

**Exploring the support needs of
Pakistani families with disabled children:
a participatory action research study**



A thesis submitted for the degree of Doctor of Philosophy

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Abstract

Pakistani families with disabled children are among the most disadvantaged population groups in the UK. Previous research has indicated difficulties with accessing support services as well as problematic attitudes towards disability within the Pakistani community. As no substantial improvement in their situation was evidenced since early studies in the 1990s, a participatory action research study was undertaken with six Pakistani families to explore how an action-oriented, emancipatory approach could facilitate them to explore their support needs and how these might be met, in further depth. An occupational justice perspective was used to clarify how cultural and familial expectations influenced family members' occupational balance and well-being.

After an exploratory phase in which all family members were interviewed and family interactions observed in their own homes, three action research groups were formed for women, men and children respectively. Each group carried out their own action research around their chosen topic. Through participation in the project the participants gained important skills as well as a better understanding of their situation and how they could be more proactive in improving it. Furthermore, the fact that all family members were actively involved in the project helped them to start implementing changes in behaviour and communication at home.

Key findings of the study were that the importance of faith in accepting the disabled child and dealing with negative community attitudes needs to be recognised and fostered; that the social model of disability needs to be more explicit about the influence of religion and culture on the lived experience of disabled people; that the central support need of parents is for practitioners to build up a supportive relationship with them as persons in their own right; and that (the lack of) belongingness had a very significant impact on the disabled child's and their mothers' well-being.

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Dedication

This thesis is dedicated to my father, Dr. Klaas Kramer, who taught me, by example and by his gentle teaching, what matters in life. His encouragement throughout my professional career and choices in life, leading eventually to my decision to pursue my PhD studies, has been a great source of inspiration to me.



Klaas Kramer 1932 – 2007

“The Lord has shown all you people what is good. And what does the Lord require of you? To act justly, to love mercy and to walk humbly with your God.”

(Holy Bible, Micah 6:8)

Acknowledgements

A host of people have been instrumental in making it possible for me to pursue my PhD studies and complete this thesis.

First of all I would like to thank the participants, who offered me their time, their trust, their ideas and artwork – without them there would have been no participatory action research! Thanks is also due to the contact people at the two local Mosques for helping to find participants and providing the venue for meetings. Other contacts in the Pakistani community, who supported the project were important too, in particular Fauzia who spent many hours translating and writing the invitation leaflets with me.

Secondly I would like to thank my supervisors, professors Peter Beresford and Judith Harwin, whose support, expert advice and faith in me have been of immense value throughout the process. I am also grateful to Brunel University for making the PhD studentship available, which made it financially possible to pursue this venture, and gave me the opportunity to learn from and alongside academic staff and students over the past three and a half years.

Thirdly there is my family – standing by me at every stage of the process. Special thanks are due to my husband Michael who encouraged me to apply for the studentship and consequently put up with the separation by thousands of miles from me and the children. Hanna and Nicholas have been very patient with their busy and often stressed mum and with only seeing their dad in the holidays, and eagerly await the end of the PhD journey!

Fourthly I would like to thank my friends: longstanding friends for being interested in my study, encouraging me and understanding that I was less

available to spend time and communicate with them over the past few years; new friends for making us welcome in our new area, helping out with practical things like moving house and looking after the children, and being constantly on hand to listen to my successes and frustrations.

Finally I would like to thank my Heavenly Father for providing such perfect timing for this PhD to happen, both in terms of my professional development and in terms of my personal need to reassess our journey as a family. Being confident that this PhD was the right thing to do at this time in my life gave great reassurance at the times the going got tough.

Terminology and definitions

The following notes clarify the meanings of frequently used terms and concepts:

Disability and impairment

Throughout the thesis, the terms disability and impairment have been used according to social model understanding. The term 'impairment' refers to the functional limitation within the individual, caused by a physical, mental or sensory impairment and the term 'disability' refers to the restrictions imposed on the individual by society through physical and social barriers, leading to limited participation in the normal life of the community. However, in verbatim quotes I have not changed the terminology used by the participant or author.

Nature of children's impairments

The children's impairments have been described on the basis of the diagnosis or terminology used by the parents, and/or on their presentation. As the approach taken in this study is based on a social model perspective on disability the exact nature or severity of the impairments is not often of interest. The nature of the child's impairment is only mentioned where it has directly impacted on the situation described.

Quotations

Participants' words are generally quoted verbatim. All direct quotes of participants' words are given in **comic sans font** and their name and the occasion at which they said it is indicated.

When the participant spoke in Urdu I have given a translation and indicated this in brackets as follows: (Urdu).

Children's ages are given in brackets with each quotation.

Confidentiality

Pseudonyms are used throughout the thesis.

Photographs of participants have been used with express permission only. Even so they have been digitally edited (e.g. 'oilified' or changed to a line drawing) where possible so people are not recognisable (see appendix F).

Venues

Two Mosques were used as a meeting venue: the large local Mosque and the small local Mosque. Any other Mosques mentioned have been described according to their location related to the local area.

Islamic terminology

The Islamic scriptures referred to consist of the Holy Quran and the Hadith. The Hadith consists of a number of ancient texts which describe the sayings and acts of the Prophet Muhammad.

All quotations from the Quran have been taken from "The Qur'an. A new translation" (Abdel Haleem, 2004).

An Islamic scholar is a person who has studied the Islamic scriptures, or part thereof, in depth. In other words, a Muslim theologian.

An Imam is a person who leads the prayers at a Mosque and delivers sermons. An Imam does not necessarily have as deep a knowledge of Islamic scriptures as a scholar does.

Publications

The following publications based on this study have either been published already, or accepted by the editors and in the process of being edited:

Kramer-Roy, D., 2007. Researching the support needs of Pakistani families with disabled children in the UK. *Research, Policy and Planning* 25(2/3), pp143-153.

Kramer-Roy, D. (forthcoming). Occupational injustice in the lives of Pakistani families with disabled children in the UK: a Participatory Action Research Study. In F. Kronenberg, N. Pollard & D. Sakellariou, eds. *Occupational Therapies without Borders*. Oxford: Elsevier-Churchill Livingstone. (Final draft has been accepted and at the final editing stage).

Kramer-Roy, D. (forthcoming). "We want to understand his different, 'virtual' world better, so we can make him happy": Pakistani children use participatory action research to explore their disabled siblings' needs. In: Rizvi, S. *Multidisciplinary Approaches in Educational Research: Case Studies from Pakistan and the UK*. Karachi: Aga Khan University, Institute for Educational Development. (Feedback on first draft received, second draft in progress).

See appendix Q for a copy of the first two (finalised) publications.

Conference Presentations

Making presentations at conferences was one of my strategies for ongoing reflection on and analysis of the data, to inform further choices within the emergent research design. The following table details the presentations made:

Date	Conference	Title of presentation
July 2006	PhD Students Conference Brunel University.	Improving the lives of Pakistani families with disabled children in the UK (poster).
January 2007	Inclusion and Exclusion Conference 2007. Race Equality Foundation and the Social Studies Research Group, London.	Support needs of Pakistani families with disabled children (Led to published article).
July 2007	PhD Students Conference Brunel University.	Gaining access to Pakistani families with disabled children. (Vice Chancellor's Conference Prize).
December 2007	Researching Children Conference Innsbruck, Austria.	Participatory Action Research by/with Pakistani families with disabled children.
March 2008	Action Research Study Group, London (small forum).	Exploring the support needs of Pakistani families with disabled children in the UK using an occupational justice framework: a Participatory Action Research study.
May 2008	Council of Occupational Therapists for the European Countries (COTEC) Conference, Hamburg, Germany.	Occupational Justice in the lives of Pakistani families with disabled children in the UK: a PAR study.

June 2008	College of Occupational Therapists (COT) Annual Conference, Harrogate.	<p>Concepts of disability and occupation in Pakistani families with disabled children in the UK.</p> <p>Crossing borders: career progression for the wandering OT (poster). (Student bursary provided by COT).</p>
September 2008	Disability Studies Association Conference (DSA), Lancaster	<p>Concepts of and attitudes towards disability in the Pakistani community in the UK. (VC Travel Prize).</p>
November 2008	Inclusion and Exclusion Conference 2008 (Race Equality Foundation, the Social Studies Research Group and INVOLVE, London)	<p>The outcomes of a participatory action research project exploring the support needs of Pakistani families with disabled children in the UK. A collaborative presentation by research participants and the lead researcher. (VC Travel Prize).</p>
July 2009	PhD Students Conference Brunel University	<p>Reflecting on Religion and Relationships: Pakistani families with disabled children explore their support needs through participatory action research. (poster; Vice Chancellor's Conference Prize).</p>

In addition to the above, I also attended a number of courses and conferences as a participant to gain further knowledge and skills relevant to the study. See the next page for an overview of events attended.

Date	Event	Reason for attending
September 2006	Disability Studies Association Conference (DSA), Lancaster.	Getting acquainted with the DSA and the principles of emancipatory disability research.
September 2006	5 th Occupation UK & Ireland Symposium "Health Through Occupation: The Evidence" .	Gaining up to date knowledge on occupational science. Networking.
November 2006	Searching for Dad: Exploring Muslim Fatherhood. Fathers Direct and the An-Nisa Society. Paddington Hilton Hotel.	Networking and hearing about current research and approaches related to Muslim fatherhood.
March 2007	"Can we Count them: Disabled Children and their Households". University of Warwick	Networking and hearing about current views on counting and reaching families with disabled children.
March 2007	"Making Life Better: Improving knowledge and practice in health provision for black and minority ethnic communities". Racial Equality Foundation, London.	Networking and gaining broader view on health inequalities.
June 2007	"Should we intervene early in children's lives? Lessons from research and best practice". Brunel Interdisciplinary Centre for Child and Youth Focused Research and Children Law UK. Brunel University.	Participating in the Centre's activity. Hearing about current best practice on early intervention with families.
October 2007	"Using basic therapeutic arts for participation and consultation". Young Minds, London.	Getting inspiration on using arts / creativity in the research process.
Year 1, 2 and 3 (5 days each)	Research Students Training Modules. Brunel University.	Compulsory for PhD students. Many of sessions were useful (encouraging, inspiring or practical).

PART 1: SETTING THE SCENE

**Chapter 1.1:
Introduction to the thesis**



Imran's artwork

1.1: Introduction to the thesis

The aim of this first chapter is to provide a brief overview of the thesis, starting from the background and rationale for choosing the research topic and methods, followed by the relatively important issue of positioning myself as a researcher in this study, and finally an explanation of the structure of the thesis.

This thesis reports on a participatory action research project carried out in an inner city area in the United Kingdom (UK) with a group of Pakistani families with disabled children.

Against a backdrop of well-documented difficulties in supporting Pakistani families with disabled children (see chapter 1.2), the purpose of the project was twofold. The first was to identify the support needs of Pakistani families with disabled children and to explore how these needs could be met more effectively. The second, equally important, purpose was to explore how engaging the participants in undertaking participatory action research in groups of men, women and children could facilitate their active role in achieving the first objective.

Getting to know Pakistani families with disabled children

My choice of research focus and methodology is based on a long history of working with Pakistani families with disabled children in both Pakistan and the UK. This experience has led to significant professional development and a fundamental conceptual shift in understanding of impairment and disability issues, as well as to a personal affinity with and commitment to the wellbeing of these families. See Appendix A for a poster presented at the annual conference of the College of Occupational Therapists 2008, which visualises these processes.

Having gained a few years of initial clinical experience as an occupational therapist, I decided to spend three years in Pakistan working with disabled children and adults in poor communities in the early 1990s. Disabled people were largely 'invisible' in society; those who were seen tended to be beggars whose impairments were lucrative for their 'employers' as they prompted people to give more money – but not respect - out of pity. The disabled children I worked with in their homes hardly left the house, due to the stigma and shame surrounding impairment, as well as a lack of mobility aids and infrastructure. Within these families a mixture of positive and negative attitudes towards the disabled child were seen, the latter often influenced by the abject poverty they lived in and the subsequent worries about feeding the family: paying for treatment or special school fees (if indeed available) was far down the list of family priorities. Yet much love for the child was often evident and mothers found great encouragement in finally being offered some support through the community health workers I trained, and through being brought together with other mothers of disabled children they hadn't known were living around the corner all along.

On return to the UK I chose to work in a multi-cultural borough in order to use my language skills and understanding of the cultural and religious background of Pakistani and other South Asian families. I soon realised that the situation of Pakistani families living in England was not necessarily much easier than it was in Pakistan, but that the mix of issues they faced was quite different. I noted the complexities of bringing up a disabled child for these families who lived in two cultures, faced discriminatory attitudes within their own community as well as general society, and struggled to understand and access the British system of services and benefits.

I also observed the difficulty the multi-disciplinary team had in providing effective services to the Asian families and my role developed into one of interpreter, buffer, bridge, advocate, etc. Whilst language was a major issue for many families (with my Urdu I was able to communicate with Hindi and Punjabi

speakers too), a Bangladeshi father, whose first language I did not speak, expressed his dismay when I told him I was leaving to return to Pakistan, because “you accept us as a family like any other family; you do not show the reserve and anxiety about our religion which we see in other service providers”.

Yet, in a multi-cultural society a good relationship between families and service providers should not depend on the personal experience the latter happens to have of living in the family's country of origin. The cultural competence of service providers needs to be developed so that they are committed and able to support families of any cultural background. This cultural competence complements the need for accurate and nuanced information about each population group being available.

After another six years in Pakistan, having gained more experience of working on disability awareness, inclusive education, community development, and training of health and education workers in Pakistan, I noticed on return to the UK that the professional support of Pakistani families with disabled children had not improved noticeably. While government policies appeared more favourable, and some useful guidelines and reports had been published, Pakistani families still struggled to gain adequate support in raising their disabled child.

The need for further research

Rather than repeating earlier studies that had provided a broad overview of issues faced by these families, I saw the need for a participatory study that aimed not only to add further clarity about their specific needs, but also invited the participant families to take an active role in the research process, because meeting support needs depends as much on appropriate services being available as it does on the families being able to help define, access and receive them.

The literature review in chapter 1.2 will provide details on the very disadvantaged position of the Pakistani community in the UK. Key issues faced are poverty, poor housing, unemployment, high rates of poor health and impairments, limited English proficiency, religious discrimination and the need to redefine family relationships in light of outside influences on the family. When there is a disabled child in the family additional issues arise, such as difficulty accessing services, securing impairment-related benefits, and dealing with negative attitudes towards disabled people within the Pakistani community.

Participatory Action Research

It has become evident then that these families are caught up in a complex web of marginalisation made up of issues related to ethnicity, religion, disability and - for most carers - gender. In order to start unravelling this web, a critical social paradigm of research, which has emancipatory goals, was most appropriate for this study, as discussed in chapter 2.1.

I used participatory action research to engage the families actively in identifying and starting to address their support needs within their families, in the community and through the service system. The action research process is participatory and democratic, and consists of an exploratory phase followed by cycles of reflection, planning and action. All family members were invited to play their part in telling their family story; identifying key issues; and planning, implementing and reflecting on action taken to address these issues. Separate action research groups were formed for the men, women and children of the families to engage with the issues in ways most appropriate to them.

The families and the individuals within them benefited from participating in the project in a number of ways, relating to gaining knowledge (e.g. about impairment and disability, Islamic teaching and available services), skills (e.g. reflecting on their experience of living with a disabled child, prioritising issues, planning and taking action) and attitudes (e.g. gaining confidence in approaching community members and leaders for support, becoming more

aware of their families' attitudes towards the disabled child and developing these more positively).

The complexities of the research process

However the research process was highly challenging and complicated throughout, as the findings chapters in part 3 of the thesis will show. The first challenge was to make contact with community / Mosque leaders and through them with families. At this stage my in-depth knowledge of Pakistani culture and my ability to behave and respond accordingly were vitally important. However despite my persistence and patience no families were identified through the Mosques. Whilst no mistrust towards me was expressed explicitly, it is quite possible that this was an issue, in view of the fact that I was neither a Pakistani, nor a Muslim. Consequently I had to diversify recruitment strategies by requesting statutory and voluntary agencies to invite families to participate on my behalf (see chapter 3.1).

Once families started to commit to participating in the project, the initial home-based exploratory phase was a very positive – though time consuming – experience for the participants as well as me (see chapter 3.2).

However, organising the three different action research groups for women, men and children was logistically very challenging. Organising the Mosques as a venue for the men's and children's group, and encouraging all group members to attend required much time and persuasion. Furthermore participants tended to be enthusiastic and actively involved in the meetings, but often found difficulty following up planned actions between meetings. In addition I needed sensitivity and wisdom in finding a balance between confidentiality within each group and linking up the processes between groups.

Finally the initial delays and difficulties in identifying participant families meant that only five months were available for the action research group processes, instead of the nine months I planned for, which meant for each group that the

practical implementation of their action plans, which had resulted from their reflections, was very limited. Nevertheless the participants provided very positive feedback about how they benefited from the process (see chapters 3.3 to 3.6).

Significant findings

Despite the challenges faced in conducting the research project, very rich data were gathered which provide deeper insight into the lives of Pakistani families with disabled children. Significant themes were the role of faith in explaining causes of impairments, accepting the disabled child and dealing with negative responses; cultural influences on family relationships; difficulties in accessing services; and the potential of participatory approaches to improve the support available to the families (see chapters 4.1 and 4.2).

Positioning as a researcher

Participatory action research is an intensive and rather personal endeavour for all involved. A good match between the researcher and the participants is therefore very important, and essential for building a relationship of trust that is so important for the process to be positive and productive.

I have already emphasised how my experience of living and working with Pakistani families in Pakistan and the UK has contributed to the choice of research focus and methods, and has been helpful in communications with participants as well as other community contacts.

My professional background in occupational therapy also contributed to the choice of participatory action research for this study. Both occupational therapy and action research recognise the importance of being engaged in purposeful occupation (or 'action') for developing knowledge, skills and attitudes that enable people to gain more control over their lives. My application of occupational therapy skills in a variety of roles 'outside'

occupational therapy has further prepared me for taking a facilitating rather than directive approach to conducting research with people.

Finally the fact that I am not a Pakistani myself appeared to hold an advantage too, as I did not fit into the social hierarchy and therefore had no fixed status within the Pakistani community. A group of Pakistani women I talked to during proposal development, as well as a number of the participants in this study pointed out that this meant I was perceived as impartial. In addition there was no culturally defined role I was expected to fulfil and I was therefore no threat to the honour of families in engaging with both the male and the female family members. However this perception of me may not have been universal and it is not possible to gauge the extent to which participants communicated their views and perceptions with me openly.

Structure of the thesis

The structure of the thesis is complex for two reasons. The first reason is the dual purpose of the study: one concerning the content and one concerning the process. The second reason is the fact that there were essentially two action research processes taking place: the participants' and my own (see chapter 3.1).

In view of this the thesis has been organised in four parts as follows:

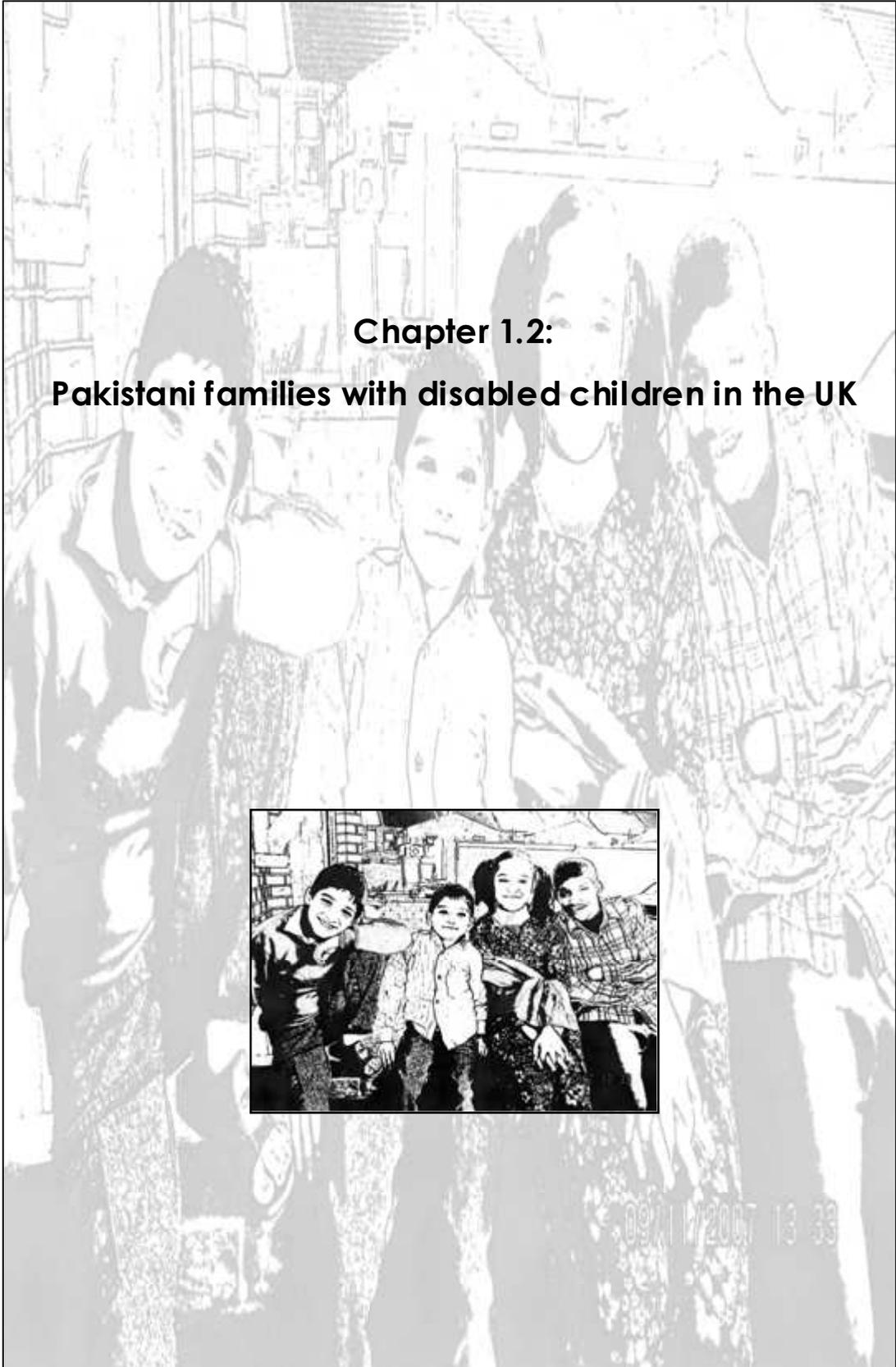
Part 1 sets the scene by providing the background and rationale for the study and reviewing relevant literature on Pakistani families with disabled children, models of disability, and occupational science.

