent can be mutually facilitated. The need to engage with alterative understandings of disability is crucial in this as Miles (2000) has demonstrated. Not only is it important to take time to understand the parents experiences, but also knowing how to engage with parents who may feel marginalised. The stance of a cultural broker would be helpful by not expecting to master the complexities of communities, but knowing what questions to ask, being open to asking such questions and truly listening (Hasnain et al 2008).

Friends were identified as a coping mechanism, with a desire to meet other mothers of children with disabilities being expressed. Interestingly the mothers also expressed the importance of ignoring individual that they felt were insensitive. This suggests that the mothers may be more selective or cautious about whom they choose to engage with since becoming parents of children with disabilities. This also indicates some benefits of support groups although Fazil et al (2002) found that many parents from the Pakistani community were not aware of parent groups and were keen to meet with other Pakistani Muslim parents. This notion has been strongly supported within this study with the mothers taking action themselves in setting up a parents support group (see post thesis script). However it does raise the need for professionals to make parents aware of existing parent support groups.

5. Perception and Experience of Service Providers

A complex relationship with professionals emerged. Whilst some mothers such as Mrs H expressed their gratitude and support for the levels of support, other mothers such as Aneesa and Naveen expressed some frustrations. As previously stated none of the mothers expressed a reluctance to engage with services, thus supporting Bywaters et al's (2003) argument. This is further reinforced by the finding that being proactive and engaging with services served as an important coping mechanism for some mothers.

However as previously stated, systems surroundings professional advice and support were not equally accessible to both the mothers and fathers. For some mothers, such as Mrs H and Mrs Q, their husbands attended professional meetings and were able to access some of the information. However Mrs K felt that her husband could almost be a hindrance as his inability to understand what was going on could be a distraction and confuse the discussions being held. However for Naveen and Aneesa, professional support acted a source of conflict between themselves and their husbands. Whilst reluctance to access services was not expressed by the mothers, barriers inhibiting an equal access to services were highlighted for the fathers. Language emerged as a significant barrier for the fathers.

No use or offer of interpreters was expressed for the fathers. All mothers appeared to be the prime carer for their children and the parent with whom the professional had most contact with. Aneesa expressed a desire for an interpreter that doesn't *"cost an arm and a leg"* suggesting she perceived interpreters to be expensive, in line with Shah's (1992) argument that interpreters are often perceived as a luxury and used voluntarily i.e. when specifically requested. The lack of interpreters acts as a significant barrier for the fathers despite Shah (1992) arguing it is the duty of services to ensure all parents have the right of access to information. This study demonstrates that this is clearly not the case. The question arises as to why interpreters have not played a greater role in supporting the fathers in accessing professional meetings. It may be assumed that information would be relayed to the father by the mother, as argued by Bywater et al (2003). However for some mothers this can impinge on the decision making process and provide increased anxieties.

It may be argued that this dual role of parent and interpreter is also inappropriate as the mother will have the associated thoughts feelings and emotions as a parent of a child with special needs, without the additional pressure of acting as an interpreter for their partner. This can be especially difficult if differences of opinions exist between parents as well as with the professionals involved. Additionally it cannot be assumed that information will be shared, which can result in one parents being more informed in regards to professional opinion (Bywaters et al 2003). This leads to an imbalance of knowledge of parents due to the inaccessibility of professional advice and systems to individuals whose first language isn't English.

For some mothers such as Naveen and Aneesa, this acted as a source on conflict and increased martial tensions, thus impacting upon their experience as second generation Pakistani parents of children with special needs.

A lack of fluency in English coupled with a meeting in which the language used is difficult to comprehend, with their child's needs as the main focus of discussion cannot surprisingly lead to a lack of engagement. This subsequently can lead to increased anxieties for some mothers as there is a greater sense of accountability and responsibility. This highlights that socially created barriers exist for minority parents in accessing services (Bywaters et al 2003).

The mother's perceptions of resources and services available in Pakistan was also quite negative, in which it was unanimously felt that there are more services available for individuals with disabilities in Britain than Pakistan. This may impact on some of the father's expectations of service providers as growing up in Pakistan (Hasnain et al 2008). This too was acknowledged by some mothers who highlighted growing up in Pakistan as a contributing factor to differences of opinion. However the current existing language barriers do not promote the understanding of the systems of support centred around children with disabilities.

It is crucial for professionals to work with the key individuals in a child's life. Bywaters et al (2003) suggest that professionals should more representative of the communities that they work with whereas Fazil et al (2002) found mixed responses from families in regards to this. The notion of the advantage of the professional being of the same ethnicity as the family they are working with was certainly challenged within this study. Niggat, Aneesa and Naveen all questioned the appropriateness of a second generation Pakistani male assigned to work with ethnic minority carers of individuals with disability. Additionally Aneesa felt that a Pakistani Muslim social worker acted inappropriately, assuming their shared identity equated shared practices and beliefs and failed to recognise the diversity that exists within the Pakistani Muslim identity. However Naveen expressed reassurance in being able to talk to myself as she felt I understood her cultural and religious background.

Firstly it is important to note that an assumption should not always be made that having a member of the same ethnicity will always be advantageous. Clearly the skill set and interpersonal skills of the professional play an important role. Additionally there may also be other cultural factors to take into consideration. In this instance the fact the worker was male acted as a barrier as culturally some mothers felt it inappropriate to contact him.

Within discussions in the focus group a worker who shows a genuine interest was highlighted as an ideal quality in a professional. Naveen mentioned a transport worker with whom she has established a close relationship, who understood her anxieties as a mother and also embraced her cultural and religious background. This resulted in a friendship being formed and the worker being invited to Naveen's home on Eid. Naveen stated the worker "*totally embraces everything*" reflecting an example of effective cultural brokering in which the parent felt truly listened to and with culturally appropriate interventions based on mutual respect.

However this wasn't the case of all the mothers' experiences who reported perceived stereotypes as well as cultural insensitivity and a lack of cultural awareness. Stereotypes around the submissiveness of Pakistani women and the assumptions of extended family support were expressed as identified by Bywaters el al (2003) and Hasnain et al (2008). Aneesa felt such stereotypes influenced both the support offered by professionals as well as her interactions with some professionals. Such stereotypes led to feelings of frustration resulting in Aneesa feeling that professionals do not understand her individual needs. Additionally Aneesa expressed that dispelling stereotypes can be difficult especially when attending meetings alone. This highlights that differential treatment is experienced by ethnic minority parents of children with disabilities, due to one or more aspects of their perceived identity (Ali et al 2001).

Cultural insensitivity and a lack of awareness also lead to frustrations for the mothers as well as an inability to access services. For example suggestions that marrying cousins may be a cause of disability frustrated Mrs K. Support groups meeting in pubs resulted in non attendance for Aneesa as well not being able to invite other Pakistani mothers due to fear of offending. Naveen highlighted her frustrations as to being used as a tool for knowledge of the Pakistani Muslim community by professionals. Whilst this demonstrates that a step is being taken to learn more about the culture of the individual, it has to beneficial to the individual and a professional should have a cultural and religious awareness of the groups of individuals they are working with. It is important that parents feel their story is heard, in which individual differences and diversity is valued, rather than the parent being used as a means to find generic information about a culture, religion or way of life.

However language still exits as barrier to services for many individuals whose first language isn't English. Professionals representative of the families they are working with may help reduce language barriers, but the skill set of the professionals should be held as central importance. Additionally if professionals can act as effective cultural brokers the ethnicity of the professional becomes less central. Additionally greater access to interpreters is required with protocols and consideration given the emotional responses that may be made in meetings.

On reflection on my own role within this research I am unsure as to whether my religious and ethnic identity contributed to the relationships established with the mothers or the skills I have developed as a trainee educational psychologist. My use of the Urdu and Punjabi language is limited and the majority of the interviews were conducted in English. The mothers were able to use terminology such as "tawees" and "durbars" without the need for further explanation, which have made them feel more comfortable and allowed them to perceive me as not only a professional but an 'insider' too. However I do feel that my genuine interest in the mother's experiences was conveyed and the position of a cultural broker was key to the relationships established. In conclusion I feel, my ethnicity and religious identity held secondary importance to my skills as both a cultural broker and trainee educational psychologist. It may further be argued that the skills of each are interlinked.

Chapter 7

Limitations, Conclusions and Recommendations

This chapter is concerned with the limitations of the research, the conclusions drawn and future implications for practice and research.

Section 1: Limitations

As previously outlined there are a number of limitations in using IPA. The approach is dependent upon the participant's ability to express themselves. There was a focus on the experience of two mothers whose stories highlighted significant barriers that exist for some parents. However Aneesa and Naveen were the most articulate of all the parents interviewed. The focus may have emerged due to their ability to articulate their experiences and the barriers that exist within their lives. Whilst as a researcher I feel the focus was appropriate, the approach may not have helped to identify as effectively the experiences of the mothers who were less articulate. The articulation of the mothers was certainly a consideration in the selection processes and may have impacted upon the parents put forward by other educational psychologists for this study. The issue of deceit is a further consideration as the knowledge presented is recalled from the perspective in which the participants understand their experiences. However long interviews can help address this and regular meetings for over a year were held with a number of mothers. The mothers were also recommended by educational psychologists who had established relationships with the parents.