Part 2 presents the research methodology, detailing the theoretical background as well as the reasons why participatory action research was deemed to be the most appropriate choice for this study. Following this the study design and methods are presented in detail.

Part 3 presents the findings from six distinct but interrelated research processes, which consisted of gaining access to the community and potential participants, the exploratory phase, the women's group, the men's group, the children's group, and making connections between the three groups.

Part 4 provides the analysis and discussion. First the analysis of and direct conclusions from the findings are presented. The final chapter goes beyond the direct findings to discuss how they are relevant to, and impact on, current theory and practice around impairment and ethnicity, and the role emancipatory and participatory approaches can play in bringing improvements in this area. It also includes the recommendations from the study for further research, policy and practice.

**Chapter 1.2:
Pakistani families with disabled children in the UK**



1.2: Pakistani families with disabled children in the UK

This purpose of this chapter is to present literature review around the situation of Pakistani families with disabled children in the UK. It shows how their situation differs from families of the majority population as well as, to some extent, other ethnic minority groups. It is important for the reader to understand the nature of the relatively disadvantaged position of these families as it forms an important underpinning for the rationale for the research focus and methods chosen for this study.

Prevalence of childhood impairments

It is difficult to obtain accurate data about the prevalence of childhood impairments in the UK. Although data is collected at national and local levels, they are collected by different organisations, for different purposes and using different definitions of 'impairment' and 'disability', making it difficult to aggregate the data into a reliable overall picture (Read et al, 2006, p30). The report of the Parliamentary Hearings on Services for Disabled Children (2006) confirms this situation, stating that "the hearings were not informed of a single local authority that could accurately state their population of disabled children", which interferes with the planning and commissioning of services (p22). Sloper and Beresford (2006, p.928) state that there are around 770 000 (7%) children and young people with impairments according to criteria defined in the Disability Discrimination Act (DDA). According to the DDA "a person has a disability if he has a physical or mental impairment which has a substantial and long term adverse affect on his ability to carry out normal day to day activities" (the Disability Discrimination Act, 1995). However, Mooney et al (2008) who conducted a large survey of local authorities on behalf of the UK government's Department for Children, Schools and Families, found the estimated incidence varied considerably between local authorities, from 3.0 to 5.4% of all children, leading to an overall estimated number of between 288,000 and 513,000 disabled children in the UK (p5). The Family Fund Trust, a registered charity

which provides grants to low-income families to meet the additional needs of caring for a severely disabled child, has around 165,000 children with severe impairments on its database (Family Fund Trust, online). The database is estimated to cover around 60 to 70% of severely disabled children (Dobson et al, 2001, p3), giving a total of around 245,000 children.

Prevalence of impairments in families of Pakistani origin

There have been a few studies comparing the prevalence of impairments in different ethnic populations carried out at local levels, which indicate significant differences. For example Morton et al (2002) conducted a study in Derbyshire comparing Pakistani, Indian and remaining mixed (95% white) groups, using data from the local Special Needs Data Base and records held by the local Child Development Centre (CDC). The study focused on the incidence of severe impairments and the catchment area was clearly defined. The data consisted of a random sample of the mixed group (100 out of 764 children attending the CDC from a total child population of 110,075) and the complete sets of data on Pakistani (53 from a total of 2724) and Indian (20 from a total of 3513) children. The cause of the impairments was recorded, including confirmed and probable genetic factors.

The Pakistani group (all Mirpuri from the Pakistani administered Kashmir area) showed significantly higher prevalence of severe intellectual impairment (three times more than the mixed group), hearing impairment (six times more) and visual impairment (four times more) and a slightly higher prevalence of autism and cerebral palsy. Language disorders were significantly less prevalent, or perhaps less diagnosed due to difficulty in detecting these problems when the first language is not English (p91). Importantly genetic disorders causing impairments were ten times more common in the Pakistani group than in other groups, probably as a result of the cultural practice of consanguineous marriages (p91) combined with difficulties in delivering effective genetic

guidance (p92). The authors quote studies carried out in other areas showing similar patterns.

The findings of this particular study on its own can not be generalised due to small sample size, the fact that all children originated from the same small area of Pakistan and the fact that only a sample of the mixed group was used in comparison with the full sets of the Indian and Pakistani groups. However the national study of Progressive Intellectual and Neurological Deterioration (Devereux et al., 2004) also found that 19% of all reported cases in the UK occurred in Pakistani families, whereas the total Pakistani under-16 population constitutes only 1.8% of the total (p11). The authors suggest that consanguinity is likely to be one of the reasons for this difference in prevalence, with approximately a quarter of cases being children of parents who are related, most of whom are Pakistani (p10).

The statistics of children with special educational needs served by the Local Education Authority in the local area where I conducted this study provide a similar picture (LEA, 2008), although slightly less extreme. The prevalence of different impairments among Pakistani children compared to white British children is as follows:

- four times more for hearing impairment,
- three times more for visual impairment,
- almost two times more for severe intellectual impairment and
- five times less for "specific learning difficulties" (such as dyslexia).

These numbers reflect only those children attending schools run by the Local Education Authority and do not include children attending private and/or out-of-borough schools. The local borough council is in the process of building a complete database of all disabled children living in the borough, but has not achieved this yet, so at present the school census is the most comprehensive data set available.

Another national study analysed data from the 2005 Pupil Level Annual School Census (PLASC), representing all 6.5 million children in maintained schools in the UK, to establish over- and underrepresentation of children of different ethnic groups in different categories of special education needs (Lindsay et al, 2006). After controlling for year group, gender and socio-economic status, Pakistani children were found to be two to two and a half times more likely to be identified as having profound and multiple learning disabilities, a visual impairment, hearing impairment or multi-sensory impairment than white British children (p4). They were also less likely to have special education needs in relation to behavioural, emotional and social difficulties (BESD), specific learning difficulties and autistic spectrum disorders (p8).

Genetic causes are unlikely to be the only causal factor of this higher prevalence of impairments in the Pakistani population, as the Pakistani population also has a higher percentage of members living in poverty and faces difficulties in accessing health and social services (Reith, 2001), as will be described later. The fact that the PLASC study, which controlled for the variable of socio-economic status (and other factors), presents a less extreme difference in prevalence of some types of impairments, suggests that poverty and disadvantage may indeed impact on the overall incidence.

This section has shown that estimates of the local and national incidence of impairments in children vary considerably depending on the criteria and data sources used. This makes it difficult to ascertain the difference in incidence between the general population and the Pakistani community, but the few studies that are available suggest a significantly higher incidence in the Pakistani community. Suggested causes for this difference are consanguinity and unfavourable socio-economic indicators.

Difficulties faced by families with disabled children

Families of all ethnic or socio-economic backgrounds face a whole range of challenges and difficulties when a disabled child is born. Beresford's (1995) national survey of over a thousand families provides a broad overview of the impact of having a disabled child and subsequent dealings with public services. She compared her data with the General Household Survey of 1992 as well as research on families with disabled children in the 1970s. The sample was taken from the Family Fund Trust database and included families from across the country. As the Family Fund provides financial support to families that are entirely dependent on benefits, or have modest levels of income and savings (Family Trust, online), and as families must take the initiative to apply for funds, their database is not entirely representative of the total population of families with disabled children. However, as it is estimated that the Family Fund Trust has had contact with between 60 and 70% of all families with severely disabled children in Britain, it is the best available sampling frame (Dobson et al, 2001). In addition the link between impairment and poverty has been well documented (see for example Sharma, 2002) and it is therefore likely that Beresford's study reflects the circumstances of the majority of families with disabled children in the UK.

Financial and practical problems

Beresford (1995) found that caring for a disabled child almost always involves significantly more time and effort than caring for a non-disabled child, particularly in areas of personal care, special care needs (therapy, medicine, diets), behaviour management and/or mobility problems. Although parents tended to accept this increased level of care in the context of a loving parent-child relationship, it often meant that the main carer (usually the mother) was unable to work outside the house (less than 20% of mothers of disabled children as compared to around 60% of mothers in the general population). Consequently 9 out of 10 lone-parent families and a third of two-parent families depended on benefits alone for their income. Extra costs in terms of laundry,

clothing, heating, bedding and transport further impacted on their financial situation. Another major problem was inadequate housing. Almost half the families in the sample had moved house due to the needs of the disabled child, but 40% of those found there were still problems. Common problems in terms of housing were difficult stairs, lack of space or facilities downstairs, and cold and damp. The survey further found low levels of support from the extended family, with four out of ten families reporting they did not receive any support at all. Families from ethnic minorities were even less likely to receive this kind of support.

Limited professional support

Beresford further found that about half of the families did not feel well-supported by professionals, that half of them had not had contact with a social worker in at least twelve months and that two thirds did not have a keyworker. The most common concerns expressed by parents were that professionals did not seem to understand what it is like to look after a disabled child, that parents have to fight for everything the child needs, that everything takes very long to sort out and that parents were not sure what services were available to help them. Most parents reported that their child had at least one unmet need and over half said they had five or more unmet needs. Families from ethnic minorities and those with very severely disabled children were most likely to have many unmet needs.

Poverty and accessing benefits

The Every Disabled Child Matters campaign (2007) states that families with disabled children are disproportionately likely to be living in poverty because of the considerable additional and ongoing expenses incurred in caring for their children (p3). Based on 1998 figures the cost of bringing up a child with significant impairments is GBP 7,355 per annum, as compared to GBP 2,100 for a non-disabled child. On a weekly basis this works out as an extra GBP 99 for bringing up a disabled child. Even if families receive the maximum level of

benefit entitlement for their child, they do not meet minimum essential costs. However most parents do not receive the maximum level of benefits, due to lack of information and complicated application procedures. The main reason mothers give for not working is the lack of good affordable child care (p4).

Apart from the financial implications of raising a disabled child, Gordon et al (2000, p70), who re-analysed data from the Office for Population Censuses and Surveys (OPCS) Disability Survey, found that children were three times as likely to have impairments "if their father was an unskilled manual worker as compared to children of fathers who were professional workers", indicating that a sizable proportion of families were already struggling financially before the added cost of having a child with impairments. A more recent report by the Institute for Public Policy Research (IPPR, 2007) also found that

there is a two-way relationship between disability and poverty in childhood. Disabled children are among the most likely to experience poverty and poor children are more likely to become disabled than those who are better off.

Dobson (2001) conducted a further study into the impact of childhood impairments on family life using questionnaires about general household data, inventories about items owned by the child or that s/he had access to, diaries to record actual spending over a week, children's questionnaires and focus groups. The sample for this study consisted of 273 parents who had responsibility for the day-to-day care of a child with severe impairments (p5) and was also taken from the Family Fund Trust database. The study focussed mainly on financial impacts, confirming and giving further detail to Beresford's (1995) findings.

Social stigma and exclusion

In addition Dobson's (2001) study explored with the parents how they reconstructed family life after the disabled child was born or the diagnosis

given. This part of the study showed how slow and difficult it was to rebuild their family life following the initial shock and devastation they experienced on learning that their child had impairments (p26). Many parents talked of the fact that they had to adjust to not being a 'normal family' and that this was made extremely difficult by the fact that they felt excluded by people outside the nuclear family. They found that other people no longer wanted to associate with them and that they had to deal with harsh stares and unthinking questions and reactions (p27). Even within their own extended families many experienced blame or rejection and often normal social relationships with family and friends became strained. Many found that once a clear diagnosis had been made they felt more confident in knowing that they were not to blame and making this clear to people around them (p27). The dual situation of being sidelined and ignored by people on the one hand, but being treated as a public entity on the other hand, for example being stared at and talked about, was not only felt in general social situations, but even in the way they were treated by professionals:

By equating the family with the child's condition, they were disassociated from most of the attributes of family life, leaving the condition as the only thing to treat or assess. Their needs as a family often were not addressed or acknowledged (p28).

The loss of privacy, with many professionals coming to the home and assessing various aspects, often talking about intimate problems in front of the child, was experienced as very distressing.

Dealing with these problems involved renegotiating and reconstructing relationships and all parents talked about how they had changed as people. Many explained how they had had to become more aggressive, pushy and obsessive in order to be able to fight to get the best for their child. This led to both positive changes, such as becoming more driven and determined, and to

negative impacts, such as being tired and exhausted all the time and less well-liked by others (p31).

Another change that affected mothers' sense of identity was that many were not able to return to work and that their whole 'social' world became the hospital, the waiting room and the home. This led to a great sense of isolation. Many fathers also changed their working patterns or even their jobs in order to have more flexibility to enable them to help with day-to-day tasks. This had consequences for their career prospects and families had to adjust to less prosperous futures (p32). In addition "never having time together put added strain on relationships, as did the day-to-day practicalities of providing intensive, round-the-clock care" (p34). Sharma (2002) states that "there is a higher incidence of lone parenthood in families with disabled children, which is likely to be the result of increased stress and lack of support" (p12).

Read et al (2006, p32) describe how

there has been a growing consensus about the fact that some of the greatest restrictions and limitations experienced by disabled children and adults are undoubtedly created by the way that society is organised to exclude them, by other people's damaging attitudes, by limited and unequal opportunities and by inadequate service provision.

Although this awareness is gradually leading to more efforts to challenge these issues and to develop better services to counter them, the additional and complicating issues faced by disabled children and adults from diverse backgrounds including ethnic minorities have been given less attention than needed (p33). They go on to state that

service providers and policy-makers (need) to realise the degree to which social and ethnic background and characteristics affect children's and their families' access to services that meet their needs...

sometimes those under the greatest pressure because of a combination of stressful life events, social exclusion and very limited resources are the least likely to find their way through the maze and come out at the other end with something that really meets their needs. (p34).

The following section will address these additional issues and difficulties faced by families from ethnic minority backgrounds.

Difficulties faced by black and ethnic minority families with disabled children

Chamba et al (1999 and 1999b) conducted a study of just under 600 families from ethnic minorities with disabled children in which they compared their findings with those from Beresford's (1995) study among the general population. 27% of the families (n = 158) were Pakistani Muslims and for many of the findings comparisons are made with the families from other ethnic origins, which were Indian, Bangladeshi and Black African / Caribbean (Chamba, 1999, p40). Again, the sample for this study was taken from the Family Fund Trust database (p37). The response rate was 60%. They used a postal questionnaire which was available in five Asian languages as well as English. If needed, families were helped to fill in the form (p38).

More unmet needs

The researchers found that "with few exceptions, minority ethnic families were much more disadvantaged in all areas explored and had higher levels of unmet need" (1999b). For example most families had lower incomes than the white families, fewer parents were receiving benefits, and if they did, these were less likely to be awarded at the higher rates. Parents who did not speak or understand English were even less likely to receive benefits (1999, p5). Lack of information about their child's impairment was also a bigger problem than in

white families, which was partially due to a lack of written information in languages other than English and a lack of suitably trained translators (p9 -12).

The types of unmet needs for the children were not dissimilar to those of white families, but the extent of them was, with half the parents saying that their child had seven or more unmet needs, as opposed to four or more in the white families (p27).

Parents who received a lot of help from their extended family and/or considered their home to be suitable for the care of their disabled child reported fewer unmet needs for their child (p27).

On the other hand a positive relationship with professionals did not lead to fewer unmet needs; even though these parents felt supported by individual professionals, the fact that services are "inadequate, under-resourced and poorly coordinated" still led to many needs not being met (p28).

Similarly there was also a higher incidence of unmet parental needs in this sample than in Beresford's (1995) sample from the general population. The most frequently reported needs in both samples were for more money, help with planning the child's future, help during school holidays, help with finding out about services, learning the best way to help their child, a break from care and more time with the other children (p29). Three factors influencing the level of need were found to be the suitability of the home, support from the extended family and the number of children in the family (p29). Pakistani mothers were least likely to report high levels of practical support and emotional support from their partners (p15). However the amount of support received from the extended family was similar to the general population in Beresford's study (p17).

Communicating effectively with professionals was a problem for one in five families, and common problems reported by both Asian and Black African / Caribbean parents were insensitivity to the family's religion and culture and to

the desire of both parents to be involved in the child's welfare (p22). The researchers had expected these problems to be more common and suggest that it may in fact be under-reported, as most "families are so preoccupied with addressing the basic needs that they may find it difficult to find fault with any support service they do receive" (p22-23). In addition many families are not accessing the services where cultural sensitivity is most essential, such as short-term care services and would therefore not have had a chance to experience problems with them (p23). This issue of under-using services is emphasised again in the final paragraph of the report, which states that

practitioners need to be aware of the influence that social and economic factors may have on parents' expectations and demands for support. For some these factors will mask the true extent of the support needs a family may have (p34).

Difficulties faced by Pakistani families with disabled children

A number of smaller scale studies have been conducted with South Asian families with disabled children, in which Pakistani families were in the vast majority (e.g. Fazil et al, 2002; Hatton et al ,2004; Emerson et al, 2003). As not many studies have been carried out so far, it is important to consider the findings of these small-scale studies in some depth. The high level of congruence between the smaller studies, which will be described below, as well as with Chamba's larger study (1999) gives some confidence that the findings represent the reality for many of the families. These smaller studies suggest that among ethnic minorities Pakistani and Bangladeshi families are experiencing the highest level of disadvantage and distress. Part of the reason for this may be that Pakistani and Bangladeshi communities have by far the highest percentage of people living in poverty: 60% as compared to less than 20% of white families and between 30 and 45% of other ethnic minority families (National Statistics Website, 2002).

However, the studies suggest there are many reasons related to their specific ethnic background that impact on the situation, as the title of one reporting article implies: "Disadvantage and Discrimination Compounded: the experience of Pakistani and Bangladeshi parents of disabled children in the UK" (Fazil et al, 2002). The authors of this study obtained information from 20 families (15 Pakistani and 5 Bangladeshi) with a disabled child between 5 and 19 years. The study was designed to test the impact of providing a new advocacy service to the families (p240). Families that were included in the sample were those that were referred to the organisation piloting the advocacy service over a given six month period (p241). The overall aim of the first phase of the study, which is reported on in this text, was "to add to the understanding of the lives of these families, the barriers they face in accessing services and the consequences for their well-being", rather than making further comparisons with the national surveys described above.

Accessing services

In Fazil et al's (2002) study families reported very little contact with service providers other than the school and the general practitioner (GP). Even if other service providers came to the house families had difficulty identifying who they were or where they came from, often only remembering the first name of the person visiting (p244). Although families were generally satisfied with their GP, they evidently had not ensured their access to other services (p247), whereas two thirds of the families stated they did want contact with service providers (p245). One service more than half of the families would welcome was respite care (p247), a service often assumed to be unnecessary because of care being provided within the extended family. Only two of the 20 mothers had help from a member of the extended family, an even lower level of support than found in Beresford's study in which one in five parents stated they received such help (p249).

Mental health needs

In Fazil et al's study 28% of parents were found to be above the severe depression threshold score on the General Health Questionnaire (a standardised measure by Goldberg, 1981). This score was significantly correlated with the level of satisfaction with scores on the Social Support Questionnaire (by Saranson, 1987). However the authors point out that

in addition to being amongst the most socially and economically deprived in the population, doing most of the caring and receiving little or no social support outside the family, some women also reported experiencing domestic violence and/or being blamed for bearing a disabled child (p249).

Several other studies have found a high incidence of mental health needs in Asian parents of disabled children as well. In Hatton et al's (2004) study more than 47% of Pakistani parents were affected by depression and 32% by anxiety, based on the same standardised interviews used in the National Community Survey about ethnicity and mental health (Nazroo, 1998). Parents attributed this to having to care for their disabled child without support (p149). Emerson et al (2003) report an even higher incidence of psychological distress among South Asian carers in their sample, 93% of whom were of Pakistani origin. They found around 70% of primary carers experienced psychological distress, compared to 47% in their sample from the majority population, according to their scores on the General Health Questionnaire (Goldberg and Williams, 1998). The authors point out that this higher rate is unlikely to be due to their ethnicity per se, but is more likely to be due to the higher level of social deprivation they experience (p81). In addition higher levels of distress were related to behavioural problems of the child.

Whilst it is difficult to make precise comparisons between these studies because they used different measures and terminology, it is evident that in all of them the incidence of mental health needs was high.

Challenging assumptions

Another article, drawing on data from the same study as Fazil et al's article, focuses on attitudes towards impairments among Pakistani and Bangladeshi parents of disabled children and indicates that this may be a further contributing factor to the level of distress experienced by the parents (Bywaters et al, 2003). This article starts out by questioning how accurate the stereotypical view of 'Asian' parents by service providers is and indicates four key elements in this: the assumption that Asian and in particular Muslim parents would necessarily adopt theologically based explanations for their child's impairment (e.g. God's punishment); the assumption that Asian parents may feel a greater sense of shame than white parents; the assumption that the previous two factors contribute to low uptake of health and social care services; and the assumption that such attitudes lead to low expectations of their child and therefore not encouraging him/her to achieve maximum independence (p503). As the findings are very particular to the Pakistani community, I will discuss them here at some length.

Explanations of impairments

A minority (number not specified in the text) of interviewed parents did refer to God, whether they just saw it as His will, or that he was 'testing' or punishing them. The majority however thought their child's impairment was due to an illness or consanguinity, particularly if doctors had told them that this was the case. A number of parents had a mixed explanation, using both medical and theological reasons. Many (number not specified in the text) parents were unclear about the cause of the impairment often because they had not understood explanations given by doctors. None of the parents mentioned the socially created obstacles and negative attitudes as a cause of disability.

Bywaters et al quote Begum (1992) as stating that the idea that impairments are a punishment is not an Islamic belief (p503). This view is shared by Bazna and Hatab (2004) who conducted a detailed study of the Qur'an to establish

what it teaches about disability. They concluded that physical conditions are morally neutral, so that they are neither curse nor blessing, but just a part of the human condition, thus removing any stigma and barrier to inclusion (p25, see chapter 1.4 for a more in-depth discussion on this). Croot et al (2008, p4-6) in their study of perceptions of causes of impairments among Pakistani families found that parents described both theological and biomedical reasons for their child's impairment. They often used biomedical explanations to dispel negative attitudes and stigmatising views prevalent in the community. At the same time their own faith-based explanations related to seeing the child as a gift or a blessing, in contrast with the negative faith-based explanations prevalent in the community which related to seeing impairments as a curse or a punishment. Bywaters et al (2003) point out that religious beliefs may be an important element in the coping mechanisms of families and should therefore not be off limits for service providers who do not share the same beliefs (p508). This study confirms and illustrates this view as will become evident in the findings chapters in Part 3 of this thesis.

Shame and stigma

Bywaters et al report that a number of parents did express such feelings or had been on the receiving end of negative disablist attitudes from others. Not having a clear diagnosis made it difficult for parents to deal with such attitudes. However there was as much evidence that families' lives were curtailed by practical and material problems as they were by family or community attitudes. It is also important to remember that Dobson et al (2001) described very similar issues in the general population. Although the expression of negative attitudes may differ in different cultures, they are not necessarily worse or based on formal sources of knowledge in these cultures.

Failing to find help

Bywaters et al found there was little evidence that parents had failed to seek help (p507). There was evidence that it had been very difficult for families to

actually get the services they needed despite their efforts. This had to do with a lack of information available, which was often compounded by the language barrier experienced by many of the families. Achieving success in terms of improving housing and living conditions was very difficult due to the slow and often inappropriate response of the services concerned. In addition services did not always meet the need of the families, for example, although around half of the families would have liked respite care for their children they might not necessarily want this overnight and they were not always confident that their child would be safe.

Expectations for the child's future

Parents tended to be clear that their child's impairment would have an impact on their future and most parents expected that their child's future care would depend on them (p507). Again a lack of awareness of available services seemed to have a greater impact on the nature of expectations they had than their personal view of the child's impairments.

Support within the family and community

Hatton et al (2004) conducted in-depth interviews with 26 South Asian families and 136 filled in questionnaires. The sample was obtained from local education authority areas with the help of schools and other services. Families were not initially approached by the research team directly, but received a letter by the relevant services explaining the purpose of the research and clearly stating their participation was voluntary. Due to data protection issues the research team did not know how many families were invited to participate, so that the response rate for this study is not known (p18-19). Most of their findings largely correspond with findings from studies already mentioned above. One aspect that they describe in more depth than the other studies is support within the household. Among two-parent families 48% of carers reported receiving little or no practical help from their partner and 30% no emotional support (p68). This made the carers' lives practically difficult and was a source of emotional

distress. Examples are given describing husbands having difficulty accepting the child's impairment, being unwilling to accompany the child on doctor's appointments, refusing to accept that consanguinity had caused the impairment, or even being unable to talk about the children's problems at all (p71).

The extended family

Support from the extended family was even less frequent, with almost 68% reporting no help and 21% reporting a little help. Reasons for this were that extended family members were too busy, or not interested in the child, did not know help was needed or could not cope with the child. Parents were often reluctant to ask for help (p74). Help from friends outside the extended family was even less common and parents tended to feel uncomfortable talking about their disabled child to their friends (p77).

The Pakistani community

When asked about support from local communities, parents reported negative attitudes, stigma and a consequent lack of support. Support from religious organisations was not forthcoming and parents generally did not take the initiative to try and get support from this source (p79). Only around 10% of parents had sometimes received help, but 44% had found them unhelpful and 46% had found them unavailable for support (p79). Some parents expressed that they felt that "our Muslim people aren't doing enough to help Muslim people... Pakistani Muslims need a push" (p114).

Chapter Summary

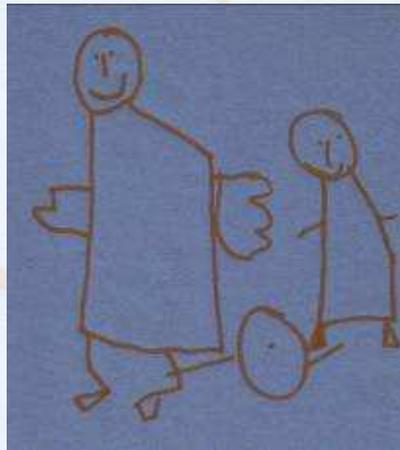
This chapter has discussed both the incidence of impairments and the experience of disabled children in the general population, as well as in the Pakistani community. Although there are many similarities, it is evident that the Pakistani families find themselves in significantly more disadvantaged situation

through a range of complicating factors, some of which appear to be specific to their cultural and religious background, but many of which are related to their relative poverty and difficulty in accessing appropriate services.

Although a number of studies have been undertaken at various levels of depth and breadth, they have tended to be descriptive and not undertaken any action orientated research with the families. Especially descriptions of differences in the experience of impairment in the family in the light of religious and cultural beliefs and practices remain rather superficial. This makes it difficult to formulate explicit advice to service providers about adjustments they need to make to their approach and actions when they deal with Pakistani families. Whilst the link between general social disadvantage on the one hand, and the incidence of impairments and ability to access services on the other hand, is evident from this literature review, no reports of emancipatory research with Pakistani families with disabled children in the UK was found. Part 2 of this thesis will present how this study sought to explore how such research might be undertaken.

Before that additional literature reviews around two theoretical concepts that are important to this study – occupational science and models of disability - will be presented in the following two chapters.

Chapter 1.3 Concepts of Occupational Science



Tariq's favourite occupation: football

1.3: Concepts of Occupational Science

The purpose of this chapter is to introduce the reader to aspects of the conceptual framework that relate to my professional background in occupational therapy as they have informed my reasoning at all stages of the study. This chapter describes key concepts that add a useful dimension to the construction of a better understanding of the support needs of Pakistani families with disabled children, as well as to the rationale for using a critical research approach to identify ways to improve their situation. The concepts that will be discussed are occupational therapy, occupation, Community Based Rehabilitation (CBR), culture, the congruence of occupational therapy and participatory action research, and the parallels between occupational science and other recent developments.

Occupational therapy

I have chosen the World Federation of Occupational Therapists' (2005, p3) definition of the profession, because it puts the ability and opportunity to participate in meaningful occupation firmly at the centre of occupational therapy practice, phrased in a way that allows for variation in practice depending on the context:

Occupational therapy is a profession concerned with promoting health and well-being through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of daily life. Occupational therapists achieve this outcome by enabling people to do things that will enhance their ability to participate or by modifying the environment to better support participation Occupational therapists believe that people can be supported or restricted by physical, social, attitudinal and legislative environments. Therefore occupational therapy

practice may be directed to changing aspects of the environment to enhance participation Clients are actively involved in the therapeutic process, and outcomes of occupational therapy are diverse, client-driven and measured in terms of participation or satisfaction derived from participation.

This definition draws on the profession's roots, which are generally traced to "moral treatment", which introduced a more humane treatment of people with mental health problems during the 18th and 19th centuries in the USA and the UK. Cruel and humiliating treatment regimes were replaced by engaging people in purposeful activity. For this to happen a different view and position of people with mental health problems was advocated (Wilcock, 1998, p167).

However Wilcock (1998) describes how from the 1920s onwards

changes in medical services occurred in which reductionist practice, pharmaceutical intervention and technology-based skills gained importance, and personal skill development ... in which occupational therapy specialized, became devalued (p166).

Although occupational therapy does not share this reductionist base of medical practice, it has always been considered a health profession, and has in the process become contaminated with, or been forced to work according to, the medical model. The rapidly growing need for rehabilitation services as a result of the high number of injured soldiers during World War II afforded an opportunity for occupational therapy to develop new approaches and techniques, which gave it renewed credibility, but also increased the pressure to fit into the medical system.

The struggle to maintain a holistic approach to working with clients has always continued, although many occupational therapists in clinical settings have been unable to apply this (Chapparo and Ranka, 2005). This has often led to

difficulties in profiling occupational therapy as a legitimate profession which has a unique contribution to offer in the (re)habilitation of disabled people and those living with other issues that impact negatively on their functioning in society.

The new discipline of occupational science, which started to emerge in the 1970s, partly in response to these profiling difficulties, is providing the theoretical basis for the recovery of occupational therapy as a profession that can facilitate individuals to reach their (occupational) potential through addressing social and environmental barriers as well as improving individual abilities. The following section gives an overview of key concepts within occupational science, followed by an explanation of why and how these enhanced the process and outcome of my study.

Occupation and occupational science

As might be expected with a new science, occupation and related concepts are defined and redefined slightly differently by different thinkers. In its most basic understanding, occupations are all the purposeful and meaningful activities a person carries out:

Occupation comprises all the ways in which we occupy ourselves, individually and as societies. Everyday life proceeds through a myriad of occupations, imbedded in time and place, and in the cultural and other patterns that organize what we do (Townsend, 1997, p19).

The importance of occupation in our lives is not limited to 'maintaining' ourselves through productivity (work), self-care and leisure, but it has transformative potential in terms of the opportunities it creates to choose and engage in occupations for the purposes of directing and changing either personal or social aspects of life, with the aim of realising dreams and goals (Townsend, 1997, p20). It is through our ability to make choices about what we

do and how we do it, that we gain more control over our lives and health, and participation in meaningful occupation has an important positive influence on health (Sinclair, 2005, p.xiv).

The therapeutic effect of engaging in occupation is probably the most fundamental assumption underlying the practice of occupational therapy:

health flourishes when people's occupations give meaning and purpose to life and are publicly valued by the society in which they live (Canadian Association of Occupational Therapy, 2008).

Doing, Being, Becoming and Belonging

Wilcock (2006) expresses the all-pervading nature of occupation in the following aide memoire: $d + b^3 = s h$. Or, put in words: doing, being, becoming and belonging equal survival and health. As this concept proved very useful in reflecting on the participants' family lives, I describe it here at some length.

Doing

It is through our occupations that we act (doing). 'Doing' is not restricted to observable physical activity, but includes anything a person chooses to do that has purpose or meaning.

Being

Our actions are informed by who we are as individual humans (being) and becoming more conscious of who we 'are' is very important for our survival and health. Wilcock (1999, p5) explains that "'being' is about being true to ourselves, to our nature, to our essence and to what is distinctive about us to bring to others as part of our relationships and to what we do". Who we are is influenced by and influences our world-view, values and relationships with others.

Becoming

Our actions also influence how we further develop our sense of identity, abilities, worldview and ideals. 'Becoming' essentially means "to change or develop into something" (Encarta Dictionary: English, online) or "to come to be" (Merriam-Webster online dictionary), suggesting a sense of future. However who and how people 'become' in many ways depends on "what people do and are in the present, and on our history, in terms of cultural development" (Wilcock, 1999, p5). Our becoming is therefore grounded in our past and present 'being'.

Belonging

These processes can not take place in a vacuum and a real sense of belonging (in the family, in various formal and social groupings) is essential for a person to be able to participate in occupation optimally. The concept of 'belonging' not only emphasises the importance of the love and/or acceptance by people around us, which contributes to our sense of self-esteem, but also points to the fact that human beings and their occupations are interdependent both at micro and macro levels. Thus

occupation also provides the mechanism for social interaction and societal development and growth, forming the foundation of community, local and national identity, because individuals not only engage in separate pursuits, they are able to plan and execute group activity to the extent of national government or to achieve international goals for individual, mutual, and community purposes (Wilcock, 1998, p25).

Occupation and health

Occupation, conceptualised in this way, becomes a whole new way of understanding health, which moves well beyond "the absence of disease"

(WHO, 1946, p2). This renewed theoretical underpinning of the profession of occupational therapy, poses the challenge to work not only with people with impairments of various kinds, but

also with those suffering from the disorders of our time, such as occupational deprivation, occupational alienation, occupational imbalance and occupational injustice (in order) to enable occupation for personal wellbeing, for community development, to prevent illnesses and towards social justice and a sustainable ecology (Wilcock 1999, p10).

I will explore this wider application of the concept of occupation in the following paragraphs.

Occupational injustice

Townsend and Wilcock (2004, p251 - 253) describe occupation-related threats to health and well-being in terms of occupational (in)justice and identify three major risk factors, which are occupational deprivation, occupational alienation and occupational imbalance.

Occupational deprivation is a lack of opportunity to participate in meaningful occupation, associated with isolation or overcrowding. An example of this is when children are deprived of opportunities and resources to play because of poverty, impairments, or economic and social forces that lure them into child labour, leading to restricted physical, social and/or mental development.

Occupational alienation is the consequence of being engaged in occupation that is not meaningful, associated with loss of purpose. An example of this is repetitive work like packing items at a conveyor-belt (although not every worker may experience this as alienating; for example an autistic person might find this predictable routine activity calming and rewarding).

Occupational imbalance is described as having too little or too much to do, leading to boredom or burnout. At society level this is seen when some people are over-occupied whilst others are under-occupied.

As most circumstances leading to these risk factors are forced on the person by others, or by general social and political circumstances outside the person's control, the authors have framed them in the concept of occupational injustice, which is described as "socially structured, socially formed conditions that give rise to stressful occupational experiences" (Townsend and Wilcock, 2004, p251).

Health promotion

The concept of occupation and its importance to human beings thus resonates well with the concept of health promotion, as described in the Ottawa Charter (1986). It defines health promotion as

the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, social and mental well-being an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment (p1).

From this basis the Ottawa Charter advocates an approach to health promotion, which does not only focus on individuals, but consists of the following five components:

- building healthy public policy
- creating supportive environments
- strengthening community action
- developing personal skills
- reorienting health services from being mainly curative to contributing to the pursuit of health with a focus on the individual as a whole person who participates in health decisions and building partnerships with service users in

planning, implementation and evaluation of health promotion activities (p2-4).

Key approaches in achieving this are to 'advocate', 'enable' and 'mediate'.

Occupation and Community Based Rehabilitation

Although these concepts of occupation and health promotion are not yet widely understood and adopted by occupational therapists, particularly those working in Western clinical contexts, Pollard et al (2005, p525) observe that

occupational therapy is on the verge of recognising a broader global and social responsibility and there is now a need for the profession to address the challenges of inequality and poverty.

These concepts are more readily recognised and understood by occupational therapists working in Community Based Rehabilitation (CBR) in majority world contexts. Accordingly the World Federation of Occupational Therapists' position paper on CBR (Kronenberg and WFOT-CBR Project Team, 2003) builds on broad concepts of human rights and inclusive communities, as well as on occupation and related concepts. It defines occupational justice as "building inclusive communities in which people can reach their potential" (p7), for which it is essential that occupational therapists develop their role as social change agents. The position paper describes the core principle of CBR as enabling disabled and disadvantaged people themselves, and their families, to define their needs, methods and paths of self-empowerment and self-integration, and they suggest that participatory action research or similar research approaches are essential in facilitating this process (p9).

Before continuing this line of argument a critical note regarding CBR needs to be made. CBR is

a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities. CBR is implemented through the combined efforts of people with disabilities themselves, their families, organizations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services (ILO, UNESCO, WHO, 2004, p6).

CBR can be a very effective strategy, provided disabled people and their families play a key role in planning, implementing and coordinating projects, and provided CBR is indeed an integral part of general community development initiatives (SHIA and WHO, 2002). However it must be recognised that many so-called CBR projects work in isolation and function more like institutional services located in – rather than based in - the community, and not planned or run by disabled people and their communities (Kramer-Roy, 2000; SHIA and WHO, 2002). Ndaziboneye et al (2006, p31) point out that these types of services might as well be received from existing health care providers and do not contribute to community development. They go on to point out four key aspects that hinder the integration of CBR into community development, namely too much focus on the individual, limited involvement of the community, ill-directed political action, and cultural aspects relating to concepts of disability (Ndaziboneye et al, 2006, p32-37). Having supported CBR projects in Pakistan, I am acutely aware of the difficulties involved in developing truly community based initiatives. However there are strong examples available of where communities have succeeded, such as Project Projimo in rural Mexico, which was set up by disabled community members in 1982 and is still a truly community based project (Werner, 1987, p515; Healthrights, online). Occupational therapists therefore need to develop their "role as social change agents" (WFOT, 2003) so that prerequisites for the central role of disabled people themselves in developing CBR may be facilitated both at individual and at community, organisational and national levels.

Occupational therapy and human rights

To further emphasise the need for the profession to develop its potential to work with communities and disabled individuals effectively, the World Federation of Occupational Therapy has issued a position statement on human rights in relation to human occupation and participation (WFOT, 2006). It proposes a number of principles, the first of which is that

people have the right to participate in a range of occupations that enable them to flourish, fulfil their potential and experience satisfaction in a way consistent with their culture and beliefs.

Another key principle outlines possible abuses of the right to engage in occupation as taking

the form of economic, social or physical exclusion, through attitudinal or physical barriers, or through control of access to necessary knowledge, skills, resources, or venues where occupation takes place.

Occupation and culture

The WFOT position statements on CBR and Human Rights acknowledge that occupation must be considered within the cultural context people find themselves in.

Dyck (1998, p68) gives a useful description of culture as

shared meanings through which members of a culture interact and communicate with each other. Shared meanings involve ideas, concepts and knowledge, and include the beliefs, values and norms that shape standards and rules of behaviour as people go about their everyday lives.

Watson (2006, p152) emphasises the fact that culture is dynamic and interactive, a fluid concept that is the result of a community's joint production of meaning. As values and beliefs are formed and sustained in social groupings, families and communities, culture provides therapists with a lens for perceiving and understanding how people live socially and not simply as individuals. Watson goes on to explain that culture matters because it shapes the identity which people assume, a process that is complicated by globalisation and cross-cultural living as individuals are not usually associated with just one single group or culture anymore. The third important aspect of culture Watson points out is that culture strongly influences people's worldview. As shared values and beliefs are so pervasive people often take their own worldview for granted and a cultural awareness and appreciation of other people's worldview is needed to understand behaviour and motivation.

Iwama (2005a, p247) cautions that "current definitions of occupation demonstrate a valuing that is particularly reflective of Western experience and worldviews". Applying the concept in different contexts or with minority groups in a Western context is therefore not unproblematic and its importance and meaning needs to be explored within each context or population group. Iwama goes on to say that

to an outsider – a person who has constructed his or her perceptions and views of the world through a set of traditions, religious and philosophical tenets, beliefs of what is true, worth knowing and worth doing – our current definitions of occupation look particularly individual-centred and rational.... (p247).

The author suggests that in different cultures there are likely to be differences in the relative importance given to 'being' and 'doing' and to 'independence' and 'interdependence'. Therefore the concept of occupation must be re-defined in each new cultural context.

Iwama (2005b, p129) concludes that

in order to bring occupational therapy safely, equitably and beneficently into the lives of other peoples, whether they be marginalized here or in some other location, culture in occupational therapy needs to be understood in its own terms from the other's vantage-point.

Finding a balance between respecting the culture and traditions of communities and promoting universal human rights is a precarious process. A transparent process in which community members reflect on newly introduced concepts of human rights, participation and occupation in the light of their own culture and traditions is essential for communities to attain better health in a way that fits in with their worldview and is not alienating for them.

In this study a beginning has been made with reflecting on the meaning of occupation in the lives of Pakistani families with disabled children and the implications for meeting their support needs.

Occupational Therapy and Participatory Action Research

An in-depth literature review and discussion about participatory action research will be presented in chapter 2.1. In this project, in which I took on the role of a researcher working alongside a group of co-researchers, I found that participatory action research is "consistent with the values of occupational therapy and occupational justice" (Trentham & Cockburn 2005, p440) in three ways, relating to the view of participation in research as a meaningful occupation; the ethos of client-centred practice; and the fact that action and collaboration are of central importance.

Research as occupation

Firstly, Trentham & Cockburn (2005, p446), writing about their experience of using participatory action research as occupational therapists, suggest that

when people ask questions and also propose solutions, implement change, and disseminate new knowledge, they are participating in an occupational form that helps to develop the skills and knowledge necessary to take greater control over their own lives; in so doing, they promote their own health as well as the health of other community members.

Client-centred practice

Secondly, the approach to working as a team of co-researchers is very congruent with the principles of client-centred practice, which is defined as

a partnership between the client and the therapist that empowers the client to engage in functional performance and fulfil his or her occupational roles in a variety of environments (Sumsion, 2000, p308).

The concept of client-centred practice started to emerge in the 1980s when the concept of health promotion became important in health care and formally promoted through the Ottawa Charter (WHO, 1986, see above). This has led to increased consumer awareness of their rights and the development of self-help groups and more information being available to people outside the realm of professional involvement (Sumsion, 2006, p2). Client-centred practice is formally supported and encouraged by the College of Occupational Therapists in the UK within the professional code of ethics and professional conduct (COT, 2005, p5, p9) and recognised by many occupational therapists as an important aspect of their ethos and treatment approach, although not yet universally understood and implemented. Key aspects of client-centred practice are respect for people's skills and insights, taking responsibility for one's own

choices, enabling participation, flexibility, and keeping in view the links between the person, their environment and occupation (Letts 2003, p83-4).

Action and collaboration

In both occupational therapy and participatory action research “action” and “collaboration” are central, whether applied with individuals or groups. The successful outcomes of both processes depend much on the therapist or researcher’s openness to learn from their partners, rather than viewing oneself as the ‘expert’. Occupational therapists’ values and skills are very helpful in conducting participatory action research.