An additional vulnerability is that when using IPA, the whole approach is dependent upon the researcher's subjectivity and interpretation, thus making the processes difficult to check. However whilst the process is subjective and difficult to assess, the outcomes of the research can be examined. The reader has been provided with information relating to the research process, the analysis techniques and personal information the researcher is aware of which may impact upon the research. Additionally examples of annotated transcripts have been provided in the appendix. The outcomes of this study have also depended on regular consultations with my tutor, dialogues with colleagues and the completion of a research diary.

Whilst the views of the parents were predominately sought using semi-structured interviews, an approach well matched with IPA (Smith and Osborn 2003), an additional focus group was also conducted. Smith (2003) argues the benefits of individual case studies when using IPA. IPA assumes individuals have their own ideas, understandings and opinions. The researcher's aim is to access these "cognitions." However it may be argued that it is difficult to capture the individual lived experience of each participant in a focus group. Whilst similarities existed between the mothers, stark differences also existed such as the nature of their child's special educational needs, the number of children they had with additional needs as well as family support available. Clearly such factors impact on the experiences of parents. However the focus group was used to obtain multiple perspectives providing a more detailed and multifaceted account of the phenomenon. The approach is increasingly being used with focus groups. This can also be argued to be one form of triangulation (Reid et al 2005). Whilst there may be difficulties in using IPA solely with focus groups, the use of the focus group was beneficial in providing more detailed accounts that were generated in the individual parent interviews.

The relationship established between the researcher and the participants also requires further thought. The shared cultural and religious demographics of the researcher with the participant group was beneficial in building initial rapport with the mothers and allowed for Punjabi Urdu and English to be used in the interviews as well as some terminology and references not requiring further explanation. However through my own reflections I feel that whilst similarities were identified; stark differences also emerged relating to lifestyle and religious beliefs. Whilst close relationships were established with some mothers, researcher- participant boundaries were maintained, resulting in the participant disclosing more information than the researcher. This raises the question of what impact my cultural and religious background had upon the research and whether the mothers perceived similarities which may not have exited. Further to this differences also emerged between the mothers regarding lifestyle and their religious beliefs. As previously stated Hasnain et al (2008) argue that "*even specialists who are knowledgeable about a given ethnic background, language and culture, and religion admit the complexities and varieties are hard to describe or comprehend*" (p12).

Wall (2003) highlights a current focus of literature on the experiences of mothers. This study has identified language as a significant barrier to service providers and the methodological approach selected was dependent upon language. Whilst appropriate for the participant group of second generation Pakistani Muslim mothers who were articulate in the English language, the methodological approach would not have been appropriate if the experiences of the fathers were being explored due to my functional yet limited use of Urdu and Punjabi. Whilst some of the mothers have highlighted barriers they feel exist for their husbands, their accounts may not reflect the direct experiences of the fathers. References made to the experiences and views of the fathers within this study are therefore the mother's perceptions of their husband's experiences. It would be of benefit to understand the experiences of fathers particularly for those who seem to oppose professional advice and services, such as Aneesa's husband. The exploration of the experiences of the husbands of the mothers within this study would be appropriate for a researcher who is fluent in Urdu and Punjabi and familiar with IPA.

An attempt at validation of interpretation has been made through the use of a focus group following the initial individual interviews, on going discussions with some mothers through monthly attendance at the newly formed parents support group, on-going discussions with tutors and sharing the interpretative analysis with an Educational Psychologist colleague familiar with IPA. The limitations the researcher is aware of have also been outlined.

Section 2: Recommendations for Future Research

On examination of the research process, including the literature review and limitations of this study, the following areas have emerged as recommendations for future research:

- Future research should aim to examine the views of individuals from minority groups who have disabilities. This is an area that has been given little attention (Hussain 2005). Thus, it is through taking into consideration the views of the community, family and the individual, that fears of ethnocentrism and stereotyping can be reduced.

- Hasnain et al (2008) importantly point out that many Muslim families with disabilities cope without professional intervention and succeed using their own mechanisms of support. This is an area worthy of further research, as many families may have alternative and enhanced ways of providing support for their families.

- As previously stated the views of fathers has been much neglected and an important areas of research (Wall 2003). The views of fathers of children with special needs is an area worthy of investigating further but in particular the views of fathers from minority backgrounds.

- In order to address the religious accessibility of individuals with disability, the views of religious leaders in the community needs to be elicited in relation to greater inclusion of individuals with disabilities. In particular the current facilities available in places of worship need exploring. This includes identifying areas for development to improve inclusion and examination of the accessibility of religious scripture to individuals with additional needs. The need to work alongside religious leaders is crucial to ensure culturally appropriate approaches that allow 'experience near' interventions to be generated.

Section 3: Conclusions and Recommendations

This study aimed to examine the experiences of second generation Pakistani Muslim parents of children with special educational needs. One purpose of exploring the experiences of such parents was to inform professional practice. Whilst the responses of the mothers have varied some key points relating to the research question have emerged:

- Identity emerged as a complex issue with differences in identity being attributed by some mothers to different responses and understandings of disability. This was made in reference to some of the mother's partners and some members of the Pakistani Muslim community. There was a sense of belonging but also not belong to the Muslim community. A Muslim identity was expressed by all mothers and concerns were raised regarding the religious accessibility for their children

- The mothers, although varied in their responses, expressed some religious understanding of their child's special educational needs. Faith and religious belief emerged as not only an important coping mechanism but as an important empowering element in understanding their child's disability as a manifestation of Allah's will. However the perceived focus upon the hope of divine intervention as a sole source of support for their child's difficulties appeared to create additional tensions for some mothers. This highlights the need to understand the impact of the interplay of ethnic, religious and cultural identities and the impact they have on the experiences of families.

- Complex relationships with family members emerged in which levels of support available to the mothers varied. However the mothers who had the benefit of supportive families felt that such support was not in place of professional support and advice. However the accessing of professional support for some mothers was a source of conflict between themselves and their husbands in which it appeared competing coping mechanisms existed. There seemed for some fathers a resistance to access professional support.

- On examination of the mothers perceptions of professional support, significant barriers seemed to exist particularly for individuals for whom English was a second language. In addition to this frustrations were expressed with some mothers indicating inappropriate cultural practice and a lack of cultural awareness as well as perceived stereotypes held by professionals. However there was an overwhelming agreement that the services available in Britain, for their children, were superior to those available in Pakistan. Gratitude for the support provided by some professionals was expressed with a genuine interest expressed as a crucial quality for professionals.

- A number of coping mechanisms emerged for the mothers including religious faith and engaging with services and friends. It seemed that the mothers had altered their socialisation patterns in that they chose to block out individuals who they perceived to not understand their child's needs. Similarly there seemed a need to meet with other parents of children with disabilities, with similar cultural, religious and ethnic backgrounds.

Recommendations for Practice

Whilst this study was based on a small sample, some key points have emerged to help inform multi-agency practice. These are as follows:

All agencies should:

- Listen to and understand the unique lived experiences of the parents, to develop experience near interventions based on individual need and circumstance.
- Aim to develop the skills of 'cultural brokers' in all professionals engaging and working with families.
- Develop training which raises the awareness of culturally specific practices and beliefs but also acknowledges diversity and the individual differences that can exist within shared identities.
- Recognise, listen to, respect and engage with religious understandings and responses to disability.
- Recognise the importance of engaging both carers of child, particularly if for one parent English is a second language.
- Actively engage both carers of a child and if language barriers exeunt, interpreters should be used both effectively and frequently.
- Re-examine protocols and procedures in place for the use of interpreters, allowing for greater accessibility and consistency in their use, as well as examining how responses made to emotional reactions when using an interpreter.

Final Thoughts

The reader is invited to judge the 'credibility' of this research. Within the domain of Educational Psychology, this study has demonstrated how interpretative methods can be utilised to inform professional practice.

Post Thesis Script

Parent Support Group

Following the focus group a desire to set up a parent support group was expressed by the mothers in this study. In particular Aneesa stated that after the issues raised in her individual interview, she felt very strongly about the need for a support group for mothers from the Pakistani Muslim community who have children with special educational needs. As an employee of a children's centre with a high population of Pakistani Muslim children, it was felt appropriate by Aneesa to take her ideas to her line manager. Subsequently, the set up of a parent support group had been set as a core target for her and her colleagues to achieve. It was agreed at the focus group that flyers would be sent to all schools and a consultation date set to discuss what the aims and purpose of the group would be.

Regular monthly contact has been maintained by myself and the parent support group. The parent group has evolved into an open forum for all parents with children with additional needs. Thus the decision was made not to make the group accessible to specific ethnic or religious groups or children with specific needs. The group has been attended by a high number of mothers from the Pakistani Muslim community, including those who took part in this study. A variety of professionals have also attended the support groups on the request of the parents. Throughout the whole process, Aneesa has acted as both an effective interpreter and cultural broker. The parent support group also reflects an experience near intervention that emerged through listening to the experiences of parents, which is constantly evolving based on the changing needs of the parents.

The support group reflects an emergent intervention shaped through interactions with participants. This research exceeded initial expectations and indicates the research process has had some impact upon the participants. This resonates with Salmon (2003) who argues that *"research is not a self-indulgent activity for the researcher. It has to matter to others"* (p26). Furthermore, on reflecting on his own research, Oliver (1992) states that research should not only be empowering for the participants but that participants should be able to empower themselves and the research process should be able to facilitate this:

> *"the (emancipatory) research paradigm is not how to empower people, but, once people have decided to empower themselves, precisely what research can then do to facilitate this process. This does then mean the social relations of research production do have to be fundamentally changed; researchers have to learn how to put their knowledge and skills at the disposal of their research subjects. For them to use in whatever ways they choose"* (p111).

Whilst this research may not completely reflect Oliver's (1992) definition of emancipatory research, it certainly highlights the importance of research impacting and empowering its participants. On reflection it could be argued that the educational psychologist role should ensure that involvement with children and their families should assist in facilitating empowering interventions.

References

Ali, Z., Fazil, Q., Bywaters, P., Wallace, L., & Singh, G. (2001). Disability, ethnicity and childhood: A critical review of research. *Disability & Society,* 16 (7), 949-968.

Amin, B. H. (2000) Hajj in a Wheelchair. *Azizah Magazine.* Retrieved from www.nod.org/index.cfm?fuseaction=feature.showFeature&FeatureID=1226&C;?CFusionMX7/verity/Data/dummy.txt on 22/09/08.

Asad, M (1980). *Message of the Qur'an.* Lahore, Pakistan: Maktaba Jawahar Ul Uloom.

Atkin, K. (1991) Health, Illness, Disability and Black Minorities: A Speculative Critique of present day discourse. *Disability Handicap Society, 6,* 37-49.

Bazna, M.S., & Hatab, T.A. (2005). Disability in the Qur'an: The Islamic alternative to defining, viewing and relating to disability. *Journal of Religion, Disability & Health, 9*(1), 5-27.

Billington, T (2000). *Separating, Losing and excluding Children: Narratives of Difference.* London. England:Routledge Falmer.

Blamires, M, Robertson, C and Blamires J (1997) *Parent-Teacher Partnership. Practical Approaches to Meet Special Educational Needs.* London: David Fulton.

Brocki, J.M. and Wearden, A.J. (2006) A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology, *Psychology and Health, 21* (1): p 87-108.

Bywaters, P., Ali, Z., Fazil, Q., Wallace, L. M., & Singh, G. (2003). Attitudes towards disability amongst Pakistani and Bangladeshi parents of disabled children in the UK: Considerations for service providers and the disability movement. *Health and Social Care in the Community,* 11 (6), 502-509.

Communication Limited (2008) Retrieved from www.communicationlimites.co.uk/howtouseasignlang.html. on 24/10/08.

Crabtree, S.A. (2007). Family responses to the social inclusion of children with developmental disabilities in the United Arab Emirates. *Disability and Society,* 22 (1), 49-62.

Dale, N (1996) *Working with Families of Children with Special Needs.* London: Routledge.

Denzin, N. (1989) *Interpretive Interactionism.* Newbury Parl, CE: Sage.

Dosanjh, J.S. and Ghunman, P.A.S. (1996) *Child-Rearing in Ethnic Minorities.* Clevedon: Multilingual Matters.

Drotar, D (1975) The adaptation of parents to birth of an infant with a congenital malformation: A hypothetical model. *Paediatrics (56)* 7 10-717.

Eatough, V. and Smith,, J.A (2006). I feel like a scrambled egg in my head: An idiographic case study of meaning making and anger using interpretative phenomenological analysis. Cited in Willig, C and Stainton-Rogers, W (2008) *The Sage Handbook of Qualitative Research in Psychology.* Sage Publications.

Fazil Q., Bywaters P., Ali Z., Wallace L. & Singh G. (2002) Disadvantage and discrimination compounded: the experience of Pakistani and Bangladeshi parents of disabled children in the UK. *Disability and Society 17* (3), 237-253.

Ghunman, P.A.S (1999) *Asian Adolescents in the West,* Leicester: BPS Books.

Giorgi, A. (Eds). (1985). *Phenomenology and Psychological research.* Pittsburgh: Duquesne University Press.

Gray, D. E (1993) Perceptions of Stigma: the parents of autistic children. *Sociology of Health and Illness* (15) 102-20.

Hasnain, R, Shaikh, L.C, Shanawani, H (2008). *Disability and the Muslim Perspective: An Introduction for Rehabilitation and Health Care Providers.* Retrieved from http://cirrie.buffalo.edu/monographs/muslims.pdf on 14/05/08.

Holloway, W and Jefferson, T. (2000). Doing qualitative research differently: free association, narrative and the interview method. London. Sage Publications.

Holloway, W and Jefferson, T (2006). Paradox in the Pursuit of a Critical Theorization of the Development of the Self in Family Relationships. *Theory and Psychology. 16*(4) 465-482.

Holstein, J. & Gubrium, J. (2004) The active interview. In Silverman, D. (ed) (2004) *Qualitative Research: Theory, Method and Practice.* London: Sage Publications.

Hussain, Y. (2005) South Asian Disabled Women: Negotiating Identities. *The Sociological Review, 53* (3), 522-538.

Intaglio, J and Doyle, N (1984) Enhancing social support for parents of developmentally disabled children: Training in inter-personal problem-solving skills. *Mental Retardation (22)* 4-11.

Jezewski, M., & Sotnik, P. (2005) Culture and disability services (with a focus on culture and foreign-born characteristics). In J. H Stone (Ed*), Culture and disability: Providing culturally competent services* (pp. 15-31). Thousand Oaks, CA:Sage.

Kagan, C. & Burton, M. (2001) Critical Community Psychology Praxis for the 21st Century. Retrieved from http://homepages.poptel.org.uk/mark.burton/GLASGOXS.pdf on 14/05/08.

Khedr, R. (2006). Putting disability on the Muslim agenda. Retrieved from http://www.islamonline.net/English/family/2006/05/article02.shtml on 19/09/08.

Krueger, R.A and Casey, M.A (2000) *Focus Groups: A Practical Guide for Applied Research.* Sage Publications: London.

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

Miles, C. (2000). Imran's Djinn, and theories of epilepsy. Retrieved from http://www.independentliving.org/docs7/miles-christine2000.html on 18/09/08.

Moustakas, C. (1994). *Phenomenological Research Methods.* London. Sage.

Mulveen, R and Hepworth, J (2006). An Interpretative Phenomenological Analysis of Participation in a Pro-anorexia Internet Site and its Relationship with Disordered Eating. *Journal of Health Psychology.* Sage Publications.

Oliver, M. (1992) Changing the Social Relations of Research Production. *Disability, Handicap and Society*, 7 (2) p101-115

Opie, C. (ed) (2004) *Doing educational research: A guide to first time researchers.* London: Sage Publications.

Osborn, M and Smith, JA (1998) The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. *British Journal of Health Psychology* (3, 1) 65-83.

Potter, J (1996). *Representing reality: Discourse, rhetoric and social construction.* London: Sage

Raghavan, R., Waseem, F. (2006). *Disabilities and mental health issues: Mapping of service use.* Retrieved from http://www.learningdisabilities.org.uk/our-work/children-and-young-people/making-us-count/#supporting on 18/09/08.

Reid, K, Flowers, P and Larkin, M (2005). *Exploring Lived Experience*, The Psychologist, Vol 18, No.1.

Rennie, D.L (2000). Grounded theory methodology as methodology hermeneutics. *Theory and Psychology*, 10, 481-502.

Salmon, P (2003). How do we recognise good research? *The Psychologist* (16, 1) 24-27.

Scaife, J. (2004) Reliability, validity and credibility. In Opie, C. (ed.) *Doing Educational Research: A guide to first time researchers.* London: Sage Publications.

Shah, R. (1992) *The Silent Minority: Children with Disabilities in Asian families,* London: National children's Bureau.

Sharif, S (2001) Parents and Youth: Perceiving and Practising Islam. *Journal Institute of Muslim Minority Affairs* 5 (p20-28).

Sloper, P and Turner, S (1993) Risk and Resistance factors in the adaptation of children with severe disability. *Journal of Child Psychology and Psychiatry (34)* 167-188.

Smith, J.A. (1997) Developing theory from case studies: Self-reconstruction and the transition to motherhood, in Hayes N (ed) *Doing Qualitative Analysis in Psychology.* Hove: Psychology Press.

Smith, J.A., Jarman, M. and Osborn, M. (1999) Doing Interpretative Phenomenological Analysis in Murray, M and Chamberlain, K (Eds), *Qualitative Health Psychology: Theories and Methods,* London: Sage.

Smith, J.A and Osborn, M. (2003) Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Methods.* London: Sage.

Smith, J A (ed) (2003) *Qualitative Psychology: A Practical Guide to Research Methods.* London.:Sage.

Smith, J.A. (2004) Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology, *Qualitative Research in Psychology, 1* (p39-54).

Starks, H and Trinidad, S, B (2007). Choose Your Method: A Comparison of Phenomenology, Discourse Analysis, and grounded Theory. *Qualitative Health Research.* 17 (10) p1372-1380.