Occupation and Pakistani Families with Disabilities

Problems associated with the principles put forth in the World Federation of Occupational Therapy position statement on human rights can quite readily be recognised in chapter 1.2 about Pakistani families with disabled children in the UK. The way participation in occupation is compromised in this context needs to be carefully considered not only with and/or regarding the disabled child, but also their family members. In this study both reflecting on their situation from an occupational science perspective, and observing the effect of the nature and level of their engagement in occupations have been used to define these concepts from their cultural, religious and social viewpoints.

Exploring the situation of families with disabled children in the light of these concepts of occupation and health promotion enabled the research participants (and the researcher) to analyze how the current occupations of the various family members influence their own and each other’s state of health and sense of well-being. Considering which factors within the family, community and wider society have contributed to this current (im)balance of occupations was an important part of becoming aware of and starting to address problems at their roots, rather than feeling disempowered by their impact on their well-being. In addition the occupation of participating actively

in the research process further developed personal skills and motivated the participants towards community action, both of which have the potential to be sustained beyond the research period.

Parallels between occupation and other concepts

Finally it is quite evident from this chapter how the development of a more holistic conceptualisation of health and well-being over the past four decades or so has led to the parallel development of theories and practices that primarily emphasise the social and political causes of ill-health and lack of well-being, as opposed to the medical causes at the individual level. Each of the concepts discussed - occupational injustice, WHO's approach to health promotion, CBR, participatory action research, as indeed the social model of disability described in chapter 1.4 – are therefore congruent to a great extent.

My own professional development also progressed from occupational therapy training based on the medical model, to a community-based and family-centred approach based on the social model (see chapter 1.1). The gradual integration of concepts and their practical applications over a number of years convinced me of both the rightness and the potential of using participatory action research with Pakistani families with disabled children.

In doing this, it has been very important to be clear about my role, which was one of a researcher and not a therapist. However much the research can be considered a meaningful occupation, for it to be effective my relationship with the participants needed to be as researcher and co-researchers, and not as therapist and clients. "That is not to say that research is not an occupation in which individuals might find satisfaction" (Letts, 2003) or that it might not lead to enhanced occupational participation, as is evident from the section on the transformational potential of participatory action research in chapter 2.1 and from the findings chapters in part 3 of the thesis.

Chapter summary

This chapter has shown how the concepts of occupational science informed this study. They gave a concrete and easy to understand focus on 'who does what and why' in the families; provided opportunities to question how choices may be influenced by cultural and social factors; and facilitated the understanding that injustices in society, including the current status of the statutory service provision and benefits system, impact on the families' health and well-being.

The congruence between the ethos of occupational science and participatory action research further confirms the latter is an appropriate choice for an occupational therapist undertaking emancipatory research. The study illustrates how occupational science can be a useful conceptual framework for increasing our understanding of health inequalities experienced by ethnic minority families, including those with disabled children. At the same time it may also inform the literature around occupational science about how participatory action research can increase our insight into how 'occupation' and 'occupational justice' may carry different meanings for people from different cultures.

Chapter 1.4
Models of disability



Karachi, 1992

1.4: Models of disability

The purpose of this chapter is to give an overview of the main models of disability that are described in the literature and to clarify how this is important for this study. It is argued that there is a need to make more explicit how elements from the earlier models, namely the traditional and the medical model, are still relevant within the social model of disability, though with a different emphasis. This is particularly relevant for disabled people from minority ethnic and/or religious backgrounds.

Three models of disability

In the literature three broad models of disability can be identified, although each may manifest in different ways according to the context and worldview of those describing them. The three models are:

- the traditional or moral/religious model
- the medical or individual model and
- the social model

I will describe each of these models in turn, before discussing how occupational therapy and occupational science have developed in the context of these prevailing models and may be helpful in refining the social model further.

The traditional or moral/religious model

This model probably represents the oldest and most pervasive framework for understanding disability. It is based on religious and cultural beliefs and tends to concentrate on looking for a cause for the impairment, often related to the concept of God's, or gods', punishment or testing. This concept is sometimes used by religious leaders to instil fear of the supernatural among people with the aim to regulate and control behaviour (Whalley Hammell, 2006, p55).

Miles (1995) describes disability in an eastern religious context and points out that in the early history of most religions there are examples of institutions set up to care for the disabled (Buddhist), or laws to enable their social participation (Hindu and Muslim). Morad et al (2001) similarly describe how medical and social care was offered to disabled people in early Muslim history. Miles (1995) goes on to argue that modern apologists of different (eastern) religions may claim that current positive views of disabled people merely reflect what their religion taught humanity centuries ago, but also points out that Asian disabled activists do not find that people's professed beliefs are borne out in prevalent societal attitudes.

Selway and Ashman (1998) present a literature review around the spiritual dimension of disability across religions, cultures and history. They note inconsistent cultural attitudes across and within religions and eras, quoting examples of people with intellectual impairment being considered either demon possessed or blessed in the middle ages, and of closely related tribes in East Africa either leaving disabled people to die, or using them to ward off evil. However Selway and Ashman (1998) point out that only a limited amount of research is available and it is difficult to draw conclusions from the rather anecdotal information available from that. An additional issue is that religious scriptures appear to refer to disability in both negative and positive terms making it difficult to draw a quick, straightforward conclusion to influence the believers' views and attitudes. The following two sections briefly discuss these issues in the context of the Christian (as it has influenced concepts of disability in western societies) and Islamic (as the participants in this study are Muslim families) traditions.

The Christian tradition

There are a number of passages in the Bible, mainly the Old Testament, that appear to see disabled people in a negative light (e.g. linking sin and disability) or disadvantaged position (e.g. no 'blemished' priest being allowed to go into

the holiest part of the temple to make sacrifices to God). Whilst it is beyond the scope of this thesis to debate these issues in depth, McCloughry and Morris (2002, p36) caution that there is a danger in using ones own contemporary views and norms as criteria with which to judge ancient practices. They point out that the overall relationship between humanity and God in the Old Testament is closely linked to the way people treat each other: "to mistreat a person is to mistreat God, since God made (all) human beings in his own image" (p 40).

Nevertheless the view that there is a link between sin and impairment was still prevalent in New Testament times, causing Jesus to explicitly explain that impairments are not caused by the person's own or their parents' sins. When He did heal people it was to reveal God's glory (Holy Bible, John 9: 1-3). In addition He knew the importance of the person to be restored as a fully accepted community member, for example when he sent the people he healed from leprosy to the temple for the priests to declare them ceremoniously clean (Holy Bible, Luke 17:11-19). In response to prevalent judgmental and exclusionary attitudes at the time, Jesus showed a compassionate and accepting attitude, meeting people's spiritual as well as physical and mental needs, and through that demonstrating that 'ritually unclean' people were acceptable to God as they were (McCloughry and Morris, 2002, p53).

In recent decades Christians and churches worldwide have reconsidered what the Bible teaches about impairment and disability and in 2003 the World Council of Churches presented a statement for churches to study and discuss (World Council of Churches, 2003; also see Fritson and Kabue, 2004, pp 64-88). In this statement the response of churches to disabled people through history is acknowledged. Both the churches' positive role in showing compassion and establishing supportive and caring services, and the negative role in alienating disabled people by linking their impairment to sin and/or their failure to be healed to a lack of faith, are recognised. The statement emphasises the need for churches to re-examine their theologies of disability and, on the basis of that,

to build inclusive Christian communities in which acceptance of the fact that all were created in the image of God and the need for interdependence in order to fully understand God's purposes for each person, are of central importance.

The Islamic tradition

A similar tension can be observed in Muslim cultures. For example, while attitudes towards disabled people tend to be poor in contemporary Muslim societies such as Pakistan, authors who have gone back to the Islamic scriptures have also found there is no ground for beliefs about divine punishment in them, but rather a challenge to believers to afford disabled or otherwise disadvantaged people their rights and to take up the responsibility to ensure this happens (e.g. Morad, M et al, 2001; Bazna and Hatab, 2004; Al-Munaizel, 1995).

Al-Munaizel (1995, p22) describes 5 applicable Islamic Human Rights:

1. all people are born equal and free
2. the right to protection and material support in the family
3. equality and prohibition of any form of discrimination
4. security and freedom, including protection against injustice and abuse
5. right to education at a level appropriate to one's abilities.

He also describes how Islam gives meaning to suffering, as it gives the hope that it will be an atonement for their sin, with which they can reach the goal of eternal life (p23). In addition, the Muslim is encouraged to "speak to them with friendly words" (Holy Quran, Sura 4: 5) and ensure their care and financial support (p24). The latter gives the disabled person the right to ask others for financial support, which is often done through begging or through Zakat funds (compulsory alms giving into central funds). Muslims are also told they can eat with them, i.e. associate closely (Holy Quran, Sura 24: 60).

Bazna and Hatab (2004) examined both the Qur'an and the Hadith (the sayings and teachings of the prophet Muhammad) to establish what the Islamic

position and attitude towards disability is (p1), uncontaminated by cultural or societal influences (p6). They start with the concept of 'perfection' and find that in both the Qur'an and the Hadith physical perfection is not significant in a spiritual sense, but rather that "the noblest of you in the sight of God is the one who is most deeply conscious of Him" (p9, Holy Qur'an 49:13). Bazna and Hatab also point out that there are many exhortations in the Qur'an related to protecting the rights and dignity of 'needy' members of society, arguing that many disabled people are among them due to the many social barriers put in the way of their full participation in society.

Issues arising from the traditional model

Despite the fundamentally positive teaching of the scriptures, the traditional or moral/religious model has been and still is prevalent in its detrimental forms in most cultures and religions. Although in this model the causes of disability are ascribed to the individual, the underlying religious concepts also inform people's beliefs about how they should treat disabled people, and subsequently their attitudes. In other words they also give a social perspective, even if it is a contentious one when viewed from a social model perspective. For example the religious obligation to show charity through alms-giving may guarantee disabled people's survival, but it also creates distance between the charitable giver and the recipient, as it gives the false sense of having done one's duty, which tends to stop the former from seeing the latter as a human being of the same value as oneself with the potential to fulfil a positive role in society (see Coleridge, p47). This dehumanizing attitude can be clearly and frequently observed by the traffic lights in Pakistan where drivers hand out small change to beggars who come up to their car window, without even acknowledging their existence.

The medical model of disability

In the West the traditional model has largely been replaced by the medical model, which is basically an extension of the same idea, in that it still locates the

problem in the disabled person and looks for a clear-cut cause. Impairments are viewed as 'abnormalities' that must be corrected, cured or overcome if at all possible (Coleridge, 1993, p72). This model arose during the "Enlightenment" period in Western history, with the belief that all phenomena could be described and explained by science, which could thus solve any problem (Whalley Hammell, 2006, p58). This can be seen as a reductionist worldview. It sees the human body as flexible and alterable and the social environment as fixed and unalterable, thus laying the full responsibility for change with the disabled person (Coleridge, 1993, p72). Any support or intervention offered to the 'patient' tends to be focused on either reducing the impairment as much as possible, or on helping the patient to adjust to their disability as well as they can, without challenging the social, political and physical environment about the barriers it puts in the way of disabled people. This is basically still a 'charitable' approach, which seeks to 'help' disabled people in a way that prevents them from claiming their rights as active citizens, in effect keeping them in a dependent and inferior position.

Although this model of disability has important limitations due to its narrow view on disability by concentrating mainly on the reduction of impairments, much of the medical, pharmaceutical and therapeutic knowledge and skill that has been developed through this perspective has contributed greatly to the quality of life and possibility to participate in society of many disabled people. These resources and knowledge remain important in limiting the levels of impairments disabled people live with. For example, having worked with disabled children both in the UK and in the poorest communities in Pakistan, I am well aware how relatively mild physical impairments may either lead to near normal functional ability if treated in the child's early months and years, or to severe restrictions when treatment is not available until the child is older. At the same time achieving optimal functional ability on its own is not enough to improve the lives of disabled people in their communities and societies and a social model perspective is required to understand the influence of the social context on quality of life.

The social model of disability

The social model has its roots in the efforts of the Union of the Physically Impaired against Segregation (UPIAS), who in their *Fundamental Principles of Disability* (1976, p3-4) stated that

it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.

Although UPIAS reacted against the negative consequences of being 'helped' from a medical perspective, which had meant disabled people were treated as problems to be solved by experts, their initial documents do not reject medical treatment, but rather demand that professionals should support their full participation in society as a priority, rather than curbing their abilities to attain it (UPIAS 1974/6, clauses 14 and 16).

The social model challenges society about its responsibility for creating barriers for disabled people, and therefore in removing them again, but it also urges disabled people who have often internalised the oppression faced in society to re-evaluate the perception that they may be at fault for failing to participate in society themselves. The social model has thus been an emancipatory force in the lives of many disabled people and provided a motivating philosophical rationale for the activities of organisations of disabled people (Tregaskis, 2002, p457).

Despite the clear focus on social oppression and the empowerment of disabled people to challenge societal attitudes and barriers, much debate and theorising within the discipline of disability studies in the UK has led to a number of different takes on the social model of disability. A key concept in the social model is the distinction between 'impairment' – the functional limitation within

the individual, caused by a physical, mental or sensory impairment – and 'disability' – the restrictions imposed on the individual by society through physical and social barriers, leading to limited participation in the normal life of the community. As disability studies theorists use a social oppression paradigm (Thomas, 2007, p4), their main focus is on the latter, i.e. the social aspects of 'disability', as opposed to the individual (physical or mental) aspects of impairment. In the heat of the discussion the influence of the nature and severity of individual impairments on the possibility of participating fully in normal life in the community has often got lost. Although this led to a clear position opposing the medical model, it has made it rather difficult to have a fruitful debate with health professionals and other service providers, which seems to have caused a lack of communication and understanding between the two apparently opposing camps. This issue has been raised in the disability studies literature and more balanced views, which are therefore more likely to convince health professionals, are being brought forward.

For example, Thomas (2007) in her book 'Sociologies of Disability and Illness' compares and contrasts the disciplines of medical sociology and disability studies. She argues that medical sociology views disability through a 'social deviance' lens, studying both societal responses to people designated chronically ill or disabled, and the social experience of living with stigmatised bodily states (p4). Although both disciplines operate within very different paradigms, Thomas points out that there are important ways in which they can inform each other. She suggests that disability studies needs to develop "a sociology of disability *within* the social oppression paradigm" and in doing so make use of theories that engage both with social structure and social agency, accommodating analysis of the social relations and social forces that construct, produce, institutionalise, enact and perform disability and disablism (the social oppression of disabled people) (p181-2). An important aspect of this is that the *lived experience* of both disablism *and* impairment should be highlighted more, with attention being given to social 'difference' such as gender, 'race', sexuality, age and social class, as well as impairment type (p182).

Thomas' (2007) suggestion that there is a need to study and conceptualise disability in relation to other social injustices is not new and was described as a "more holistic definition of disability" by Pinder (1996, online). An important aspect of the motivation for this study was my interest in gaining a more holistic understanding of the disability experience of Pakistani families with disabled children.

Occupational therapy's models

Having described the three major models of disability, I will now discuss how developments in occupational therapy have been influenced by these models, particularly the medical and social models. I will then move on to suggest that these occupational therapy concepts may be helpful in identifying how those aspects of the social model of disability that relate to disabled people's additional social differences could be made more explicit.

Although many of the specific occupational therapy interventions for various impairments are based on the medical model of disability, the more comprehensive models of human occupation, which are applicable to any person regardless of impairment or circumstances, are based on the concept of "health and ability as personal adaptation", appearing around the same time as the social model. Chapparo and Ranka (2005, p58) argue that the roots of this concept lie in post-modern thinking, which questions the medical model in terms of its reductionist view on disability and ill-health, and its focus on needing to fix the problem at individual level and through specialist intervention only. Instead more person-centred and personally-directed approaches to rehabilitation were developed, which recognised the complexity of disability as it is influenced by the social and physical environment as well as the specific impairment of the person.

There are a number of occupational therapy models, developed in the context of different (Western) countries and clinical specialities, but in essence they all recognise the interplay between the person, occupation and the environment, as well as the autonomy of the person in taking decisions about how issues faced might be best addressed. Most visual representations put the person and their physical, cognitive, affective and spiritual characteristics in the centre of the model; with a further band of occupation / occupational performance (productivity, self-care and leisure); and the final, outer band representing the physical, social, cultural and institutional environment. Figure 5.1 gives a representative example of a model, i.e. the Canadian Model of Occupational Performance (Law et al, 2002, p32).

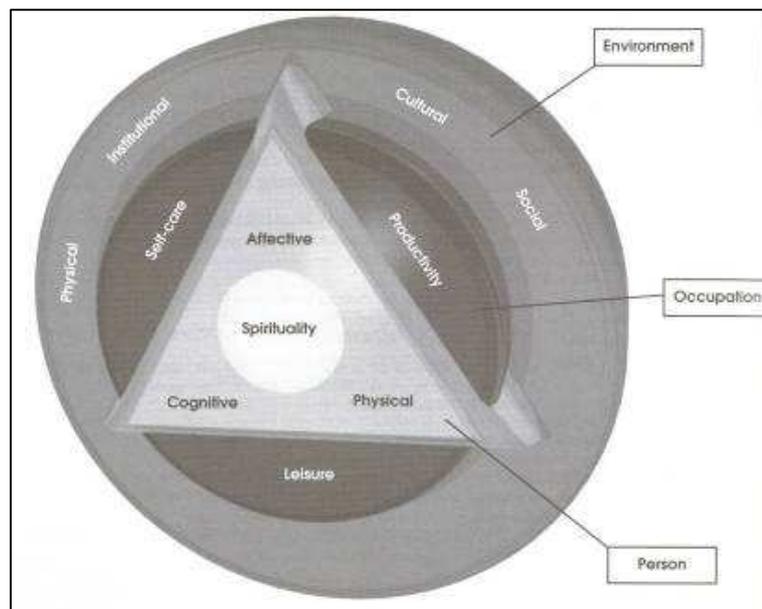


Figure 1.4.1: The Canadian Model of Occupational Performance
Source: Law et al, 2002, p32

The models tend to recognise that the person needs to gain as much insight and control over the process of increasing their participation in occupation as possible. Although the models look at the situation holistically, the intervention or action tends to start from the individual, and any change pursued in the environment would usually be in direct relation to that particular individual,

therefore not necessarily challenging why social or physical barriers exist in society in the first place.

Human Rights and Community Based Rehabilitation

As described in chapter 1.3 however, more recent theorising around the concept of occupation has identified that many reasons for limited participation in occupation lie outside the disabled person, and the current models of occupational therapy intervention are starting to be reviewed in that light. The WFOT's position papers on Human Rights and CBR seek to influence occupational therapists' approaches to working with individuals and communities.

Occupational Therapy and the International Classification of Functioning Disability and Health

Another development that describes an understanding of disability as an interplay between factors at individual level and at environment level is the World Health Organisation's International Classification of Functioning, Disability and Health (ICF). Like occupational therapy, the ICF addresses (1) people's capacity to engage in activities, (2) their actual participation and (3) the ways their environment inhibits and supports that (Wilcock and Hocking, 2004, p223) and has therefore been helpful in reviewing occupational therapy models, particularly in view of increasing the emphasis on environmental factors. One of the strengths of the ICF is its acknowledgement that there is no simple cause and effect relationship between impairment, activities and participating in life situations:

Not only do ill health or impairment affect what occupations people are capable of doing (activities) and actually do (participation), but conversely, participation and activities can affect body structures and health condition. This, of course, is the premise on which occupational therapy is founded (Wilcock and Hocking, 2004, p224).

The following figure shows this multidirectional influence clearly through the use of double-pointed arrows linking all factors.

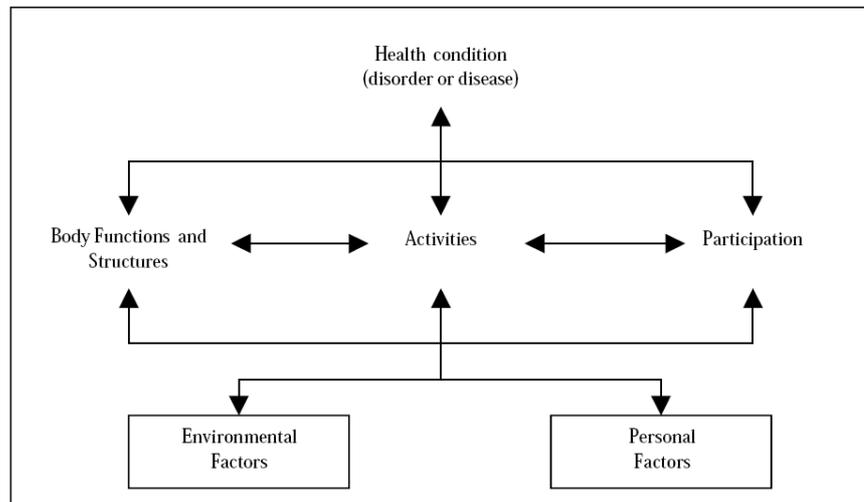


Figure 1.4.2: The ICF. Source: WHO (2001), p18.

An integrated model

The College of Occupational Therapists (COT, 2002) has used the ICF in combination with the Ottawa Charter for Health Promotion (see chapter 1.3) and occupational therapy concepts to present a strategy for modernisation and more effective integration of occupational therapy services provided in local health and social care settings in the UK. In doing so a very comprehensive model is created, which is set in an overall public health and health promotion approach, but also values the therapeutic intervention at individual level (see figure 1.4.3).