Stopes-Roe, m. and Cochrane, R. (1990) *Citizens of this Country: The Asian British.* Clevedon: Multilingual Matters.

Thompson, M (1997). *Philosophy of Religion.* Illinois. Contemporary Publishing.

Todd, E (2003) Disability and the restructuring of welfare: The problem of partnership with parents. *International Journal of Inclusive Education* (7,3), 281-296.

Vertovec, S. Muslims, The State and the Public Sphere in Britain in Nonneman, G, Niblock, T & Szajkowski, B (eds) *Muslim Communities in the New Europe* (1997). Reading, Garnet Publishing Limited.

Wall, K (2003) *Special Needs and the Early Years: A Practitioner's Guide.* London: Sage Paul Chapman Publishing.

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

Willig, C. (2001) *Introducing qualitative research in psychology: Adventures in theory and method* Buckingham: Open University Press.

Willis, B (2007) Listening *to Parents of Children with Autistic Spectrum Disorder.* Unpublished Thesis. Sheffield University.

Wresinski, J. (1980) Une connassance que conduise au combat. In Kagan, C. & Burton, M. (2001) Critical Community Psychology Praxis for the 21st Century. Retrieved from http://homepages.poptel.org.uk/mark.burton/GLASGOXS.pdf on 14/05/09

Appendix

Appendix 1a-Partcipant Invitation Letter

July 2008

To Mrs H

As part of my doctoral training at the University of Sheffield I am carrying out a research study on the views of second-generation Pakistani parents, who have children with special educational needs. The title of this research is:

What are the experiences of second-generation Pakistani parents, who have children with special educational needs?

I would like to invite you to take part in this research. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish

Purpose of the research

It is of vital importance that the views of parents are sought by professionals, particularly in regards to their children's special educational needs. As an educational psychologist, it is key to our role, to form effective relationships with parents, and hear their voice about their children, and how best to meet their needs.

I am particularly interested in hearing the views of minority groups, being a second generation Pakistani myself. In particular I would like to hear about the experiences of second-generation Pakistani parents, who have children with special educational needs. I think it would be useful to explore what factors you have found to be helpful in meeting your child's needs, and what factors have made it more difficult. I would also like to know what your views are about the services available to parents like yourself who have children with additional needs and what you feel is needed to form good effective relationships with parents.

The findings of this research will inform my doctoral thesis. I hope to, in the future, use the results and deliver them to a rage of professionals who work with families from minority backgrounds.

Why have you been chosen?

You have been chosen to participate in this project as you meet the criteria for the sample population, and it is felt that your views would be of great value for this research.

Several other parents will also be asked to take part in the research.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be contacted and a time, date and location for an individual interview will be arranged. You can still withdraw at any time. You do not have to give a reason.

What will happen during the research?

If you agree, and a time date and location is agreed upon, an individual interview will take place, in which your views will be explored. The interview will be centred around your experiences of services available for children with special educational needs. You would only be expected to volunteer information you feel comfortable discussing, and if at any point you wish to withdraw, you will be able to do so.

Further to this interview, you will also have the opportunity to meet with other second generation Pakistani parents who have children with special educational needs, as part of a focus group. Within the focus group there will be a chance to further explore issues relating to experiences of being a second generation Pakistani parent with a child with special needs. However, if you not wish to meet with other parents and discuss these issues further, you do not have to.

It is hoped that this work will benefit the families of children with special needs from ethnic minority backgrounds, by listening to and sharing the experiences of parents like yourself.

Confidentiality

All the information collected about you during the course of the research will be kept strictly confidential. Your name will not be used in any reports or publications.

The audio recordings of discussions and interviews made during this research will be used only for analysis. No other use will be made of them without your written permission.

All records both recorded and written will be held and analysed by the researcher and will be destroyed appropriately on completion of the research. Only anonymised information will be shared with other professionals.

All information discussed in the focus group is confidential and if you do wish to take part, it would be expected that you would abide by the governing confidentiality rules.

The research will be published as a University Thesis (DEdCPsy Educational Psychology)

This research forms part of the DEdCsy (Educational and Child Psychology) Course at The University of Sheffield. The research has been ethically approved via the University of Sheffield School of Education department's ethics review procedure (every academic department either administers the University's Ethics Review Procedure itself, internally within the department, or accesses the University's Ethics Review Procedure via a cognate, partner department). The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

Please contact for further information:

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I shall be contacting you shortly to find out if you do wish to partake in this research.

Finally thank you for taking the time to read this information sheet.

Yours sincerely

Samana Shah

Trainee Educational Psychologist

Appendix 1b: Focus Group Letter

Our Ref: EPS//
Date:

Dear Aneesa

Following our individual interview and phone conversation I would like to invite you a focus group on **Monday 17th November at 1.00pm at Normanton Town Hall- Block C (Please find enclosed map and directions).**

As part of my doctoral training at the University of Sheffield I am carrying out a research study on the views of second-generation Pakistani parents, who have children with special educational needs. The title of this research is:

What are the experiences of second-generation Pakistani parents, who have children with special educational needs?

All information discussed in the focus group is confidential and if you do wish to take part, it would be expected that you would abide by the governing confidentiality rules.

Confidentiality

All the information collected about you during the course of the research will be kept strictly confidential. Your name will not be used in any reports or publications.

The audio recordings of discussions and interviews made during this research will be used only for analysis. No other use will be made of them without your written permission.

All records both recorded and written will be held and analysed by the researcher and will be destroyed appropriately on completion of the research. Only anonymised information will be shared with other professionals.

The research will be published as a University Thesis (DEdCPsy Educational Psychology)

This research forms part of the DEdCsy (Educational and Child Psychology) Course at The University of Sheffield. The research has been ethically approved via the University of Sheffield School of Education department's ethics review procedure (every academic department either administers the University's Ethics Review Procedure itself, internally within the department, or accesses the University's Ethics Review Procedure via a cognate, partner department). The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

I look forward to seeing you.

Please contact for further information:

Samana Shah
Educational Psychology Service,
Normanton Town Hall,
Normanton,
WF6 2DZ

Yours Sincerely,

Samana Shah

Trainee Educational Psychologist

Appendix 2: Participant Consent Form

Participant Consent Form

What are the experiences of second-generation Pakistani parents, who have children with special educational needs?

Name of Researcher: Samana Shah

Participant Identification Number for this project:

Please tick box

1. I confirm that I have read and understood the information letter for the above project and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐
   Contact number for researcher:
   Samana Shah: Trainee Educational Psychologist Tel: 01924 307403

3. I understand that my responses will be anonymised before analysis. I give permission for members of the research team to have access to my anonymised responses. ☐

4. I agree to take part in the above research project. ☐

Name of Participant	Date	Signature

If willing to take part:

1. Please give any dates (holidays etc) when you are not available.

2. Preferred time (morning*/afternoon*/evening*)

3. Any days not available?

________________ ________________ ________________

4. Telephone number______________________________

5. Any other relevant information

Signed______________________________
Date______________

(* please delete as appropriate)

Please return to Samana Shah, Trainee Educational Psychologist,
Educational Psychology Service, Normanton Town Hall, Normanton, WF6 2DZ.
Thank you for returning this slip.

Appendix 3: SEMI STRUCTURED INTERVIEW SCHEDULE

- **Tell me about your child's special educational needs**
  Your feelings-what do you perceive as your child's SEN?
- **Tell me about how you became aware of your child's special educational needs.**
  Who first raised concerns? Your feelings during this time?
- **Tell me about early support**
  Support from family/community/professionals
  Knowledge of services?
  How have family/community responded to your child's special educational needs?
- **What are your views on your child's special educational needs?**
  How do you personally view your child's needs?
  How do your views compare to the "professionals" view?
  Do you think they are similar/different? Why?
- **What are your views on your child's learning?**
  Your child's capabilities?
  Your child's potential?
  Your personal aspirations for your child?
  Your personal expectations?
- **Tell me about the reactions of others**
  Family
  Siblings
  Your partner
  Friends
  Professionals
  Community
- **How do your own views compare to the views of others?**
- **What sort of experiences have you had within the community?**
  Positive-in what way?
  Negative-in what way?
  Religious support?
- **HYPOTHETICAL QUESTION: What kind of experience do you think your child would have had, if he/she had been educated in Pakistan?**
  Your own personal experiences of education
  How was your education viewed within the community?
- **What are your experiences of services involved in supporting your child in Wakefield?**
  Experiences of social work/portage/hospital/EPS
  What worked well?
  What did not work so well?
  Were there any barriers?
- **Which services were of most benefit? Why?**
- **Are there any improvements necessary? How?**
- **How could services be improved?**
- **Tell me about your own coping mechanisms/strengths.**
- **Tell me about your concerns about the future.**
- **Tell me about your hopes for the future.**
- **Any other issues?**

Appendix 4: Focus Group Schedule

- Welcome and Overview of study given. Confidentiality Issues Stressed.
- Group Introductions
- What is your understanding of Islam's teaching on disability?
- Do you feel Islam's teachings on disability have been reflected from the Muslim community you live/associate with?
- What have been your family's responses to your child's special educational needs?
- Thinking about the professionals you have encountered, what have your experiences been regarding their understandings/perceptions of the Pakistani Muslim community?
- How has being a second generation Pakistani Muslim influenced your experience of being a parent with a child with special educational needs?
- What has helped improve your experiences?
- What has made your experiences more difficult?
- What hopes do you have for the future?
- Summary of main points.
- Have I missed anything?
- Discussion of plans for the future of the group.

Appendix 5-Example of analysis

Reflections of overall text	Reflections	Transcript	Super-ordinate Themes
Desire for diagnosis	Mum has an understanding of her daughters main needs as being mobility related.	Mobility, yeah. Her gross motor's really you know, it's quite delayed and for [unclear] needs to be about a year now she started bottom shuffling so one of the **main goals of the staff at the nursery is like just to encourage her to like stand and to try to move about and things like that.** Yeah, that seems that, that is one of the main issues.	
Frustration with service providers Better service in PKK	Mum unhappy with services in the UK that she went to PKK-felt like she could get better service there?	Well first, to be fair, **we got the diagnosis diagnosed her in Pakistan. That's one of the issues that I'm not very pleased with, you know, because we waited about nine months.** The health visitor first diagnosed something was wrong with her. This was about nine months old that she hadn't… nine months I spoke to Maltby [?] Health Centre and she first pinpointed that, you know, [phone ringing] something's not right.	Personal Feelings Perception and Experience of Service Providers
Frustration with service providers Strong desire for diagnosis	Mum has had concerns for a long time. Mum dissatisfied with the initial responses she got from medical staff in this country. Sense of mums frustration.	**There was like a question mark that, you know, next to her thinking why isn't she walking, why isn't she crawling at nine months?** And then we started having appointments to see the specialist at the hospital, Doctor Tarfiq [?]. He's a human [?] paediatric and even then he did all the tests and everything and he said that, **oh, some children are delayed but I gather there were no like proper answers.**	Perception and Experience of Service Providers Personal Feelings

Frustration with service providers Diagnosis results in better understanding of child	Mum frustrated with waited-goes to PKK-but has it confirmed in the UK-wants both opinions. Goes to PKK to get the service that she wants. Diagnosis form PKK kick starts the support in the UK.	And they said to us that they'll carry out a CT scan and an MRI **but we waited nine months then eventually went to Pakistan and had it done from there,** an MRI where we were told that she's got a condition called Joubert Syndrome. **When we came back here they analysed the reports again and confirmed that yeah, she has got, she has got and that's when everything got… you know, came to highlight that she actually had… that she's a special needs child.**	Personal Feelings Perception and Experience of Service Providers
Frustration with child	Delay-waiting-increased mums frustrations. Pleased with lots of diff agencies involved but frustrated that no concrete answers were given. Strong need for a diagnosis-want to know what it is "wrong" with her so that they can help her.	There was so much delay in getting results in this country. We were just on a waiting list and the physio would come home. We'd had all the **different like agencies involved**, like physiotherapy and the health visitor, and things like that **but again we're getting no proper answers so** we… **you can only help a child when you actually… when you know exactly what's wrong with them.**	Perception and Experience of Service Providers Personal Feelings
Initial denial Perceived better service in PKK	Mum angry with professionals. Told that her daughter was "normal" so therefore got very frustrated with daughter when she was not able to walk.	You know, we were like pushing her, you know, and there'd be some days like I'd get so frustrated, **I'm thinking God why can't you sit, you know, why, well why can't you hold a bottle? You know, others does those things, why can't you? But, from my point of view, she were like a normal child because obviously that's what the health visitor told us, oh**	Personal Feelings

Desire for Diagnosis	Optimism-that delay is something that she will overcome. To get what she wants-mum HAD to go to PKK. Going to PKK helped relive mum's anxieties-she got what she wanted when she wanted it.	she could be delayed, some children are delayed but, **you know, she will eventually catch up**. **So we thought well the only way to get results is if you go out**… if you go private and obviously, going private in this country costs a lot of money. And my husband's got a whole family in Pakistan so we went to Pakistan and **we went to the backdoor from there.**	Personal Feelings Perception and Experience of Service Providers
	Quick and fast-issue of being able to have the money to get what she wanted.	To be fair in Pakistan, it's just a case of you paid them and you get the job done. [laughter] It might sound a bit harsh and, you know, a bit unfair but it's the way it is. **We paid them and within like a couple of days they gave us an appointment, and we went there and we got the class… test done and we got the results in like I think 24 hours we got the results.**	Perception and Experience of Service Providers
	Paying enabled her to get what she wanted-Mum wanted to know-wanted answers.	Yeah. It's just a case of paying them, you know, to do all the analysis and everything and just getting the results.	

Support from family Medical Model Desire for Diagnosis	Has additional support form her brother who is a GP. Brother is able to get the ball rolling for her. Additional support and understanding available because her brother is a doctor. "Answers" Make sure no mistakes-does mum want it confirmed from someone in the UK?	Well what it is, **my brother, he's a GP** at Midland [overtalking]. We first showed him the reports and obviously, you know, he said there, you know, **that she's got Joubert Syndrome and explained about cerebella and everything and, you know, what's lacking up… you know, developed inside her brain and everything.** Then **he wrote a letter to the paedio-specialist [?], Doctor Tarfiq, and then they sent us an appointment to see him** and to see the genetics department, who was Doctor Joss from Leeds that came and they, again, looked up the reports and **everything and the MRI just to make sure there was no mistakes and they just confirmed what we'd already been told.**	Family and Community Relationships Perception and Experience of Service Providers Personal Feelings

Appendix 6: Religious Responses to Disability Quotations

Appendix No 6:	Source	Quotation
6:1	Mrs H Individual Interview	*"It's places where, you know... where we go for like peace of mind and the places where, um, religious people [unclear] Allah have been buried, who have been worshippers of God in a good way and people just go there and basically pray in front of them just for health and happiness and peace. That's one of the reasons why I want to go, yeah."*
6:2	Mrs K Individual Interview	*"he wants to go to Pakistan now, they have special places like Durbar and stuff like that, go round there and maybe doing a couple of things for her in Pakistan might help. It might help some people but, I think if we do try it might do, but you never know really."*
6:3	Naveen Individual Interview	*"I know he has a friend who has got some sons with special needs, he like goes and pays three and four hundred pounds and gets jars and stuff to heal, they have these special powers and you know it's that healing and sometimes people can be mislead. Its silly. Well I don't know if its silly."*
6:4	Naveen Individual Interview	*"..in my heart, I suppose, I think... I've never got the tawees and stuff because I think at the end of the day it's in God's hands and, you know, you can... you should pray to God and that's it."*
6:5	Naveen Focus Group	*I think that if God's made your child like that then, you know, what's this water going to do*
6:6	Mrs Q Individual Interview	*"I think Allah can do anything, He can do, Allah, He is Allah, mercy, you know. Allah wants to give somebody this, so we accept it. What we can do? Nothing."*
6:7	Mrs H Individual Interview	*"He brought us onto this earth and He brought my daughters onto this earth."*
6:8	Mrs H	*"I've got faith in him up there, you know. If*

	Individual Interview	*he's put me in that situation then he's going to get me out of the situation."*
6:9	Aneesa Focus Group	*"My religious side was quite shaken when all this happened, because the emphasis that was put onto me, that God's doing this to you, that made me think differently in God. So my religion was quite shaken for a short time, which is okay for me to accept that now, that it doesn't make me a bad person."*
6:10	Mrs H Focus Group	*"People have said it. God's children don't commit sins but it's you as parents who have committed sins and that you're getting punished for it now."*
6:11	Aneesa Focus Group	*"I've always been able to pick up the strength and say they're wrong and that they have no right to say that and they can think otherwise."*
6:12	Mrs H Individual Interview	*"I just believe that it's a test from the last plan of the Allah Abult he loves us and loves my daughters [crying] I just think it's a test, a very hard one but I think it's going to be one that we'll get through. Inshallah, yeah."*
6:13	Aneesa Focus Group	*"And Niggat said you know this is our Hajj. Bringing up our children and raising them is our Hajj. Its from Allah to see how to see how you cope."*
6:14	Aneesa Individual Interview	*"I'm not really religious, only what I ever used to do when I went to the Mosque, but I contacted a few people and found out what he does is wrong with just dumping us and the comings and goings, and it was kind of like brought to everyone's attention."*
6:15	Mrs H Individual Interview	*"I discussed it with my mum and me dad, and what they suggested was that we go see like a scholar, an Islamic scholar, and see what he says in terms of like, you know, what the Islamic rules are about*

		terminations."
6:16	Aneesa Individual Interview	*"I don't have a problem with praying, I'm not anti-Islamic or anything – we have religion, we are Muslims and we practice it, and Hussain mashallah is so very good as well."*
6:17	Mrs H Individual Interview	*"Being Muslim, you'd think they'd be more understanding but they're not."*
6:18	Naveen Individual Interview	*"I didn't look into it because I didn't know if it was a religious thing or if was just... you know, you hear people say it, so if it's more of a cultural thing. Because the line is so narrow, isn't it?"*
6:19	Mrs K Individual Interview	*"that's like our as parents its our furz (duty) to teach your children Arabic and make sure they attend the mosque so they learn the Koran and I know possibly she couldn't learn."*
6:20	Mrs Q Individual Interview	*"I think personally when you've got a disabled child they don't think of asking you if you want to bring your child to mosque. It's like if you've got a disabled child, right, you're out, you know."*