This model's main strength is that it acknowledges that in order to bring structural changes which will eventually promote occupational wellbeing throughout the population, it is imperative that interventions at societal level and at individual level are coordinated. In other words, neither enhancing the disabled person's abilities, nor fighting societal barriers will be able to address the 'problem of disability' in isolation. At this time the majority of occupational therapists still work with individual clients in the health and social services, where

their intervention is becoming increasingly client-centred which enables clients and their carers to have more control over the intervention. There is also a growing number of occupational therapists working in non-traditional settings,

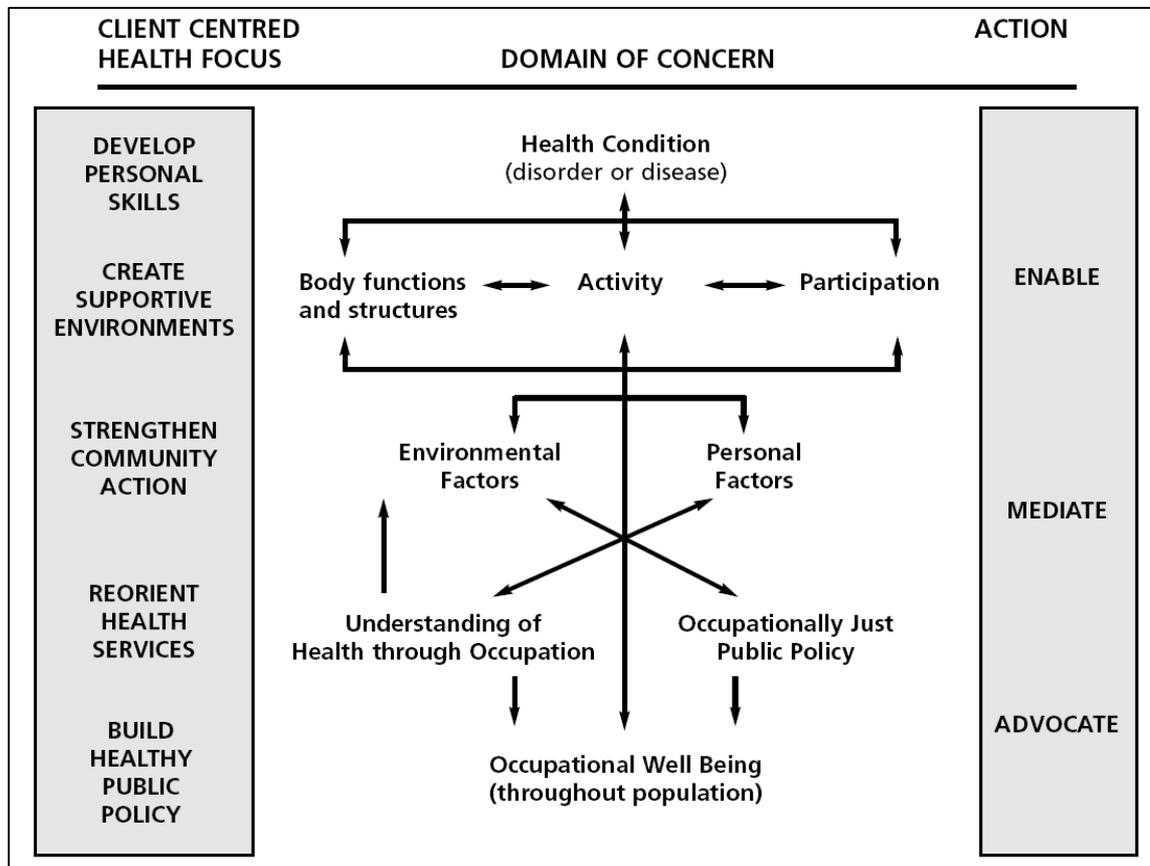


Figure 1.4.3: The ICF set within the Ottawa Charter for Health Promotion

Source: COT, 2002, p20.

developing new roles particularly in the voluntary sector where there tend to be more flexibility and opportunity to work with groups and communities.

For a researcher with a background in occupational therapy as well as community based approaches in cross-cultural settings a comprehensive model like the one presented by the COT is very useful. However the model needs to be viewed and reviewed with a cultural lens in each context, so that the relative importance and meaning of each of the factors becomes meaningful for the particular population. The influence of religion and culture on people's concepts/models of disability needs to be made more explicit and

recognised for their potentially positive effect on the way individuals, families and communities live with disability. This is as true for this occupational therapy model as it is for the social model of disability.

The COT model suggests one practical way of bringing together aspects of the traditional and medical models in an overall framework based on the social model, that demonstrates that the more explicit acknowledgment and use of the older concepts can be an enrichment of, rather than being at odds with social model thinking.

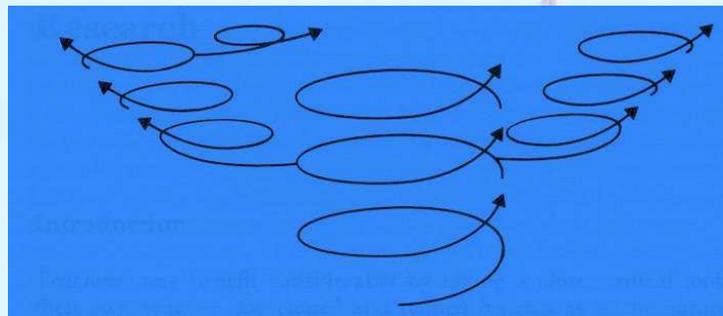
Chapter summary

This chapter has indicated that choosing a model of disability to inform a research study is not a straightforward matter. An important issue in this is that the different models are often presented as mutually exclusive, whilst in reality all three commonly described models, i.e. the traditional, the medical and the social models contain relevant elements. In the findings and discussion chapters it will become evident that this was true for the Pakistani families in this study too. A comprehensive model like the one suggested by the COT is helpful in increasing insight into how these different aspects of the lived experience of disability are interlinked.

The first four chapters of this thesis have presented the background to this study, having presented its context and rationale, an overview of previous research related to Pakistani families with disabled children and a discussion of concepts of occupational science and models of disability relevant to the study. The following two chapters, which form Part 2 of the thesis, will present the methodology and design of the study.

PART 2: RESEARCH METHODOLOGY

Chapter 2.1: Research Methodology



"Messy action research spirals"

From: McNiff (2002)

2.1: Research Methodology

This chapter presents the theoretical background for the choices I made regarding the research approach and methods used in this study. The first section explains the need to position this study within the critical research paradigm, followed by a discussion about emancipatory and participatory methods. After this participatory action research, which is the approach used in this study, is described in more depth, including key issues of underlying epistemology, nature of participation, and criteria for judging quality in action research.

Choosing the appropriate research paradigm

Before embarking on a research study, it is essential to consider what methodology to adopt. These considerations need to be based on what the study seeks to achieve, that is, the reasons for the choice of focus and research population and how the researcher believes new knowledge and information about them might be best acquired.

Dominant Research Paradigms

Two major, divergent views about the nature of knowledge, usually seen as competing paradigms, can be defined as the positivist paradigm – associated with quantitative research strategies – and the interpretive paradigm – associated with qualitative research strategies (Henn et al, 2006, p10). These paradigms are rooted in different ontologies – or sets of assumptions about what the world is – and epistemologies – or ways of knowing about that world which reflect these assumptions. These assumptions in turn will be reflected in the chosen methodology and specific methods to be used during the research (Henn et al, 2006, p 17).

The positivist paradigm starts from the premise that knowledge is based on phenomena that are directly observable, and therefore that the social world should be researched using the principles of natural sciences. The data are then analysed to show causal links and generalisations, through statistical testing of a predetermined theory, or in order to identify new theory. In order to do this, it is important that the researcher remains detached from the respondents in order to achieve objectivity of the data.

The interpretive paradigm's premise is that knowledge is based on understanding interpretations and meanings that are not directly observable and suggests the social world should be studied in its natural state, to understand naturally occurring behaviour. Explanation of the data is achieved through descriptions of social meanings / reasons and other dispositions to action. In this paradigm theory is generated from the data. In order to achieve this, the researcher needs to take an insider approach by participating in the participants' lives and/or developing closeness, so that the data is constructed jointly and therefore 'subjective' in the sense that the participant's (or subject's) experiences and views are essential for drawing conclusions about the data. The analysis of data is based on verbal, action and situation description from which theory is developed (Henn et al 2006, p16).

An alternative paradigm

Although the positivist and interpretive paradigms are still dominant in social research, a third position is gaining in recognition, which is often described as a critical or critical-emancipatory approach. The underlying ontology in this paradigm is that researchers need to take account of historical, social and political influences on human thought and action and that social structures have historically served to oppress certain groups in society, particularly the working class, women and ethnic groups. In view of this position, critical approaches have emancipatory goals and seek to bring empowerment to oppressed groups. The purposes are to expose inequalities and injustices; to

give voice to excluded and marginalised groups; and to help explain generalised oppression in order to enable positive social change (Henn et al, 2006, p15-16). Critical social researchers tend to adopt a flexible approach in using research methods, adopting as well as adapting methods that can serve the purpose of the desired outcomes of the research (p17).

The appropriate paradigm for this study

The fundamental purposes of this study were to explore with Pakistani families with disabled children what their support needs are and how these can best be met. As has become evident in the literature review, these families appear to be caught in a complex web of exclusion and disadvantage, which makes it difficult for them to be aware of what exactly their needs are, and how these needs might be met. Giving voice was therefore an extremely important aspect of the research, but was complemented by a process that had the potential to lead to positive social change. The study therefore fitted into the critical social research paradigm.

Emancipatory Disability Research

Social researchers have been researching 'disability' related issues for most of the last century (Barnes, 2003, p4). However, this research has often not sought the personal benefit for the 'subjects', but rather concentrated primarily on serving the progress of scientific knowledge, giving little importance to what the research process and outcomes might mean to the people providing the data. The approaches taken to research have been in line with the models and conceptualisations of disability that were / are prevalent in society. As Oliver (1992, p101) puts it:

in the past 100 years or so industrial societies have produced disability first as a medical problem requiring medical intervention and second as a social problem requiring social provision.

Both views have located the 'problem' of disability within the person. Those viewing disability as a medical problem more commonly worked within a positivist paradigm, and those viewing it as a social problem within an interpretive paradigm. Although this type of research may have yielded some useful knowledge,

disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life (Oliver, 1992, p105).

A major problem in much of this research production lies in the social relations that are formed for its purpose, in which a firm distinction is seen between the researcher and the researched, the former having 'expert' knowledge and with that the perceived right to be in control of the research process throughout (Oliver, 1992, p102). The core of the problem has thus lain with the fact that "it has taken place within an oppressive theoretical paradigm and within an oppressive set of social relations" (Stone and Priestley, 1996, online), which have often prevented participants' own voice from being heard. Although a lot of interpretive research appears to have the intention to be more benign than positivist research, and to present the point of view of the research participants, the social relations have tended to remain those of the expert and the informant, particularly in terms of decision making about focus and method and in terms of data analysis. In addition it tends to locate the problem of disability exclusively in the person, thus perpetuating the exclusion and oppression of disabled people.

With the birth of the social model of disability, which locates the problem of disability in the social and political structures of society, the demand for an adequate research approach to match this radically different view of disability also arose. As Stone and Priestley (1996, online) put it:

the focus of disability research will have less to do with the ability of disabled people to 'cope with' or 'adapt to' their situation and more to do with the identification and removal of physical and social barriers.

In the disability studies literature, this alternative approach has generally been described as "emancipatory disability research".

Barnes (2002, online) gives a very useful overview of key characteristics of this new approach to disability research, which I will summarise here as a frame of reference to refer to throughout the thesis:

The most crucial issue is that *control* over all aspects of the research process should lie with the participants. Although this is not easy to achieve fully, the commitment of the researcher to work towards this goal as far as possible in their situation, is essential.

Accountability to the disabled community is also a key component.

Adherence to the *social model of disability* is another fundamental requirement, as this will not only enable the researcher to form collaborative relationships with the participants, but also ensure that the focus of the research is related to the identification and removal of physical and social barriers.

Questioning the need for and validity of the concept of '*objectivity*' as demanded in traditional research paradigms.

Emancipatory disability research has generally been associated with qualitative data collection strategies. However "it is not the research strategies themselves that are the problem; it is the uses to which they are put", so if quantitative data are more likely to influence public opinion and government policy their use is fully justified. The key point made here is that the choice of method – or

combination of methods – should be determined by the purpose of the research.

A further issue to consider is the role of *personal experiences of disabled people*. On the one hand the focus of the social model on barriers imposed by society might make researchers reluctant to focus on individual disabled people, as this may carry the danger of locating the 'problem' of disability back in the person, rather than society, inadvertently reinforcing the 'personal tragedy theory' of disability. However Barnes explains that

what is important is that discussions of disabled people's experiences, narratives and stories, are couched firmly within an environmental and cultural context, in order to highlight the disabling consequences of a society that is increasingly organised around the needs of a mythical affluent non-disabled majority.

The final key characteristic of emancipatory disability research is that it should have some *meaningful practical outcome* for disabled people. This outcome should ideally not be restricted to the participants in the research, but be made available to the broader disabled community as well. Hence a high priority is placed on disseminating the findings, both widely and in various ways, keeping a number of different audiences in mind.

Barnes concludes by stating that "by definition, emancipatory disability research should be judged mainly by its ability to empower disabled people through the research process". In addition to "empowering the disabled population, emancipatory research must resonate with non-disabled people too", as they have a major role to play in reducing barriers faced by disabled people.

Researchers' clarity about methods

Although the above characteristics describe what emancipatory disability should look like, it is hard to find texts that suggest which methods might best achieve its aims. Barnes and Mercer (2006, p62) state that

there is a particular silence within the disability research literature on methodological issues, including the appropriateness and merits of specific methods for data collection, processing and analysis.

They subsequently describe the methods used for the project that forms the basis for their book ("Creating Independent Futures"). The authors urge that due to the lack of agreed guidelines and standards so far, disability research should be transparent in its research design and methods (p68). I will therefore not only present the methodology and methods used for this study clearly in this and the next chapter, but also evaluate to what extent this study met the criteria for Emancipatory Disability Research as suggested by Barnes (2002), in the analysis in chapter 4.1.

Given the fact that emancipatory disability research is not prescriptive in terms of methods to be used in order to meet its criteria, researchers and academics in the field of disability studies have drawn on a number of other research approaches. Crucially, as explained above, within emancipatory disability research it is not the existing research strategies themselves that are considered to be the problem, but the uses to which they are put, and the research relationship within which they are applied. Therefore quantitative, qualitative as well as critical research approaches may be used.

Whally Hammell (2007), an occupational therapist and researcher points out that beneficial disability research operates in the light of issues of power and participation and is therefore congruent with the principles of client-centred practice (see chapter 1.3), which is now a requirement for all therapists to apply.

Thomas (2007) points out that within the social oppression paradigm, which is the core of emancipatory disability research, a variety of research approaches have been used, though always with an explicitly stated commitment to advancing disabled people's social inclusion and full citizenship.

Firstly, materialist scholars focus on the ways in which social oppression is bound up with the social relations and practical implications of production in capitalist societies. They point out that since the industrial revolution and the rise of factory production of commodities, it became much harder for disabled people to meet the demands of the production process, leading to their devaluation and exclusion from communities. People being considered 'impaired' or 'abnormal' led to the development of medicalised systems of treatment in which disabled people became controlled by and dependent on institutional regimes or, more recently, community care. This interpretation of history also prompts materialist researchers to investigate in which ways contemporary societal structures and cultures lead to social exclusion of disabled people.

Secondly, post-structuralist researchers focus on culture, language and discourse, rather than economic (materialist) factors. They reject the binary thinking (i.e. the 'normal' versus the 'abnormal') in materialist theory and set out to show that impairment is entirely socially construed.

Thirdly, feminist approaches have also been used and become very influential within disability studies. Feminism initially focused on studying issues of choice and control in women's lives, and on their rights and access to attain these. These concepts are highly relevant to other oppressed groups too, and are now applied to study a range of '-isms', for example racism and disablism. See for example Morris' book *Encounters with Strangers* (1996), which challenges both feminist researchers and those engaged in disability studies to address issues faced by disabled women, as they are faced with multiple disadvantage.

Morris thus brought to light that many disabled people face complex exclusionary barriers, for example being disabled and from an ethnic minority group.

In addition some qualitative approaches within medical sociology have also been used, such as illness narratives, phenomenology and ethnomethodology, which all aim to construct meaning. Whilst these approaches may describe participants' situations critically at times, they do not challenge the situation (Thomas, 2007). Even though from the 1970s conflict theories started to focus on social / societal causes of ill-health (for examples inequalities in health due to poverty) and the medicalisation of society (which enforces passivity in patients whilst medical science and doctors dictate the right lifestyles and choices) the underlying assumptions remained the fact that disability and illness were a form of 'social deviance': the focus was on the 'management' of socially deviant individuals in order to limit their detrimental effect on the coherence of the social system. As these underlying assumptions are not congruent with social model theory, these approaches fail to meet at least one fundamental criteria of emancipatory disability research, being "adherence o the social model of disability" (Barnes, 2002, see above).

Another set of research approaches that have developed in different settings or situations, which have much in common with emancipatory disability research, in particularly their emancipatory goals, are used to address a broad range of social justice issues rather than disability only. Examples of this are a range of participatory approaches, action research and participatory action research. The motivation for the choice to use participatory action research for this study will be described at length below.

Researchers' commitment to the core values of emancipatory disability research

In summary, the radically different relationship between the researcher and the researched in emancipatory (disability) research as compared to traditional

research is a core value. This relationship is both essential and difficult to attain. Barton (2005, p319) points out that

research of this nature entails a demanding and disturbing process in which the emphasis is on self-reflection and criticism, ... one of the main issues that such an approach raises concerns the question of power and the realization of a dignified relationship for all participants within the research process based on trust, respect and reciprocity...which is a time-consuming, demanding and disturbing task.

Consequently, researchers need to be aware that their work is likely to be limited and incomplete. In view of this "they need to be more open and self-aware in relation to their own values, priorities and processes of interpretations", especially considering the fact that their research participants are "marginalized people who experience varying degrees of social exclusion, stereotyping and discrimination" (Barton, 2005, p320).

Different forms of emancipatory disability research

As the concept of a social model of disability and the associated concept of emancipatory disability research became more defined and more widely acknowledged, researchers from a range of backgrounds started to use and adapt existing research approaches and to develop new ones, that could meet their stated principles. This is a recent and ongoing process and definitions and terminology are still evolving. Important examples are (Service) User Controlled Research and Survivor Research (Turner and Beresford, 2005, p4), which emphasise the central importance of the participating service users or survivors having control over ALL aspects of the research process. Even large service providers such as the National Health Service, which have strong groundings in the medical model of disability, are now challenged to respond to a broader acceptance of the social model and seek to involve users in their research and development, though the extent of user control varies considerably within this work. INVOLVE, which is the NHS's national advisory

group on user involvement, acknowledges that there is a continuum of involvement ranging from 'consultation', through 'collaboration', to 'user control' (Buckland et al, 2007). Only the latter could be considered a form of emancipatory disability research.

Participatory Action Research

One of my objectives for conducting this study, was to consider whether participatory action research could be used as a research approach to achieve the purposes and criteria of emancipatory disability research. Therefore the following section describes participatory action research in further depth and explains why I considered it the most appropriate approach to use in this study.

Defining Action Research

Participatory action research is part of a family of research approaches that come under the umbrella of "Action Research". A generic definition for this family of approaches is given by Reason and Bradbury (2006, p1) as follows:

Action research is a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people and more generally the flourishing of individual persons and their communities

They go on to stress that it is "based in a rather different form from traditional academic research – it has different purposes, is based in different relationships, and has different ways of conceiving knowledge and its relation to practice" (p1).

The coining of the term 'action research' is generally attributed to the social psychologist Kurt Lewin (1890 – 1947), "a seminal theorist who deepened our

understanding of groups, experiential learning and action research" (Infed, online). Lewin developed and applied action research over a number of years in a series of community experiments in post-world-war II America, in a variety of challenging social settings. Two crucial ideas in this development were 'group decision' and 'commitment to improvement':

A distinctive feature of action research is that those affected by planned changes have the primary responsibility for deciding on courses of action which seem likely to bring improvement and for evaluating the results of strategies tried out in practice" (Kemmis et al, 2004).

Lewin described the process of action research as a spiral of cycles, each of which consists of planning, action, observation of the impact of the action, and evaluation of that action and its impact (Kemmis et al, 2004, p3, see figure 2.1.1).

This is a dynamic process in which these four aspects are not seen as static steps, but rather as moments in the action research spiral. In the process, the aim is to bring together discourse and practice through constructive (planning and acting) and re-constructive (observing and reflecting) processes, so that improvements in practice and understanding can be made systematically, responsively and reflectively. (Kemmis et al, 2004, p7).

Before embarking on the first cycle of the action research spiral, the process begins with a general idea and the sense that some kind of change is desirable. The idea of improvement prompts a reconnaissance, or exploration, of the current situation, in order to understand it better. On the basis of this reconnaissance phase the initial plan of action is decided and the first cycle of the action research spiral has begun (Kemmis et al, 2004, p3). McNiff (2002, p56-7) points out that the cycles of action research do not tend to evolve in a neat sequential process, but a messy process of different cycles being in motion

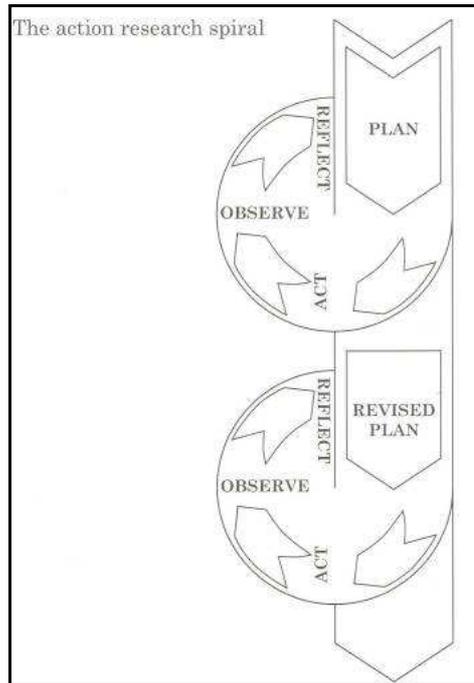


Figure 2.1.1: The action research spiral

concurrently, and there being 'spirals off spirals', and concurrent cycles influencing each other.