Appendix 7: Family and Community Relationships Quotations

Appendix No 7:	Source	Quotation
7:1	Mrs H Individual Interview	*"me mum was really helpful... me mum and me family. Me youngest brother was, you know, who I said is a GP, he's been really good, you know, since we found out. They all live near me as well which is really makes things helpful."*
7:2	Mrs K Individual Interview	*"they would actually try and help out as much as they could. If I go over they will just try and help out".*
7:3	Mrs H Individual Interview	*"I've got other, you know, aunties and uncles and things who I really miss and who, since I've had Fatima, they're like... they've been quite worried about me, how I'm coping and things and just to keep... just for their peace of mind really that, you know, I'm not in such a bad state and them being so far away, they think that I live under have... you know, how bad it is for her, and just for a break really. I could do with a break."*
7:4	Mrs H Individual Interview	*"I think if she didn't have the arthritis, she'd probably like actually bring up one of the girls for me."*
7:5	Mrs K Individual Interview	*"Well, they couldn't really do much because they've got their own lives to lead really."*
7:6	Mrs H Individual Interview	*"they'd used to come out every evening, they'd all come down and used sit with me and stuff and try to be supportive but, you know, as time goes on, and people have got their own lives to lead."*
7:7	Niggat Individual Interview	*"I've got a fair sized family. Yeah. I mean, you know, if I have to go and spend time with the other kids or I need to take Hussain they'll look after the other kids and they'll have them on, like, weekends or, you know, so... But No, I still would access stuff from services."*
7:8	Aneesa	*"I was unattached and I couldn't bring any*

	Individual Interview	*of the issues home. Nobody would understand and I couldn't discuss them with my family. You are pulled away from the support from home because the understanding from them isn't actually there of what you are doing and why you are doing it."*
7:9	Aneesa Individual Interview	*"The understanding even now isn't there, all these years on. The family all these years on have had all the literature in Urdu from the National Autistic Society."*
7:10	Aneesa Individual Interview	*"Up to this last year I've stopped sharing because it does have no effect like if he is doing anything I can't make them understand anymore. I have a lot of pride, I don't ask people to help in that respect, so that's the kind of situation we had with him."*
7:11	Aneesa Individual Interview	*"They have never had them to babysit or anything, they have always gone to holiday care in school holidays."*
7:12	Naveen Individual Interview	*"To be fair, when we first found out about Ayesha, my mother-in-law was here and she did make my life... she made my life quite difficult, to be honest with you. You know, she started coming out with things like, oh well my... how did I know my son would get punished and he's been married to you and this, this and this and all this rigmarole she came out with, but after she went, I found it a lot easier to cope with after she'd gone."*
7:13	Niggat Focus Group	*"So we've got quite a good understanding of Hussain's needs and stuff. He's from here anyway so... We've both been brought up here so we've got a good understanding as well."*
7:14	Mrs H Individual Interview	*"we were in that position, not them,"*
7:15	Naveen Focus Group	*"That's really good that you get that support from your husband and you can face them together."*
7:16	Aneesa	*"When you've been in this country for so*

	Individual Interview	*long, you are naturally going to embrace the way of working here."*
7:17	Naveen Individual Interview	*"You are more aware I think that's with the western upbringing. It's harder for me as I have got more English/western values as well. I'm lucky that he's not like completely, you know, like, he is a little bit okay, but it's still that mentality, you know, there's still a very different opinion, but he's sort of half way there, sort of thing. he's got his embedded values there and, you know... He has acclimatised a little bit but he is still embedded in that way of thinking you know. And values form there."*
7:18	Aneesa Individual Interview	*"I expected it from the time that he was diagnosed at two and a half years, but my husband's been way behind of accepting it, even to the point of letters come through the post, it was like, it's all in your head.. I think it's upbringing. There's no blame on anybody it's just the way it works – somebody works this way, somebody works that way."*
7:19	Aneesa Individual Interview	*"He's from Pakistan. That's an ongoing difficulty because I can't even get him to appointments with me, he doesn't believe in going to see people, he will go and pray and he thinks that it will be ok. If he goes to the Mosque an prays that is his way, he thinks it is going to help Zain with his bedtime routine, so I'd go and see a Psychologist who can help him stop self-harming, I need some "hands on" approach to this, I need some strategies that are going to help me so what his dad is doing isn't going to help."*
7:20	Aneesa Individual Interview	*"Our approaches are totally different. My understanding has got deep. I am working with the system because these are the people Zain's is with six or seven times a day and they are doing strategies and I want them to do the strategies if they are working and I want to use them and learn how to do it. We can't just shut the door and say we don't want that."*
7:21	Aneesa Individual	*"I mean, my husband's views were, don't take him to the appointments, just get a*

	Interview	*prayer mat out and start praying, and pray for what you want and these doctors are not going to help you, physio won't help you, speech and language aren't going to help you, what are you going to the appointments for?"*
7:22	Aneesa Individual Interview	*It's a respite place in Wakefield, but it was battling with his Dad. He puts it on me emotionally to be honest and then you just give up, because it's like "Do you really love your child to be sending him away?" and I think "I'm up at crack of dawn and I'm knackered and you're at work, you don't understand."*
7:23	Aneesa Individual Interview	*"He's saying that, you know, the shatan (devil) is making him do it. Do you know what, get over it mate, you're so, so thick."*
7:24	Aneesa Individual Interview	*"The bigger thing is that for the last three or four years I have been on anti-depressants. It was about two years ago that I tried to kill myself and that was when he realised. He wasn't distraught by it, he was constantly putting me down saying why are you on this, you don't need to be on this... you should be asking God and you should be doing this. Even then his approach was he consulted with members of his group and they said that in your house you probably have to have onions to scare the Jin away and stuff like that, and I was kind of like get away from me, you freak."*
7:25	Aneesa Focus Group	*"He needs a brain transplant. At the moment I've been going through a separation. I exhausted myself now I've come to the point, it's like, you know, I'm not willing to do it any more. Even if he wants to educate himself he's got to go and do it off his own back; I've got two kids to take care of."*
7:26	Niggat Focus Group	*"If you're out and about in a group or anything like that, the first thing they'll do is look at the child in the wheelchair and then they'll discuss it between themselves and it's like, you know, he's still my child,*

		he's still normal for me, the same as my other two children."
7:27	Aneesa Focus Group	*"And people look at you, and especially when he's creating and he's, like, grabbing every rail going past and that, grabbing every person and trying to push people out of the way. People look and stare."*
7:28	Naveen Focus Group	*"I think it's worse... at least like the white people have got a little understanding compared to our lot."*
7:29	Niggat Focus Group	*"They say things like at least you should be grateful that she hasn't got a physical disability or bent arm or leg. It gets me so mad. At least the white community don't say that to you. Or they might say how is she or she seems much better today. That sort of thing."*
7:30	Mrs H Individual Interview	*I do have people staring but not that much, but if she does it in like where there's a lot... the majority of people are Pakistanis, they'll all like stop what they're doing and just like stare. And then she knows she's getting that attention and she'll do it more, and then obviously then we find it hard to control her because we know that all eyes are on us. I've had people stopping me in the middle of the street and saying, is Hina walking yet? If she were walking, why would I be carrying her? You know what I mean? It's a question that they've got answers to but it just like they get some sort of buzz out of, [laughs] I don't know, upsetting me or something or...*
7:31	Mrs H Individual Interview	*"It's been awful. (reaction from Asian community) It's been really, really awful and that's one of the reasons why I've not sent Hina to Lawefield School... I mean it's a good two mile trek from here to Castle Grove but it's a sacrifice that we have to make for their sakes so they don't have to put up with all that".*
7:32	Aneesa Focus Group	*"I live in an old coal mining area [unclear] people. There are really backwards people there. Especially in their thinking. They*

		haven't been exposed to Asian people, let alone an Asian people with a screaming child in an oversize framed buggy, you know, it's kind of like a complete different concept."
7:33	Aneesa Focus Group	*"So in one way I think I'm in a better situation when I can be like see you later kind of thing. Whereas you might not do that. You might be a bit more, mm, you know, we can't say that. They'll tell your relations and it will just come back to you."*
7:34	Aneesa Individual Interview	*"It's not acceptable in society, but in our society, it is enough for them to be shut out."*
7:35	Mrs A Individual Interview	*"You know, they just see it as that, oh, is he not better then?"*
7:36	Naveen Individual Interview	*"They say things like God will make her better and all that they don't look at as a long term thing they hopefully feel oh well, where as I feel if she gets to the point where she can think like an 11 or 13year old even when she is an adult to me that to me would be significant."*
7:37	Naveen Focus Group	*"It's just never discussed, I think. Nobody brings it up and things. If you're in our culture, like, it's never discussed about disabilities. That's my own personal view and experience. Nobody really approaches the subject."*
7:38	Mrs H Individual Interview	*"They don't really think in depth, so if someone does ask me, I just say they've got weakness, they've got weakness in their leg muscles, that's why they're not walking. I don't tell... I don't go beyond that. People that should know like me own family, I've told them but I don't think it's anybody else's business really."*
7:39	Mrs Q Individual Interview	*"In my experience family has such a big impact. The majority of Asian people have that big family influence. So sometimes you've got to kind of like put your feelers out. You can't just go up to people, And I think I would do for both, to be honest with you."*

Appendix 8: Personal Feelings Quotations

Appendix No 8:	Source	Quotation
8:1	Aneesa Individual Interview	*"I've built this wall around me and there's only me and the kids now. Anybody else is full of crap and you keep your opinions to yourself. It makes you a bit more hard, if that makes sense."*
8:2	Naveen Individual Interview	*"I was in floods of tears and thought gosh, , but I think it was just like her future and I were like thinking god if I wasn't here what is going to happen to her in the future, she would not know who to turn to."*
8:3	Mrs K Individual Interview	*"I don't really have a support network at all, you know. so I just tend not to go anywhere any more and I just sort of stay at home by myself."*
8:4	Aneesa Individual Interview	*"And basically knowing I have to do it because nobody bloody else will. I find it very hard going to meetings sometimes. You really have got a lot of clout going there and doing it yourself. Meetings alone."*
8:5	Mrs K Individual Interview	*"There's no way of coping really, every day is different really you don't know what to expect so some days might be good, some days might be bad."*
8:6	Mrs H Individual Interview	*"Like this morning I really, really struggled, you know, to bath the girls and, you know, to clean the house and everything."*
8:7	Mtrs H Individual Interview	*"Everybody else would be thinking, what we're going to wear or what we're going to do with this and we'd be thinking, how are we going to cope? It has been very, very difficult."*
8:8	Niggat Focus Group	*"It is hard work and nothing prepares you for it. Emotionally and mentally you are constantly tired and drained. They just don't realise, you know, how difficult it is sometimes"*

8:9	Mrs H Individual Interview	*"You know, if you're hurting, just see... just think how much I'm hurting."*
8:10	Naveen Individual Interview	*"It can be quite soul destroying if you let it."*
8:11	Aneesa Individual Interview	*"The bigger thing is that for the last three or four years I have been on anti-depressants. It was about two years ago that I tried to kill myself and that was when he (husband) realised. They upped it from four to eight hours a month, but it's crap that it had to come to that. I had to try and top myself to get that! For somebody to think, wait a minute, this woman needs more help."*
8:12	Naveen Individual Interview	*"I don't want him in the future to say you made those decisions on your own and they were the wrong decisions. Especially at that time you feel that you have enough pressure without added pressure or being alone to make decisions, life changing decisions."*
8:13	Naveen Individual Interview	*"The only reason he attended the statement meeting that shows which school Ayesha went to, that's because I didn't want to accept full responsibility, it wasn't, I felt up to me to make that decision and that's why I made sure he went with me."*
8:14	Aneesa Individual Interview	*"In case it goes wrong, and then you're to blame. It's all right whilst it's all going nice, and as with any child, as soon as it goes wrong, oh, it's the mum's fault."*
8:15	Mrs K Individual Interview	*"we are still worried that we don't know what's wrong with her, why, and how to help her because we don't know what's actually causing this. If they knew, we would know what to look forward to and what's going to happen."*
8:16	Mrs H Individual Interview	*"We'd had all the different like agencies involved, like physiotherapy and the health visitor, and things like that but again we're getting no proper answers so we... you can only help a child when you actually... when you know exactly what's wrong with them."*

8:17	Naveen Individual Interview	*"It's like a game and when someone asks you what's wrong with her and she looks perfectly fine and it is quite difficult to sort of say, oh well, you have to say she has a learning difficulty."*
8:18	Mrs H Individual Interview	*"And it's got to be one of the worst day of your life. You know it's like a great big, you know, [laughs] it's like a great big burden suddenly on you It was devastating. It was absolutely devastating. I wouldn't wish that on any, anybody."*
8:19	Aneesa Individual Interview	*"You realise that it's not just your child's life, it's your life that's been changed as well. It's for the worst in the way. At that moment in time for me I couldn't read any of the information. It was going way over my head because I was just fixed on what she'd told me – the life-changing decision that three professionals had made in a multi-disciplinary. I'd know that they were working towards something and he was being assessed, but then to just give it to you one day in an appointment without even being prepared."*
8:20	Naveen Individual Interview	*"I think even like today, you asking me questions and me and my husband I don't think, I probably ever thought about it, like you do in the back of your mind but I probably haven't ever talked about them to anyone and no one has ever broached these topics before."*
8:21	Naveen Individual Interview	*"I think you know like for yourself you've got the same background and I wouldn't even have to explain some thing to you."*
8:22	Naveen Individual Interview	*"I am hoping to get to meet with some other mums to do, some research and then you know I am really looking forward to that and hopefully we can make something of that."*
8:23	Aneesa Focus Group	*"We've noticed there's a gap in the service, haven't we? It can be a very open forum and no specific disability or special needs either. It's going to be the parents' voice, it's going to be about what they want really."*

Appendix 9: Coping Mechanisms Quotations

Appendix No 9:	**Source**	**Quotation**
9:1	Mrs Q Individual Interview	*"I just think oh God, and pray and think God make Razia good, and nothing else."*
9:2	Mrs H Individual Interview	*"God forbid, but my husband is very religious. We just read our prayers now and hope for the best."*
9:3	Mrs H Individual Interview	*"We do pray a lot. We give... before we used to give to charity a lot but now I give to like, you know, organisations where, you know, children that are severely disabled and that's it. Yeah, we acknowledge children a lot more that have got disability."*
9:4	Aneesa Individual Interview	*"Friends. I wouldn't even say it's my family, it's my friends more than...My friends are my family."*
9:5	Naveen Individual Interview	*"And they said, oh, we know it's Auntie Jumi, you know, and I [unclear] that, because she's closer to me, my best friend, than my own sisters."*
9:6	Aneesa Individual Interview	*"And Zain said to me that time we went to your house, he goes, you're going to tell me something now aren't you? And I said, what? And he said, you're going to tell us, Nita, secretly Auntie Niga and Auntie Reshma are our family, aren't they? And I was like, oh, it was like kind of [overtalking] and I got quite upset."*
9:7	Aneesa Focus Group	*"And that's been kind of like fantastic for me because I've been able to take my kids in an environment to socialise with people who have got similar aged children, similar interests, and I can talk to the mums. And we've got a cultural understanding as well. And so, like, I've been really kind of like really kind of in a good position to do that recently. So that's helped us loads."*
9:8	Aneesa Focus Group	*"I take it with a pinch of salt now. I just ignore people. You have to really in order to survive."*

9:9	Mrs H Individual Interview	*"you just learn to cope. It's very, very hard to explain but I think just somehow you learn to cope and it... just somehow you learn to ignore people."*
9:10	Niggat Focus Group	*"But people they'll probably come and look at him and think, oh, what's wrong with him or, you know, why is he here or... you know, you get all sorts of questions asked, but you just get used to it."*
9:11	Naveen Individual Interview	*"I think because I keep myself so active and I'm so tired I don't have time to think and I think that's possibly worse you know and I can imagine people getting depressed cause if you are at home all the time and your child is at school and they come home and they are the only thing you focus on."*
9:12	Aneesa Individual Interview	*"I think understanding how everything and all the services fits together helps. I may not be so proactive and confident in saying things or doing things otherwise. I'd probably be sat at home chewing my own brains out! I'd probably be six feet under. I'd have lost my sanity! To be honest it's what's keeping me going."*
9:13	Naveen Individual Interview	*"I have had times when you feel like crying, then you just get over it you've just got to you're a mum you've got to look after the house, you've got three children and that and some of the time you don't just sit and think you just don't have the time."*
9:14	Aneesa Individual Interview	*"My husband spent a lot of time away from the family home because I think it was his escape away from facing the fact that there is a problem."*
9:15	Aneesa Individual Interview	*"The last time he went, we threw him out because it was the only way to say was you either face up to this or you go for good because this coming and going is not leaving any set structure for my child and it's actually unsettling because it disrupted his routine and he needs his routine to be quite in a certain way."*

9:16	Naveen Individual Interview	*"I'll do that where as I might have to ask or talk to my husband and take time you know to talk to him at the appropriate time to talk to him like some might just say yes to I might take a week to get the answer."*
9:17	Aneesa Individual Interview	*If he goes to the Mosque an prays that is his way, he thinks it is going to help Zain with his bedtime routine, so I'd go and see a Psychologist who can help him stop self-harming and actually it isn't, I need some "hands on" approach to this, I need some strategies that are going to help me and his brother because he goes into a mode of hitting people, he attacks everybody, so what his dad is doing isn't going to help.*