In the decades since the 1940s many different types of action research have been developed to serve different purposes of different types of communities. McCutcheon and Jurg (1990) describe how action research has been carried out by researchers subscribing to positivist, interpretive as well as critical paradigms, concluding that "action research can take on different characteristics because underlying it are differing epistemological assumptions, which in turn shape methodological choices as well as how problems are formulated" (p150). An example of action research from a positivist perspective is total quality management, as applied in the business sector, which incorporates cycles of plan-act-observe-reflect as well as methods of statistical control to eliminate variation in products (Herr and Anderson, 2005, p9). However, Brydon-Miller et al (2003, p11) contend that although action research is used in a broad range of disciplines,

what links them is the key question of how we go about generating knowledge that is both valid and vital to the well-being of individuals, communities, and for larger-scale social change. Action research challenges the claims of a positivistic view of knowledge which holds that in order to be credible research must remain objective and value free.

Whether research carried out on the basis of positivist assumptions can be described as action research therefore seems to continue to be debated.

Participatory Action Research

One approach to action research that is firmly grounded in the critical-emancipatory paradigm is participatory action research, an emancipatory practice aimed at helping an oppressed group to identify and act on social policies and practices that keep unequal power relations in place (Herr and Anderson, 2005, p9). Reason (1994, p6) contends that it is

probably the most widely practiced participative research approach (and that) it is important because it emphasises the political aspects of knowledge production.

It starts with concerns for power and powerlessness and aims to confront the way in which the established and power-holding elements of societies world-wide are favoured. Secondly the lived experience and knowledge of people, often oppressed groups, are directly valued and central to the process. The two major aims are to produce knowledge and action that are directly useful to the participants and to empower people through the process of constructing and using their own knowledge, a process described by Paulo Freire (1970) as "conscientization".

Another important point is authentic commitment of the researcher and the participants to the processes of genuine collaboration. For this to happen

dialogue is very important, as it causes the subject/object relationship of traditional science to give way to a subject/subject one,

in which the academic knowledge of formally educated people works in a dialectical tension with the popular knowledge of the people to produce a more profound understanding of the situation (Reason, 1994, p7).

Herr and Anderson, 2005, p16) describe how Freirian-inspired participatory research challenges traditional academic research models at almost every point:

the dualisms of macro/micro, theory/practice, subject/object and research/teaching are collapsed..... Whereas traditional action research tends to emphasize issues of efficiency and improvement of practices, participatory research is concerned with equity, self-reliance and oppression problems.

The epistemology of (participatory) action research

Having argued that participatory action research is a good choice of method for conducting emancipatory disability research, it is important to also show that it is based in a clear epistemology. Reason and Torbert (2001, online) offer an epistemological basis for action research as part of a new transformative social science.

The 'action turn'

Before going into detail they describe how they view the new, alternative paradigm in which action research fits. They describe how the debate about research methods tends to take place between the positivist and interpretive views, with the latter drawing on the 'linguistic turn'. In the linguistic turn reality is viewed as a human construction based on language and a variety of qualitative methodologies are used to portray these constructions or even

deconstruct taken-for-granted realities. They go on to argue that neither of these two broad approaches can form a suitable epistemological basis for action research and that a further 'turn' can be identified as "an 'action turn' toward studying ourselves in action in relation to others" (p2). They present the action turn as complementing the linguistic turn and placing "primacy on practical knowledge as the consummation of the research endeavour".

Four characteristics

Having located it in the 'action turn paradigm' Reason and Torbert then move on to explore four characteristics of action research (p5-10):

Firstly, as all human persons are participating actors in their world the purpose of inquiry is to forge a

direct link between intellectual knowledge and moment-to-moment personal and social action, so that inquiry contributes directly to the flourishing of human persons, their communities, and the ecosystems of which they are part.

This implies that research and action are inextricably intertwined in practice, even though they can be distinguished as two separate strands in analysis. As the 'quality of knowing' becomes the paramount concern, this form of research is not dominated by methodology; rather it uses methodology to enhance the inquiring capacity of persons, organisations and communities (p7). Similarly, Meyer (2006, p121) points out that action research is "a style of research, rather than a specific method".

Secondly,

since human persons are fundamentally social creatures, human knowing after the action turn is essentially participative, growing from collaborative relations with each other as co-inquirers into our world (p6).

Based on the view that people are agents who act in the world on the basis of their own sense making and that communities engage in mutual sense making and collective action, it becomes impossible to do research *on* persons. The only option is to do research *with* persons, including them both in the questioning and sense making that informs the research *and* in the action which is the focus of the research (p7). The importance of this goes beyond the level of epistemological assumptions and has political implications, affirming

the basic human right of persons to contribute to decisions which affect them and to knowledge which concerns them and purports to be about them (p8).

Thirdly all knowing is based in the sensing, feeling, thinking, attending experiential presence of persons in their world; this is the fundamental grounding of all knowing. This 'experiential knowing' is often tacit and pre-verbal. This implies that "research needs to be grounded in an in-depth, critical and practical experience of the situation to be understood and acted in" (p8), as only then will it be possible to know what questions need to be asked. Heron and Reason (1997, online) define four ways of knowing, of which this experiential knowing is the fundamental first form. Further forms of knowing are 'presentational knowing', an intuitive grasp of the significance of how we experience and view the world, and expressed in graphic, plastic, musical, vocal and verbal ways; 'propositional knowing', knowing in conceptual terms that something is the case and expressed in statements and theories through language; and 'practical knowing', knowing how to do something, demonstrated in skill or competence:

it fulfils the three prior forms of knowing, brings them to fruition in purposive deeds and consummates them with its autonomous celebration of excellent accomplishment.

Fourthly all movement of the attention, all knowing, all acting and all gathering of evidence is based on at least implicit fragments of normative theory of what act is timely now, or in other words

theory is intended to guide inquiry and action in the present time... We take action only in order to create a better state, so good action theory will offer a normative vision of a better state (p10).

Levels of 'participation'

As acknowledged above, not all 'participation' necessarily leads to emancipation. A number of participatory researchers has sought to clarify this issue by presenting a 'ladder' or continuum of participation (e.g. Arnstein 1969; Wilcox 1994; Hanbury, 1995; Chambers 2006).

Cornwall (1996, p96) presents a useful continuum of modes - or levels - of participation in participatory action research. Table 2.1.1 on the next page presents the modes of participation, and what type of involvement of participants and what nature of relationship between the research and participants it implies.

As for my study I did not have access to an existing, ready-made group of which I was a legitimate member, I was inevitably an 'outsider' researcher, so that the highest level of participation possible was that of Cornwall's "co-learning".

Participatory Methods: Means to What End?		
Mode of participation	Involvement of local people	Relationship of research and action to local people
Cooption	Token: representatives are chosen, but no real input or power	on
Compliance	Tasks are assigned, with incentives; outsiders decide agenda and direct the process	for
Consultation	Local opinions asked, outsiders analyse and decide on a course of action	for / with
Cooperation	Local people work together with outsiders to determine priorities, responsibility remains with outsiders for directing the process	with
Co-learning	Local people and outsiders share their knowledge, to create new understanding, and work together to form action plans, with outsider facilitation	with / by
Collective action	Local people set their own agenda and mobilize to carry it out, in the absence of outside initiators and facilitators	by

Table 2.1.1: Levels of participation (Source: Cornwall, 1996, p96)

Building on the above discussion of levels of participation and who is in control of the methodology and research process, the concept of 'positioning' in action research needs to be clarified. Herr and Anderson (2005, p29) contend that "clarity about the relationship between outsiders and insiders is necessary for thinking through issues of research validity as well as research ethics". If the researcher studies their own practice it would be seen as 'insider research'. The

various extents of cooperation between an outsider researcher and insider group of participants are essentially the same as modes of participation described by Cornwall (2006) above. The way the researcher positions themselves has an immediate effect on the mode and level of participation and subsequently on the extent of empowerment this may lead to.

The commitment to facilitating as high a level of participation as possible is absolutely essential for ensuring that participants are not merely 'used' or consulted, but can use the research process to empower themselves. When working as a highly educated researcher - with its perceived status and power position - with a group of people who have lower levels of education and are marginalised in society, it can be extremely difficult to actually shift the control into the participants' hands. Not only does the researcher need to be willing and able to hand it over, the participants also need to be able to move out of a dependency mode in order to receive it. As Reason (1994, p18) states:

There are a whole range of skills required for participatory research which are very different from those of orthodox research, and which include personal skills of self-awareness and self-reflexiveness; facilitation skills in interpersonal and group settings; political skills; intellectual skills ; and data management skills.

Maintaining a high level of participation is only possible if the researcher constantly reflects on the status of their relationship with the participants and if the participants are made aware of the desired nature of their relationship and encouraged to monitor and give feedback on it too. My experience of using participatory approaches in community development, planning and evaluation and teaching prior to conducting this study has helped me to maintain a continuous awareness of this aspect and to attain this key aspect of participatory action research to a great extent.

Transformational potential

To an extent the transformational or emancipatory potential of participatory action research is implicit in the description given so far. It is evident that it is not only the methods and processes used that facilitate participants in critically evaluating their situation and planning action to effect change, but very importantly it is also the nature of the relationship the researcher seeks to establish with the participants that determines what level of participation and, through that, what extent of transformation is going to be possible.

Cornwall (1996, p95) states that

in principle, participatory research approaches aim to create new forms of knowledge through a creative synthesis of the different knowledges and experiences of those taking part and is aimed explicitly at transforming current inequalities.

However getting to a situation that both researcher and participants are able to freely share their different types of knowledge and experience at equal footing, is not easily achieved. Soltis-Jarrett (1997, online) addresses the problem of facilitating a group of disempowered people to begin to be able to work with the researcher as equals. She suggests that initially it is important for the facilitator to provide the structure with a certain sense of 'authority', which does not seek to control the group, but rather shows the participants that the facilitator has the knowledge and skills to initiate a productive exchange whilst being willing to share that 'authority' with the group as soon as the participants are ready to take it on. So, rather than practicing in the

traditional sense of authority, where they incur a fixed, distant relationship with the participants in a group ... the facilitator seeks to have a flexible, close relationship with the participants in order to liberate the group.

Through providing this structure, participants can come “to understand the process of being and becoming a co-researcher”. This aspect highlights the congruence between participatory action research and occupational science (see chapter 1.3), as it values the way participants can develop new identities and roles through engaging in the occupation of research. Soltis-Jarrett goes on to say that it is this development of reciprocity and how it is used in critical research that encourages the participants (and the facilitator) to feel free, to use authority, and to reclaim their reality. Reciprocity in this sense is “the art and the action of what the facilitator can uniquely create in participatory action research groups”.

A critical view on participatory research

Participatory research has at times been criticized by proponents of emancipatory disability research, because ‘participation’ does not automatically lead to ‘empowerment’ or control over the research process. For example Zarb (1992, p128) states that “participatory research which involves disabled people in a meaningful way is perhaps a prerequisite to emancipatory research in the sense that researchers can learn from disabled people and vice versa, and that it paves the way for researchers to be available to disabled people – but it is no more than that”. Oliver (2002, p5) argues that participatory research fails research participants by involving them, but not giving them the control over the process. He states that the problem with this approach is that it does not confront the objective structures of oppression and despite good intentions of the researchers, disabled participants are still positioned in oppressive ways. Although this may be true in some cases, it is questionable whether this can be blamed on either the underlying theory, or the research methods used in participatory action research. It must be remembered that research that claims or intends to be emancipatory does not necessarily lead to more empowerment than does participatory research. For example Oliver (1997, online), in describing one of his own research studies explains how he did to some extent succeed in changing the social relations of research

production, but that the methodology and techniques used probably "did not challenge anything at all". More importantly he concludes he can not quite describe his research as emancipatory, although he hopes his experience will eventually be seen as having made a small contribution to that emancipation". This example just shows how difficult it is to change traditional power relationships, even if the researcher is both convinced of the ideology and a disabled person himself. Quoting this example here does not in any way imply criticism of the researcher. On the contrary, it is only through honest reflection like this that progress can be made. However it also means that the fact that a research study has not lead to emancipation, does not necessarily imply that the researcher did not set out to work towards this ideal. This reemphasises the central importance of the research relationship and the need for the researcher to continually review to what extent this is being achieved (see Barton, 2005).

Participatory Action Research and the PhD thesis

Due to the nature of action research and the assumption of the research spiral, it is virtually inevitable that the methodology will evolve throughout the research process, in other words the study has an 'emergent design'. Therefore the methodology proposed before the commencement of the study is "the researcher's best guess as to what will transpire in the field". In light of this evolving methodology "writing a close account of what the researcher actually did and the reasoning behind the methodological decisions made" becomes very important (Herr and Anderson, 2005, p76).

However even with an emergent methodology it is important to have a clear direction about the research, including participants, tentative questions and proposed methods, from the outset, but with the anticipation that there may be a shift in any of these variables along the way.

As a doctoral student who has limited time to carry out the research study and who is an outsider to the group of participants and their community, setting

research questions that reflect the focus and direction the participants might want to take, was a particular challenge. The literature review and my personal experience of working with Pakistani families with disabled children as a service provider and community development worker, ensured that the research questions at least broadly related to the participants' situation. However the questions still needed to be adjusted in light of the reconnaissance process with the participants, and even as the action research cycles were taking place (see chapters 2.2 and 4.1).

Herr and Anderson (2005) suggest that in this type of 'outsider action research', in which the researcher is not 'organic' to the group under study, the researcher is likely to stay in charge of the process to some extent. Data gathering in this case is documentation of the action research process and outcomes and it is essential that the researcher keeps a journal of decisions made, self reflections and so forth (p83).

In view of this, Perry and Zuber-Skeritt (1992 p201-203) caution that it is wise to consider the thesis as something distinctly separate from the action research project. That is, the candidate will have two projects - the core action research project and the thesis project which uses data from the action research project. The difference in primary purpose for engagement in the research for the researcher and the participants is important to keep in mind: in the action research project, action research may be an ideology, but in a PhD thesis it is primarily a methodology (Perry, 1994, online).

The relationship between the thesis project and the core action research project thus becomes one of a research project set within the context of another research project, with the former providing the core data for the thesis. The thesis could therefore be considered a 'frame tale' or story within a story. In this study, the main purpose of the 'thesis project' was to find out how Pakistani families with disabled children might best be facilitated in conducting their own action research project (the 'core project'), for which they set their own

research aims. This distinction and the participants' actual research aims will be described in more depth in the methods and findings chapters.

Figure 2.1.2 on the next page, taken from Perry and Zuber-Skerritt (1992, p204), visualises how the action research cycles of the core project fit into the action research cycles of the researcher's thesis project: the core project – which itself consists of a number of cycles - becomes the action phase of the first cycle of the thesis project. The literature review, making contacts with possible research participants and other relevant contacts, leading to the research proposal, form the initial reconnaissance and planning stages for the thesis project.

This also means that the data may be perceived differently by the researcher and the participants, although there will be an overlap in this. Therefore a careful negotiating and establishing of trusted relationships is probably the key ingredient in building a research endeavour that works for all involved... It is imperative that issues such as who owns the data and who can disseminate findings and conclusions be negotiated upfront and early on (Herr and Anderson, 2005, p83).

In my view this negotiation can also be instrumental in facilitating empowerment and ownership of the project by the participants and I see it as a positive part of the process.

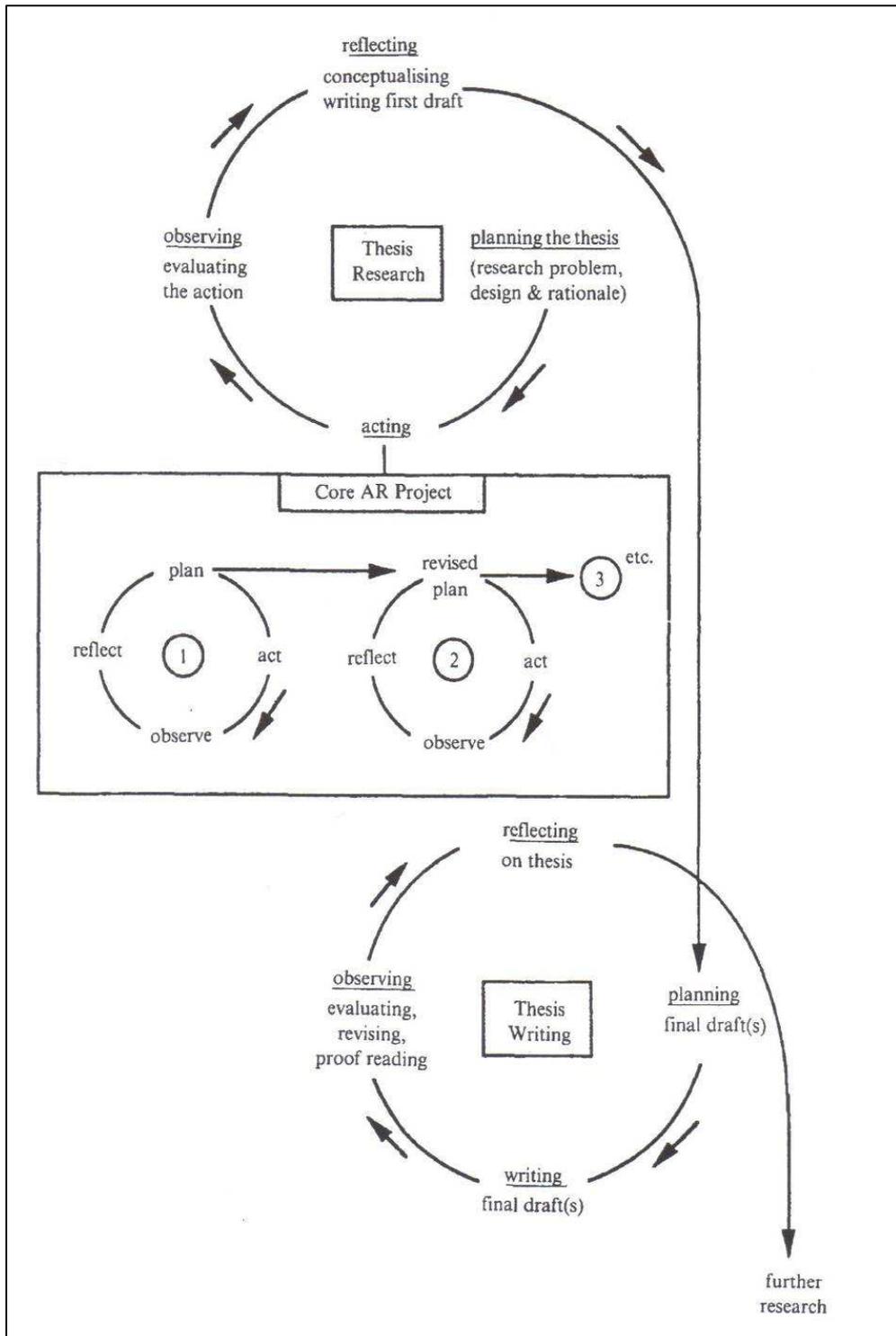


Figure 2.1.2: The action research thesis (Source: Perry and Zuber-Skerritt (1992, p204))

Quality in Action Research: beyond validity and trustworthiness

When considering criteria for 'good' action research neither the positivist idea of 'validity', nor the interpretive idea of 'trustworthiness' are quite adequate, as neither acknowledges its action-oriented outcomes "that go beyond knowledge generation" (Herr and Anderson, 2005, p49) as the learning and change processes experienced by the participants become the primary focus of the analysis.

Because of the alternative approach to research taken by action researchers, both Reason (2003) and Herr and Anderson (2005) argue that in order to judge the quality of action research a new set of criteria needs to be formulated, which relates to the purposes and characteristics of action research as outlined above. Both propose a structure for this which overlap but have slightly different emphases.

Anderson and Herr's Goals of Action Research and Validity Criteria are set out in table 2.1.2 on the next page (Anderson and Herr, 2005, p55).

Dialogic validity refers to a type of peer review process that keeps the researcher in dialogue with others about the research processes and outcomes. This can take the form of reflecting on the collaborative process with the participants and / or of working with a 'critical friend', preferably also an action researcher, to make explicit choices made and results achieved (p57).

Outcome validity relates to "the extent to which actions occur, which lead to a resolution of the problem that led the study", in other words whether the process had successful outcomes. It is important to consider for whom it was successful, either the researcher, the participants, or - ideally - both. In addition, 'resolution of the problem' is not always possible, in which case a successful outcome can mean a reframing of problems in a more complex and meaningful way, leading to a new set of questions, thus leading to further spirals of action research (p55).

Goals of Action Research	Quality / Validity Criteria
1) The generation of new knowledge	Dialogic and process validity
2) The achievement of action-oriented outcomes	Outcome validity
3) The education of both researcher and participants	Catalytic validity
4) Results that are relevant to the local setting	Democratic validity
5) A sound and appropriate research methodology	Process validity

Table 2.1.2 Quality criteria of action research (1)

Process validity asks to what extent problems are framed and solved in a manner that permits ongoing learning of the individual or system, through a series of reflective cycles of problem posing, acting and reflecting. In addition process validity also deals with the quality of relationships that are developed with participants and with the debate over what counts as evidence supporting findings. Here the concept of triangulation, or the inclusion of multiple perspectives and the use of a variety of methods to collect data, may be useful (p55-56).

Democratic validity refers to the extent to which all stakeholders affected by the problem under investigation have been involved in the collaborative research process. The nature of their involvement and the way in which the process and product of the research are relevant to them is also important (p56)

Finally catalytic validity is concerned with the way in which both the researcher and the participants have been able to reorient their view of reality, to be moved to action to change or reaffirm it, and to evaluate their role in the social situation and the research process. These new understandings are likely to develop in a spiralling fashion along with the research process and must be recorded throughout, so that they can be made explicit to those involved in

the research and those interested in the outcomes. Catalytic validity thus highlights the transformative potential of action research.

Reason and Bradbury (2006, p12) add a further two criteria relating to:

- questions of emergence and enduring consequence (linked to Herr and Anderson's process validity) and
- questions of plural ways of knowing (related to Herr and Anderson's process and outcome validity).

The question of plural ways of knowing is related to the four ways of knowing described by Heron and Reason (1997) as I have outlined in the section about the epistemology of action research above (p77). Working towards the situation that participants and researcher are able to consciously use their experiential, representational and propositional knowledge in order to influence their practice is one way of describing the action research process and provides data of different natures, aiding in triangulation and crystallization.

In terms of the emergent nature of action research, Reason (2006, p189) states that "good action research does not arrive fully-fledged in a clear research design separate from the stream of life, but evolves over time The inquiry process begins at the initial moment of inception ... and continues well after any formal research is complete". The researcher's choices about quality depend strongly on the stage of the research process and Reason therefore argues that quality in inquiry comes from awareness of and transparency about the choices available at each stage of the inquiry.

Thus Herr and Anderson (2005) and Reason and Bradbury (2006) provide a total of seven goals and quality criteria for action research as shown in table 2.1.3. The seven criteria for assessing the quality of action research described above rely heavily on the researcher's ability to reflect on the research process and the choices associated with it and to make this process explicit and

transparent. Hall (1996, p29) asserts that “reflexivity is integral to ... action research and is a part which should be made more obvious”. Hall concludes that more reflexive practice would strengthen both the ethics and credibility of action research. The researcher needs to be reflexive both during the data collection and analysis phases of research, as well as reporting reflexively in the final product (p32). I have used these seven criteria to assess the quality of this study in chapter 4.1).

Goals of Action Research	Quality / Validity Criteria
1) The generation of new knowledge	Dialogic and process validity
2) The achievement of action-oriented outcomes	Outcome validity
3) The education of both researcher and participants	Catalytic validity
4) Results that are relevant to the local setting	Democratic validity
5) A sound and appropriate research methodology	Process validity
6) An emergent, flexible design	Process validity
7) The development of plural ways of knowing	Outcome and process validity

Table 2.1.3 Quality criteria of action research (2)

The approach to data analysis is determined by these criteria, and the description and discussion of the process by which new (content) knowledge was gained is at least as important as that knowledge itself. Herr and Anderson (2005, p86) suggest that this centrality of the quality of the process may cause readers who are more accustomed to more traditional research approaches to ask what exactly the findings of an action research project were. They contend that “solid action research leads to a deepened understanding of the question posed, as well as to more sophisticated questions. The findings should demonstrate this kind of deepened understanding”. See pages 124-128 for a

description of the approach to data organisation and analysis used in this study.

Congruence between emancipatory disability research and participatory action research

Having described both research approaches, it will be useful at this point to summarise the congruence between. Table 2.1.4 is organised according to the criteria for emancipatory disability research as presented by Barnes (2002) and Barton (2005) and only uses descriptors of participatory action research used in the preceding sections.

There clearly is a very close 'fit' between these two approaches, with the only obvious differences being (1) that participatory action research has been used by a wide range of people facing marginalisation for different reasons besides disability and (2) that participatory action research tends to use a cyclical process of action and reflection, whilst in emancipatory disability research multiple methods are used. There are no evident contradicting principles between the two approaches and provided the researcher has a genuine commitment to achieving the emancipatory goals and is able to work reflectively, a participatory action research study involving disabled people should meet the criteria of emancipatory disability research.

EMANCIPATORY DISABILITY RESEARCH	PARTICIPATORY ACTION RESEARCH
Control should lie with participants	Preferably carried out by or with participants
Accountability to disabled community (in other words siding with an oppressed group in society)	Aims to facilitate an oppressed group to identify and take action on unfair social policies and practices
Adherence to social model of disability	Confronting established social power relationships
Questioning objectivity of research	Subject-subject relationship between researcher and participants
Flexible methods according to purpose of study	Emergent design – AR as a flexible style/approach rather than a set method
Value of personal experience for understanding barriers	Four ways of knowing: experiential, representational, propositional and practical
Meaningful practical outcome Empowering	Pursuit of practical solutions Concerned with equity, self-reliance and oppression problems
Researcher's need for self-reflection and criticism	Researchers need for personal skills of self-awareness and self-reflexiveness;

Table 2.1.4: Congruence between emancipatory disability research and participatory action research

The use of participatory action research in this study

It appears then that in principle participatory action research is a very suitable method to use in the pursuit of emancipatory disability research, provided it is carried out with the highest levels of participation, that is, co-learning or collective action (Cornwall, 1996, p96). A disempowered group of participants will benefit from learning the necessary skills needed for carrying out research of this nature and may therefore need an external researcher to facilitate the

research process and this skill development through co-learning, before being able to conceptualise possible future (research) projects independently through collective action without outside facilitation.

Regardless of the level of participation that has been possible for the disabled children in the families themselves - in view of the extent of their impairments – it is right and important to describe this research as emancipatory disability research. As argued at the end of the literature review about families with disabled children, the whole family is affected by attitudinal, social and service barriers faced in seeking support and can therefore be considered a 'disabled family'. Families as a whole can benefit from exploring the actual causes of their problematic situation, the nature of their needs in view of this situation and ways of ensuring these needs are met more effectively.

There are examples of action research being used with minority groups. For example Chiu (2003) describes the transformational potential of focus groups practice in action research, based on her experience of research projects with ethnic minority women commissioned by the NHS. However participatory action research studies in which both ethnicity and disability form aspects of a group's marginalised status were more difficult to find and I identified only one in which people with mental health needs were involved (Seebohm et al, 2005).

Furthermore, I have not found studies that have involved whole families in a participatory action research project. Therefore the actual methods I used have not only relied on the described literature which suggests it should be applicable to a group facing complex marginalisation, but also on my previous experience of working with families, living and working with Pakistani people and using participatory approaches.

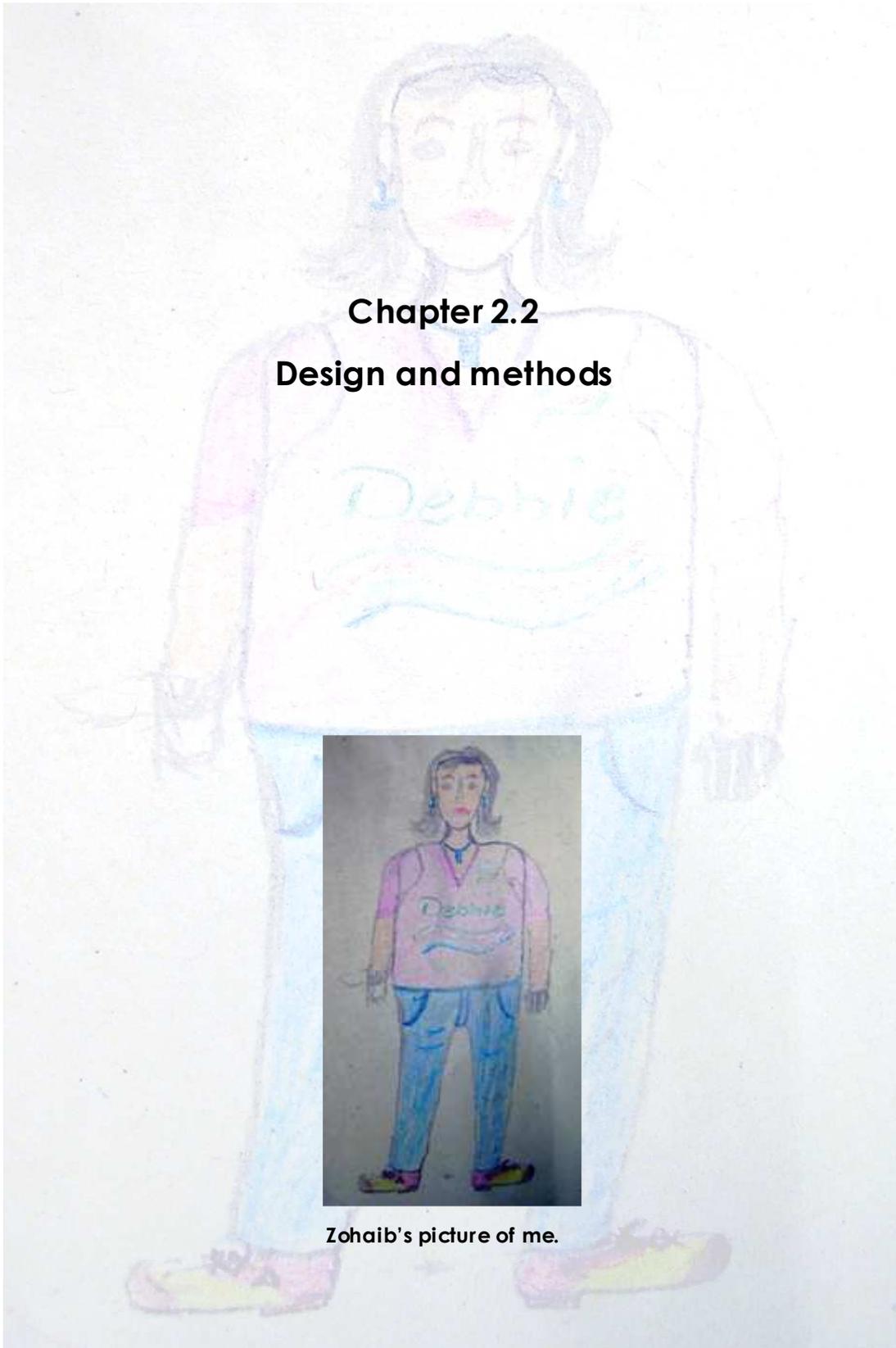
Chapter summary

This chapter has provided theoretical arguments regarding the appropriate methodology for this study. It was argued that a critical-emancipatory

paradigm was needed because the participants were members of a marginalised population group. As the key issue under study was disability, emancipatory disability research was deemed the appropriate research approach and it was proposed that participatory action research could provide a suitable method to achieve its objectives. Criteria to judge the quality of the action research and the extent to which the study could be considered to be emancipatory disability research were presented and will be used in chapter 4.1 (analysis) to assess this.

The next chapter presents the research design and methods employed in this study in detail.

Chapter 2.2
Design and methods



Zohaib's picture of me.

2.2: Design and methods

The purpose of this chapter is to describe the design of the study and the actual methods used, so that the reader gains a clear understanding of the theoretical arguments and practical reasons for the choices made in the research process. The first part of the chapter presents the objectives of the study, for which the rationale was provided in the preceding chapters, and the research questions which were used to meet these objectives. The second part describes the methods used to create practical opportunities for the participants and the researcher to find or provide answers to the research questions. The third part discusses ethical issues, with a particular emphasis on obtaining consent from both disabled and non-disabled children. The next part explains how I recorded and handled the data during the study, after which the timeline of the project is given.

The objectives of the study

The study had two main interconnected objectives, one relating to the focus of the study and the other to the methods used:

1. To identify the support needs of Pakistani families with disabled children and to explore how these needs can be met more effectively.
2. To explore how engaging the research participants in undertaking participatory action research in groups of men, women and children can facilitate their active role in achieving the first objective.

The approach chosen to achieve these objectives was participatory action research which started with an exploratory phase during which I undertook interviews and/or activities with all members of each participating family. Emerging themes from all the family histories formed the starting point for action research groups to identify issues they would like to try and understand better or

resolve through cycles of planning, action and reflection. There were separate groups for men, women and children. See the section on “nature of activity” below for a more detailed description.

Research Questions

As explained in chapter 2.1 the emergent design that is characteristic of action research meant that the research questions needed to be phrased tentatively to allow for flexibility for the participants to choose their own focus in their research groups.

The main research question was defined as follows:

How can Pakistani families with disabled children be facilitated to identify their support needs and explore how they could be met better, within the family, in their communities and through the service system?

In order to answer the main question the following subsidiary questions were defined:

- a. *How do family members describe and express their perceptions of and attitudes towards disability?*
- b. *What rationale / reasoning is given for these attitudes and perceptions?*
- c. *What attitudes do disabled children and family members encounter in the community and service system, and how do they think these attitudes influence their own perceptions and attitudes?*
- d. *How do these attitudes affect the relationships family members have with the disabled child and each other?*
- e. *How do these attitudes affect the way roles and responsibilities, particularly in relation to the disabled child, are divided?*
- f. *How does this division of roles and responsibilities impact on the occupational balance of each family member, including the disabled child?*

- g. How can an increased awareness of their current perceptions, attitudes, roles and responsibilities help families to evaluate their support needs and systems in order to identify areas that require change?*
- h. How can families be facilitated to plan and implement change in these areas?*
- i. How do these changes impact on family members' well-being and occupational balance?*

Questions a. through f. formed the basis for the interview themes in exploratory phase of the action research (see Appendix B for the interview guides for adults, non-disabled children and disabled children respectively), but continued to be explored throughout the project. Questions g. and h. relate to the action research cycles, at which stage the participants were encouraged to take more and more control over the focus and process of the research. Question i. relates to the effect participation in the research has had on the participants' family lives.

As explained in the previous chapter this thesis is like a 'frame tale' as it portrays 'a research project within a research project': the core action research project was carried out by the participants and me collaboratively, and the thesis project consists of my description of, reflection on and analysis of the facilitation process needed to make the core project possible (see figure 2.1.2; Perry and Zuber-Skerritt, 1992, p201 - 203). Hence subsidiary questions a. to f. and i. relate to the core project and question g. and h. relate to the thesis project.

Research Methods

This section gives an overview of the activities I undertook in the course of the project.

Finding participants

The methods I used to identify families to participate in this study can be described as “combination or mixed purposeful sampling” (Patton, 2002, p244), because a mixture of methods were used, making use of sampling criteria and different ways of extending invitations to families. Qualitative and participatory research studies frequently look for relatively small samples of information-rich cases or participants, selected purposefully and to be studied in depth. The purpose is not to have a sample that necessarily represents a larger population precisely, but rather one that can illuminate the question or phenomenon under study (Patton, 2002, p230). My choice of research method, for which the rationale was discussed in chapter 2.1 meant that I needed a small number of families, who were willing to be involved for a long period.

The participating families were sought from a inner-city area with a large population of families of Pakistani origin.

In reality it was difficult to identify potential participant families (see chapter 3.1) and I only recruited the sixth family seven months after starting recruitment, by which time I had completed the exploratory phase with the other five families and the action research groups had already started. There was therefore no question of selecting families from a larger number of potential participant families.

Inclusion criteria

The inclusion criteria were as follows:

1. The families should be **Pakistani and Muslim**, as the vast majority of people of Pakistani origin living in Britain are Muslims: 92% according to

the Census of 2001, with 6.2% not stating their religion and only 1.6% stating a religion other than Islam (Peach, 2005, p22). This criterion was met: I did not identify any non-Muslim Pakistani families, although I did identify two Muslim families who were not Pakistani. The mothers of these two families did agree to be interviewed on a one-off basis, but I did not include them in the action research groups. This ethnic and religious homogeneity was indeed very important. I did not only observe this in the much higher level of openness in talking about personal views and feelings than I had thought possible, but participants also said and did things that confirmed it (see chapter 3.3 for women's feedback).

2. One or both parents should preferably be **first generation immigrants**, as accessing statutory services and other sources of support tend to be more problematic for this group. This criterion was met as well, as only one mother was born in the UK.
3. The family should have **one or more child(ren) with severe impairments under the age of 12 years**, as the incidence of severe and complex impairments is proportionally very high for this group. When it became apparent that it was difficult to find enough families to participate, I relaxed this criterion to include any significant impairment, as perceived by the family. The age restriction was also removed. Of the six families who participated in the whole project, two had children with severe learning difficulties and communication problems, three had children with moderate learning difficulties and one had a child with mild physical disabilities. The disabled children's age range was from 2 ½ years to 14 years.
4. **All family members should be willing to participate** in the project. This was important for gaining the perspective of all members on what the family's support needs were. Secondly participation in the groups was intended to bring about a change or growth process in each participant

and it would be easier to talk about or implement changes in reality if all members had experienced a similar process.

Homogeneity versus heterogeneity

By defining clear criteria I tried to identify a group of families that was as homogenous as possible, as this would allow me to study the topic in depth and to bring participants together to work in groups (Patton, 2002, p 236). The homogeneity in terms of ethnicity and religion was indeed important as described above. However this relative homogeneity based on the key criteria did not prevent heterogeneity in other aspects, and the participating families were different in terms of parents being first or second generation immigrants; being one or two-parent households; the nature of impairments of the disabled child; their socio-economic status; their English language ability; their level of education (varying from less than primary education to PhD student) and age of parents as well as children. The advantage of a heterogeneous sample is that it can lead to capturing and describing central themes that cut across variation. Although this can be difficult for small samples (like mine) because individual families or persons can be so different, it can help to identify what part of the experience is common to all (Patton, 2002, p234).

Number of participants

Due to the intensity of the process, it was important to keep the group size small enough to ensure all participants were able to participate fully and to be able to manage the data. I aimed to find between 6 and 8 families willing to participate. In total I was able to make contact with 18 families, 6 of which participated in the project until the end. The mothers of a further 6 families (including one who initially signed a consent form to participate in the whole project, but whose husband was unwilling, so that the family had to withdraw) agreed to a one-off interview only, thus adding to the exploratory data around issues facing Pakistani families with disabled children in this area. The remaining 6 families did not choose to participate. Reasons for families not participating in

the whole project were either that the husbands were unwilling, or the families were struggling to cope and felt unable to commit themselves to a time-intensive project, or the children's impairments were very mild (e.g. one child had dyslexia and did not wish to be identified as 'disabled') or had resolved (e.g. a baby with clubfeet, whose treatment had been fully successful).

Although I was able to recruit the minimum number of families I had aimed for, this number was rather low in practice, as the absence of a few members at any group meeting had a strong effect on the group discussions and decision making process.

In addition the fact that several women indicated that they could not participate in the project because their husbands were unwilling could suggest that the fathers of the participant families may be relatively more interested in their disabled child and the wellbeing of their family than others.

Making contact with families

Finding the families was a major undertaking and much more difficult than anticipated. My initial attempts at contacting people through the two local Mosques by requesting announcements by the Imam, displaying posters and organising orientation meetings for families, did not have any results. I then had to change my approach and contacted a large number of local agencies and projects – special schools, carers projects, social services, etc. – which after much sustained effort led to the contacts described above.

This whole process of identifying and inviting families was difficult and frustrating, but led to many important insights around seeking access to marginalised communities for the purpose of social research. Therefore the first of the findings chapters (3.1) is dedicated to describing and discussing this important first stage of the research process in depth.

The settings for research activities

The research activities were carried out in three different settings:

1. Each family in their home: this was particularly important in the exploratory phase when I explored issues around having a disabled child with them. In principle I engaged each person in activities and interviews individually, although in most families it was difficult to achieve this with the children, who often sat together to draw and talk. In addition I engaged with the families as a whole to build a relationship of trust and to observe their interactions with each other. I also visited families occasionally during the action research phase, and at the end for evaluation purposes. Each family was visited on average five times.
2. Action research groups consisting of women, men and children respectively. Each group engaged in their own action research cycles, working on issues that were particularly relevant to them and / or they felt they could bring about change in. The venues for these groups varied, and turned out to be important for the group dynamics and therefore outcomes of the groups. The women's group met in one of their homes, which meant hospitality could be given and received, which is important in Pakistani culture, and which gave a very safe and comfortable atmosphere which helped the women to open up to each other. The men's group met in the small local Mosque, which was a public and respectable venue - which was particularly important in view of the fact that I was a woman - as well as a neutral territory, helping them feel at ease. Finally, the children's group, which consisted of the non-disabled children of the families, met in a classroom of the Islamic school above the large local Mosque, which had both positive and negative impacts. The room was safe and private, giving me the freedom to organise the group in whatever way I needed to, and to allow the children to move around and be noisy when they needed to. On the other hand the room was large and empty, making it quite hard to structure the sessions and help them focus on the activities at times.

The children's group met eight times and the men's and women's groups seven times each.

3. The total number of participants: all members of all families together, also met on three occasions so that they could meet each other as families. This happened three times (see chapter 3.6).

Nature of activity

I engaged the participants in a range of interconnected activities, in which the four ways of knowing, proposed by Heron and Reason (1997) to be an important epistemological concept in action research, were relevant (see chapter 2.1).

The individual families

The home visits were an important opportunity to explore the experiential and presentational knowledge of the participants. In addition the home visits formed an opportunity to start building up a "relationship of trust, respect and reciprocity" with the participants (see Barton 2005, p319). Data was collected through:

- Semi-structured interviews with all family members individually, in order to get a clear picture of the chronology and major milestones and events. The interview guides used for the semi-structured initial interviews can be found in Appendix B.
- Looking at photograph albums, both to trigger story telling and to get visual images that indicate the disabled child's role in family life
- Taking photographs of daily activities and special events. Each family was given a disposable camera and a log-sheet to write down where, when and why they took each picture. They were encouraged to let all family members, including the disabled child, take some of the pictures. This activity proved difficult to organise and only four families completed it. In addition the quality of the cameras was poor. Nevertheless the

story-telling generated by the viewing of the pictures was very rich in some of the families.

- Children making time-lines of daily activities and drawings of their families
- Spending time with the family to observe life at home to observe the way the disabled child was included in family life.

Not all disabled children were able to participate in the verbal interviews and drawing and writing activities. The modes of communication each child used in daily life were used as starting point for finding ways of expressing their views. Visual methods, such as the photographic activities and the use of pictures / symbols to indicate choices were used with all children. Two disabled children had very limited abilities to communicate verbally and one was very young, so I interacted with them through play with their own toys as well as ones I brought on subsequent visits, based on their abilities and interests.

At the end of the project each family was given an album with photographs and drawings made by all family members during the exploratory phase as well as during group meetings. Digital images of these photographs and drawings were retained.