Appendix 10: Perception and Experience of Service Providers Quotations

Appendix No 10:	Source	Quotation
10:1	Mrs H Individual Interview	*"Speech and language and physiotherapy, they have been brilliant. They've been God sends and thirdly I think Castle Children's Centre. They have... one, they have given me time to myself and secondly they've really helped Hina come on."*
10:2	Naveen Focus Group	*"Every day whilst Alicia went to Pathways, for that year and a half I had her, she was my support."*
10:3	Naveen Focus Group	*"You see, I still meet her for coffee. She's coming on Eid. She's fantastic. Really, really good and she's found that really embraces everything. Especially that anxiety that you naturally have as a mum. She just totally understands it and embraces everything. You know, she went out of her way, she'd ask about the cultural side of things. You know like she's been to ours to eat, I've invited her to something, you know Eid days and stuff."*
10:4	Aneesa Focus Group	*"And like you said, some people wear their hearts on their sleeves. They're not interested in the hourly pay, they're actually quite passionate about what they're doing. Yes, that genuine interest and that feeling of, you know, that they do care."*
10:5	Aneesa Individual Interview	*"The biggest battle of the moment occurred to me yesterday, which sent me into panic mode and it's while I work he goes to holiday club, which we pay for his place and the Pre-School Learning Alliance put a worker in and they pay for this but their argument is that they haven't got that kind of funding any more. It's just so poor, it's dire and now it's going to go to some Panel to decide if I'm entitled to basically working part time and having him there."*
10:6	Niggat Focus Group	*"To be honest people are battling, you can't get anything unless you've got a Social Worker. Social Services have closed books basically. So if you haven't got a Social*

		Worker you can't even access any service."
10:7	Naveen Individual Interview	*"They came out to see me and after been on a waiting list for about a year she could do like an art club every other weekend. It took me ages to talk to my husband about it then it took a year to get it."*
10:8	Naveen Individual Interview	*"I said don't tell your dad to begin with. But it just makes it that little bit harder when you've got a barrier in your home and between the professionals."*
10:9	Aneesa Individual Interview	*"There has been only one incident where his respite worker saw marks on him. Later on it made me a bit angry because I was trusting these Services. Had his Social Worker not known about the self-harming and I had nobody to back me up then it would have been just me and my word and that would have been damn difficult. That was another reason for my husband to turn round and say told you so."*
10:10	Niggat Focus Group	*"Yeah Hussain loves it there. If you could you would love to live out there, but you can't; it's just not... there are no services for them over there."*
10:11	Naveen Focus Group	*"I mean I've been to Pakistan and seen people that are really old with dementia and they've like got them tied to beds and stuff, to stop them from moving around and I think, you know, that's no life... you know, there's just no understanding at all, is there?"*
10:12	Aneesa Focus Group	*"They're only where this country was in the fifties, they lived in institutions, do you know what I mean"*
10:13	Mrs H Individual Interview	*It would be very, very difficult, a bit of a struggle because they've not got agencies there like here, you know. They haven't got like, you know, speech and language and physiotherapy and things like that. And a child with special needs, God forbid. I'm so grateful that I was born in this country and I'm so grateful that this government, that they have set up schemes and they are so*

		understanding when it comes to children with special needs. I'm very, very grateful.
10:14	Mrs H Individual Interview	*"There were no like proper answers. And they said to us that they'll carry out a CT scan but we waited nine months then eventually went to Pakistan and had it done from there. They did the scan where we were told that she's got a condition called Joubert Syndrome. . So we thought well the only way to get results is if you go out. And my husband's got a whole family in Pakistan so we went to Pakistan and we went to the backdoor from there."*
10:15	Mrs K Individual Interview	*Yes he can speak it as well, little bits and bats, he sometimes though if they talk too quick, he's a bit like, what did she say? He asks me sometimes, but he says that why are they all coming in and asking the same questions saying that? I go always to the meetings and take the kids by myself, and he never comes. I find it easier because he would just confuse everybody.*
10:16	Naveen Individual Interview	*"And it isn't that he doesn't want to go, it's just possibly that his English isn't up to scratch, because you've got to understand the nitty gritty of it. Possibly if it was in Punjabi and they were explaining it then maybe. When I go to all the meetings it is all English speaking people and a lot of times they use abbreviations and jargon and he wouldn't understand, where as I, because I'm a governor and have got links with schools, health and all that thing I probably deal with it in that sense."*
10:17	Naveen Individual Interview	*"But when there is a meeting with 6 or 7 professionals I suppose he can feel quite intimidated and you can't voice your opinion or really understand what they are talking about."*
10:18	Naveen Individual Interview	*"He did attend one and he did ask his own questions, although his English is not that good, but he did raise his own concerns and we both went to see the schools together. Straight away we both felt comfortable about the same high school. It was the best*

		decision I ever made."
10:19	Aneesa Individual Interview	*"I think for parents who haven't been brought up here it could be quite scary for them to go into a situation; the confidence might not be there. Luckily I have got enough education in the sense of if I really needed something I know where to turn to. If I didn't speak English or something or if it was the other way round and my husband was from here and I was from Pakistan, he would not have had the support he has now."*
10:20	Aneesa Individual Interview	*"Interpreters that don't charge an arm and a leg, so you don't feel guilty about having one. Services then wouldn't be scared to access it thinking there's going to be some kind of yearly contract."*
10:21	Naveen Individual Interview	*"I will go and then come home and explain things, I'll either answer or find out for him. Then sometimes I'll have to go back to another meeting and say that my husband doesn't agree with what we said."*
10:22	Aneesa Individual Interview	*"And then being an Asian woman, they will put you in the box of the majority, Asian women that may not perhaps be as vocal as... You know, and so they'll think you'll be a good old Asian woman, just sit back quietly. Mine are shocked that I talk, that I've got a view."*
10:23	Aneesa Focus Group	*"I've been going through a separation and it's like, does that actually happen in your culture? And it's like, do Asian people do that? Just take the Asian bit out and just treat me like a person, please, do you know what I mean?"*
10:24	Aneesa Individual Interview	*"I remember the shock horror of this one doctor's face that we went to see once and she just automatically assumed that I was a housewife. There is nothing wrong with being a housewife but just don't assume that I am."*
10:25	Aneesa	*"Although people don't directly say it to you*

	Individual Interview	*.They have the thinking that you have the same support network as everybody else. You're living with your mother-in-law and your mother-in-law's taking care of everything – she rules the roost and this that and the other but in fact it's a different extreme which is bloody damn harder really – I could do with a nagging mother-in-law! And probably I can't do with having to come home and do the cooking."*
10:26	Aneesa Individual Interview	*"I like to take someone with me to confirm what I am saying-that I am a busy mum and that I do work and I'm not a housewife and do need the support."*
10:27	Naveen Focus Group	*"Do you think that's appropriate? No, no. They'll all be gossiping won't they about it. Also the fact that you're going to an apna man, that everyone knows in the community and sat in an office you can't, you just can't, it's like perceived wrong."*
10:28	Naveen Focus Group	*"And I feel that we've lost out really because he'll send me invitations to meetings and stuff and that and I think, well, if I go my husband's going to say, you know, why are you going. He has probably got all the information for me but I can't approach him."*
10:29	Aneesa Focus Group	*"I have a white social worker, but her manager's an apna (one of us). He actually imposed his views on a situation, on something that wasn't religious. It was cultural, and I think culture's such a personal thing, my culture to me, traditionally where I originate from in Pakistan, is going to be slightly different from yours and is going to be different from yours."*
10:30	Aneesa Focus Group	*"He thought she's the same religion as me. I know what to do here and he was soo wrong. And I thought, well, whoa, wait a minute, do you know what I mean? That is wrong. So having someone Muslim, from our community working with services isn't always helpful."*

10:31	Mrs K Individual Interview	*"They are saying because we are closely related as well, he's my cousin's brother so close families, Asian families are like that, we marry relatives they are like that really with their kids and they shouldn't really think it's like that because a lot of families are like that now. And I don't think everybody's ill."*
10:32	Aneesa Focus Group	*"Personally for me autism one hasn't met for the last year and a half, and when they did used to meet they used to meet in a pub, so culturally kind of fantastic for me! Particularly if I put that to my husband would have been a nightmare."*
10:33	Aneesa Focus Group	*"I wanted to get Jerona's mum to go. I wouldn't have dared have even asked her, because she's have thought, my God, you know, you're going in a flipping pub."*
10:34	Naveen Individual Interview	*"When she was bout 8 she had a man come knocking on the door, she had a female escort most of the time but if she was ever on holiday it was a male escort so you know I didn't feel comfortable, but would have allowed it, but my husband wouldn't have felt comfortable at all. If there was a male escort then we would have to take her to school ourselves."*
10:35	Naveen Individual Interview	*"I think some of the time I possibly do avoid things just because I can't be bothered to explain every time to people like with Kingsland School parents some of those parents were all white in that group, just explaining trivial things like to them they might think gosh she's going a bit OTT."*
10:36	Naveen Individual Interview	*"Cause they want to know more and more using you as a tool to learn things as well I have found that quite a lot. You might suddenly think god an hour later I didn't actually get anywhere in that conversation, but they have just found out loads of information about me which they yeah it's good but it's not you know the right way or helpful to me and I haven't learnt anything from it."*