Small group meetings

These were the groups which carried out the action research in its reflective cycles and this is how participants started to share experiential and presentational knowledge with each other and to develop propositional and practical knowledge together. My role was to facilitate the stages of choosing a research focus, action planning, action, analysis and further planning. This process required a considerable amount of structure and guidance initially and I worked hard to facilitate the participants to become aware of and gain control over the process.

Each group chose a topic to explore:

- the women's group decided to explore how they could organise a support group for Pakistani mothers of disabled children in the local area
- the men's group decided to find out from local Muslim scholars and Imams what the Quran teaches about disability, in order to be better prepared to challenge negative attitudes faced in the Pakistani community
- the children's group decided they needed to understand their disabled sibling better, so that they would be better able to make him or her happy

After the end of the project, whilst I was writing my thesis, the groups met for another two times each to evaluate participants' perceptions of the process and outcomes of the research so they would be adequately reflected in the thesis, and to decide on methods of dissemination (in terms of what to disseminate to whom, particularly locally). The groups also thought about how to continue the learning process beyond the project.

All families together

These meetings were planned for the participants to have an opportunity to follow the progress of the research project as a whole and to give an opportunity for developing propositional knowledge. However, bringing all participants together proved to be difficult, so that eventually this only happened on three occasions; once at the stage when I had made contact with a number of families but before they signed their consent, once for an Eid (the festival at the end of the Muslim month of fasting) party organised by the children's group, and once for the closing party at the end of the project. None of the meetings were attended by all families and the amount of feedback between the groups was much more limited than anticipated. See chapter 3.6 for details.

Bringing the project to an end

Apart from final evaluation meetings in the three groups the participants filled in evaluation forms and prepared artwork for the closing party. The children entered their artwork into a competition and their work was judged in a democratic way by each participant placing a sticker on the scoring sheets of the three best pictures. The women sat together to show each other and discuss their artwork as a group. The families were also visited at home at this final stage. These activities did not serve purely to collect data, but also to provide a moment of closure of their participation in the research project and to invite them to think how they might continue their learning process beyond the project.

Sustained contact

Contact with the participants was not cut off completely after the project had 'finished'. There were several reasons to remain in touch. The first was for me to have an opportunity to obtain their feedback on my reflection on and analysis of the outcomes of our collaboration. Two meetings were arranged for each group in July (just before the summer holidays, at an early stage of reflection) and October (at a stage that I was developing more definite conclusions). The second reason was because we had agreed that a local dissemination event would be a very useful way of sharing our learning. This event is planned to take place in 2009. Finally - and most importantly - the relationship we built up during the project is highly valued by the families as well as by me and due to the nature and intensity of approach went beyond a functional and professional level. For example one mother told me that the most important aspect of this project was that "**it was all about relationships**". She stated that the first individual interview had struck her because it was the first time anyone had asked her with genuine interest about herself and her perspective on raising a disabled child, rather than stepping into their life briefly to solve a certain aspect of her child's disability like professionals tend to do. Breaking off contact

just because the project is officially 'over' would draw my genuine interest in doubt and adversely affect the way participants look back on the process.

Ethical issues

The following ethical considerations guided me in my relationships with the research participants:

Children's participation in the study

Over recent decades there has been a paradigm shift, which involved repositioning children as the subjects (in the meaning of 'actors'), rather than the passive objects of research (Christensen and James, 2008, p5). A key concept in this is that children are (considered able to be) social actors and therefore need to be afforded opportunities to become researchers of issues facing them themselves. An important milestone in this paradigm shift was the acceptance of the Convention of the Rights of the Child (1989), which added the child's right to "participation" to their rights to "protection" and "provision" (of education, healthcare, shelter and good nutrition), which were adopted in the Declaration of the Rights of the Child in 1959 (Skelton, 2007, p.167).

For this to happen in a research context, researchers need to move away from the idea that children are less competent than adults to take on responsibilities or to be involved in decision-making. See page 117, where I quote Alderson (1995) to argue that this idea is based on cultural and psychological concepts, which are not universal and can not be considered natural or inevitable states of childhood.

Involving children actively in research, especially if this is done in the context of their families, does not only support the child's right to participation, but can also lead to a more complete and realistic understanding of the child's life and issues faced, as children observe with different eyes, ask different questions and may have different priorities than adults (Kellest, 2005). In addition children can

gain important life skills for addressing these issues, as I will argue on page 122, where I discuss how the study benefited the (child) participants.

Once the researcher recognises that children both have the right and the capability to become active researchers, they need to consider what methods would be most appropriate to use. Punch (2002) argues that a combination of traditional 'adult' methods, which respect the child and acknowledge their capabilities, and more 'child-friendly' methods, which tend to be more practical and task-based, can provide children with the best opportunities to contribute to and benefit from participation in the study. In selecting and preparing methods (activities) it is crucial that the researcher uses a reflexive and critical approach, so that research activities are not only fun to do, but also generate relevant data, and help the children to keep the purpose of the project in view (see Punch, 2002). In this study the activities for the exploratory phase (drawings, time-lines, photography and interviews) were decided beforehand, whereas the activities for the action research phase were based on the children's response to earlier activities. For example the fact that most children had found it difficult to express any doubts or negative views in the exploratory phase led to me requesting them to write and draw about what their disabled sibling liked and was good at in meeting one (see figure 3.5.3), before moving on to activities that helped them to express negative aspects (drawing Mr Men characters and the 'feelings cube' in meeting four (see figures 3.5.4 and 3.5.5 and the title page of chapter 3.5).

In working with child participants a fine balance needs to be struck in which the children's developmental stage and associated competencies need to be catered for, without belittling the children or restricting them in what and how much they can contribute (Hart, 1997, p27). This is extra challenging in a mixed age and gender group, where not all activities might appeal to all children at all times. However, mixed groups do enable children to learn from each other and/or develop leadership skills (Hart, 1997, p35).

A final consideration, which is embedded in the issues discussed above, is the issue of power-relations between the researcher and the child participants. Whilst this issue is also important in working with adult co-researchers, particularly if they are in a marginalised position (see pages 67-70 of chapter 2.1), “wider concerns about children’s safety, combined with unequal adult-child relations and a ‘duty of care’ of the researcher result in a highly sensitive and unique research encounter with children” (Barker and Weller, 2003, p222). The challenges faced in this study are reflected on in depth in chapter 3.5 about the children’s group.

Consent

Informed consent/assent was obtained from each individual participant, whether adult or child. Separate information sheets (see appendix C) and consent/assent forms (see appendix D), all conveying the same information in different formats, was provided to adults (including children between 16 and 18 years old), children who were able to read, and those with limited or no reading ability respectively. The latter included pictures and symbols. However this form was not used as out of the seven non-reading children who assented to participating in the project, four were unable to relate to any writing or symbols due to very young age or their ability to communicate being extremely limited. The remaining three children signed the assent form without symbols as they were not familiar with symbols and answered the questions after verbal explanation. Parental consent was also obtained for all children under 16.

Designing the information-sheets to be in line with university guidelines, as well as useful for participants was a challenge and I found that only very few adults ever read the information. Both adults and children would have benefited from a much shorter information sheet, perhaps in the form of a checklist which could have formed the basis for a verbal explanation, which I needed to give in all cases anyway.

I also enlisted the help of an acquaintance with good Urdu literacy skills to translate the information sheet and consent form for adults. This was not

straightforward as some of the English words and research-related concepts were unfamiliar to her, and some of the Urdu words she used in the translation were unfamiliar to me. We talked through each section at length to be certain that the end result conveyed exactly the same meaning as the English version. Although several participants really appreciated the Urdu version, they still needed verbal explanation to understand it.

Literature used to inform decisions on obtaining consent from children

Although the Department of Health has provided general guidelines on assessing the competence of children to consent to medical treatment (DoH, 2001), little guidance is available in terms of consent to research. The "Research Governance Framework for Health and Social Care" (DoH, 2005) states that care needs to be taken when seeking consent from children, but does not lay down clear guidelines. Furthermore the responsibility for providing a national research governance framework for social research involving children currently lies with the Department for Children Schools and Families is, but this is still in preparation. In the mean time decisions are devolved to the local level and as a result there is considerable variation in practices (Harwin, 2008). I will therefore base this section on available literature and I will discuss both the more conventional approach and a more critical approach to child consent, followed by a statement of the view I have taken for the purposes of this project.

The fundamental principle to consider is that the research should not be contrary to the child's best interest (Piercy and Hargate, 2004, p257).

The DoH guidelines (2001) are helpful in determining which child may be competent to consent to participating in research. The guidelines refer to Gillick competence of those children who, although under 16, are deemed to have sufficient understanding to give consent in their own right (Brunel University, 2005, p23). They state that for the child to be considered to have the capacity to take a particular decision they must be able to comprehend and retain

information relevant to the decision and to use and weigh this information in the decision-making process (p4).

There is no particular age at which children start to be considered competent, and the DoH guidelines point out that competence is not something that the child either does or does not possess. Rather it depends on the relationship between the clinician and the child and their family, the way information is given, and the experience the child has in taking decisions about their own health (p5). Furthermore it is considered good practice to involve the parents of the child in the decision-making process, even when the child is considered competent (p5). For the consent to be valid there are two more elements besides being competent: the person must be acting voluntarily and they must have been provided with sufficient information to enable them to make an informed decision (p13). Keeping these guidelines in mind Piercy and Hargate, 2004, p255) suggest that with regard to conducting research with children and young people, good practice would suggest that they should always be involved in deciding whether or not to participate, and be encouraged to sign a relevant form to confirm this decision. They point out that legally this process constitutes assent, which they describe as

an opportunity given to the child to express their opinions and concerns surrounding participation in research, providing them with a formal means to be excluded or included (p255).

Although the rules on children's consent do not appear to be clear-cut, Weithorn and Sherer (1994, p145) point out that the competency to dissent is in principle always assumed to be present and that the objection of a child of any age should be binding, unless participation would provide a treatment benefit that would not be available otherwise. For social research this implies that the researcher must be sensitive to and respect signs of dissent shown in any way (by verbal communication or otherwise) by any child, whether they have

previously given their own informed consent or not, and accept their decision to withdraw from the study.

This principle is not only important for very young children, but also for children with intellectual impairments or communication difficulties. Marchant and Jones (2003, p11) point out that children with intellectual impairments often can not understand why they are asked to participate or how results will be used, but “they can still be competent to give and withdraw their consent by signalling whether they are willing to participate in interactions” with the researcher. Lewis and Porter (2001), whilst acknowledging that it is important to obtain consent from parents or carers when involving people with intellectual impairments in research, also stress the importance of providing opportunities to consent / assent to the participants themselves, throughout the research process. Kellett and Nind (2001) report how they involved non-verbal disabled children’s teachers, parents and carers in interpreting whether the children’s behaviour might indicate dissent at any time during the research.

Alderson (1995, p77) provides a critical appraisal of the concept of judging children’s competence, by pointing out that beliefs about children’s supposed incompetence are widely held among adults, based on the assertions of early developmental psychologists such as Piaget. Referring to historical and international situations in which young children take on responsibilities, such as earning a living for themselves and their family, Alderson asserts that the dependence of many children is “not inevitable, but is elected and enforced. After infancy, dependence is a matter of economics, of social customs and beliefs, rather than biology” (p78). She continues by pointing out that the child’s level of competence and independence follow the adults’ expectations. In addition the dichotomy of dependent child – independent adult is challenged by the fact that even adults are dependent or interdependent on others for many decisions they make. About knowledge, Alderson (p78) adds that “ignorance and dependence are mutually reinforced through popular beliefs that these are natural states of childhood” and that this idea is strongly

reinforced by the school system that is based on the assumption that children learn at pre-ordained stages of readiness, which they need to pass through before being considered an adult.

These more critical ideas about childhood are also supported by the Convention on the Rights of the Child (UNHCHR, 1989) which balances the child's right to full participation in society with the right to protection from exploitation in any form. Hart (1992, p8) emphasises that

while the child's freedom of expression and participation in community issues may often be contrary to the child-rearing attitudes of the child's parents or caretakers, it is ultimately in the best interest of all children to have a voice.

He adds that "the aim should be to encourage the participation of the whole family" to facilitate a change in children's opportunities to participate (p8), which gives the child opportunities "to share decisions which affect one's life and the life of the community in which one lives" (p5). Considering the rights perspective, which is congruent with the critical research paradigm and its emancipatory goals, it appears that children should be respected for their abilities and in a sense be given the benefit of the doubt about their competence.

Alderson (1995, p76) suggests that researchers could take the view that school age children are in principle competent, thus putting the onus on adults who disagree to prove that they are not. As many children choose to share important decisions with their parents or close, trusted adults, and can be encouraged to do so, I found this a feasible position to take for this research study.

The approach to consent used in this study

In conclusion I have considered all school age children (5 years and older) in this study to be competent to give their written informed assent, unless there

was convincing evidence that they were not. This applied to the children who had severe intellectual impairment and communication difficulties, but not to the children who had moderate intellectual impairments and were able to communicate verbally. Even children who were not considered competent were given as much information as possible and encouraged to indicate their assent and/or dissent. In recognition of the fact that children's participation should ideally be decided on by the child supported by their parents on the one hand, and the need for protection to children on the other hand, all parents were asked to also sign for their consent for their children below the age of 16 to participate in the study (see appendix E).

All participants were given the opportunity to ask questions and discuss their role in the research in further depth before they signed the consent form. Some of the participants thought about the various items on the consent form carefully, for example one child was willing to participate as long as no photographs or voice recordings were made. Others did not seem concerned about the form at all and were happy to sign without reading the information sheet or items on the consent form properly. In these cases I made sure that they knew what they were signing up to by giving a verbal explanation and checking with them that they had understood.

Consent included permission for use of products that resulted from the research process from which the participant can not be identified (e.g. drawings, stories, etc.). Any photographs that do show identifiable people were only used after obtaining express permission (see appendix F).

An important part of giving consent is the understanding that it is possible to withdraw at any time. Some of the children were not able to express their wish to withdraw verbally and I remained alert to clues given by other methods of communication, such as facial expression, agitation, or crying. In such cases I first changed or adapted the activity to resolve the problem, but in case a child

continued to show a negative response I discussed with the child and/or the parents whether the child should withdraw from the research activities.

An example of a child's expression of assent and dissent

The following two incidents are an illustration of this principle. I went on a home visit to spend some time with Dawood, who has intellectual impairment and severe communication difficulties due to autism. His mother had just given him a bath and brought him downstairs. As soon as he saw me, Dawood brought my shoes and coat from the hall, clearly indicating that he wanted me to go. His mother thought the fact that he had had a bath and been dressed in clean clothes made him expect that they were going out. I agreed with Dawood's mother that I would try to engage him by showing some of the toys I brought and playing with some of his own favourite toys with him. Dawood started to enjoy the interaction and was then able to indicate some of his preferences by sorting the symbol cards I had brought onto a felt board with columns for 'like' and 'don't like'. The photograph of a smiling Dawood with the symbol cards taken at the end of the session, bears testimony to the fact that his initial 'dissent' changed into 'assent', affording him an important opportunity to express his ideas (photo not included due to confidentiality concerns). Encouraging the child to participate is also about looking for ways in which they can exercise their right to participate and express their views. This is an additional reason why it is important not to immediately accept apparent dissent and to give the time for the child to confirm their decision.

However when on another occasion his mother tried to bring Dawood to a meeting for all families together, Dawood literally turned on his heels as soon as he saw a room full of strangers and thus gave a very strong indication that he would not be willing or able to participate in this setting – in this instance he became very agitated and it was obvious his dissent was clear and final, so no attempts were made to convince him otherwise. Therefore Dawood's participation in the project remained limited to home visits only, during which he indicated how and how much he wished to interact.

Confidentiality

Confidentiality and anonymity were maintained throughout the research, and will continue to be maintained in all reporting and dissemination. The exception was when participants chose to disseminate findings themselves and give up that anonymity for that purpose.

The need for confidentiality made my search for potential participating families long and complex. My initial strategy to find interested families by announcing the project at the local Mosques and distributing handouts and posters (see appendix G), was partly chosen because it left the decision whether or not to participate wholly in the hands of the families. I heard about a small number of families through community contacts, but because the latter did not dare to broach the subject of disability, and because I could not just knock on their door due to confidentiality concerns, I was unable to invite these families personally. For the same reasons, when I tried an alternative strategy to find families, I had to rely on contact persons in special schools, service and projects to send out invitations (see appendix H) and make phone-calls on my behalf. This was a slow process, and in most cases I had no idea how these contact persons explained the purpose and nature of the project to potential participating families, or indeed whether they made the phone calls at all (see chapter 3.1).

It was not possible to keep the identity of the participating families hidden from the Mosque management as some research activities took place in the Mosque, but under no circumstances information that I have come to know through the research has been or will be discussed with them.

The only exception to this was when a participant needed urgent professional input or pastoral care from statutory or other professional services. This only happened in one case, when I enquired for the family who only recently arrived from Pakistan why the disabled child was still not in school after 5 months in the country. I initially asked for general information anonymously so the father could

use this information in his dealings with the authorities, but when no progress was made I asked the family's permission to talk to the officer concerned directly.

Benefiting the participants

As described in chapter 2.1 participatory action research has explicit emancipatory goals and seeks to benefit the participants directly. This was done through giving the opportunity to reflect on their current situation, and to gain skills to engage in the cyclical research process of reflection, planning, taking action and evaluation. All activities were planned and facilitated with that in mind and the participants developed new insights and skills that will be helpful in ensuring their needs are met in future.

This intended benefit of the project extends to the children as much as it does to the adults, and is in line with the Convention on the Rights of the Child (CRC, 1989), which asserts that

the child who is capable of forming his or her own views (has) the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child (article 12),

and that

the child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice (article 13).

Hart contends that children need to learn that with these rights come responsibilities too and

in order to learn these responsibilities children need to engage in collaborative activities with other persons, including those who are older

and more experienced than themselves. It is for this reason that children's participation in community projects is so important (1992, p7).

Through participation in this project the children had the opportunity to develop skills in the area of evaluation, reflection, expression of ideas and feelings, planning, decision making and collaboration (see chapter 3.5).

Avoiding harm

Despite my commitment to facilitate the research in such a way that the participants would only benefit from it, there was of course a risk that they would experience harm or distress in the course of the study.

One potential source of harm was the fact that families were evaluating their current relationships, tasks and responsibilities relating to the disabled child, with the intention to seek to improve the way they contribute to their improved support. Even though each participant consented to embarking on this process, at times sensitive issues were discussed that made participants feel misunderstood or brought old hurts to the fore. It was therefore made very clear to participants that the research did not seek to attach blame to any individual family member or families as a whole.

For example, although the sharing of life stories in the first two meetings of the women's group brought a very welcome form of catharsis, one member felt her situation was significantly different (worse) in key respects so that it caused her to feel separate from the group and to consider withdrawing from the project. It took her time to see that this did not need to be a problem and towards the end of the project she saw more commonalities and potential for mutual support.

In addition I was unable to control the response of people the participants chose to contact and some disappointments were inevitable, leading to some pessimism about the potential for change, as will become evident in the findings. The potential for this kind of harm emphasises the importance of joint

reflection on and evaluation of each action undertaken, so that it can lead to successively more constructive planning of action.

Working from home

Although all direct work with the participants took place in their homes and at the mosque, all transcription and analysis of data was done at my home. In order to ensure the data were and continue to be protected from being accessed or meddled with by others raw data are stored in a locked steel filing cabinet, and any processed data (such as transcriptions and field notes) and digitally recorded data (digital photographs, dicta-phone files) are saved on the computer in a password protected log-in to separate user settings.

I used an allocated mobile phone on which participants were (and still are) able to contact me and did not provide the participants with personal contact details other than that. I use my Brunel University email account for any email communication about the research. Although the participants accepted this and understood that the university required this, they did not appreciate it as it appeared to express a lack of trust in them as individuals or families.

Organising and analyzing the data

In considering the process of data analysis in action research it is important to keep in mind that the focus of action research is concerned with the process of learning and implementing change. The action researcher's main aim is therefore not necessarily to create a comprehensive interpretation of all data that has been collected, but rather to use the data to develop ideas relevant to the participants and their situation, which they did not have before the start of the project. This may be achieved by a process of learning through critical reflection on the data (Winter and Munn-Giddings, 2003). This is in line with Reason and Torbert's (2001) explanation of the epistemology of action research (see page 79 of the thesis), which demands that the focus of action research is on the process and that the methodology is used to enhance the inquiring capacity of the participants.

However as the research process is based on the issue under study, the content must be analyzed too. In this thesis a combination of thematic analysis, mainly of the 'content' (Grbich, 2007) and ongoing critical reflection on the participants' and my own research process was used (Winter and Munn-Giddings, 2003).

Thematic analysis was first used at the end of the exploratory phase, using colour coding to identify themes emerging from the interviews and other activities. This led to a descriptive overview of the issues faced by the families, and themes relevant to each action research group (men, women and children respectively) were presented in conceptual mapping format (Grbich, 2007, p35) as a starting point for their group research process (see pages 313-320, subsidiary research questions 1 to 5).

During the action research phase my ongoing reflective field notes were a form of ongoing analysis: my own action research cycles of planning, action and reflection ran alongside the groups' action research cycles and provided the data to describe the participants' and my own learning, enabling me to illustrate the emergent nature of the action research process (see pages 320-326, subsidiary research questions 6 to 9). The thematic analysis, which had been started at the end of the exploratory phase, was then built on and continued in order to show what new knowledge was gained through the study. This was done explicitly in the section of chapter 4.1 about cross-cutting themes (pages 330-338), but also woven into the description of the research processes.

The discussion on how the study met the quality / validity criteria of action research (see pages 91-95) is an important aspect of the overall analysis (see pages 337-344) as it evaluates to what extent the research project constituted a valid action research process, including the consideration whether useful new knowledge was produced.

The data arising from the multiple processes involved in this study consisted of audio-recordings of all individual and group meetings and their transcriptions; photographs taken by the participants; drawings, poems and other products of activities; and my descriptive and reflective file-notes of interactions with participants and community and Mosque contacts. All file-notes were written on the same day as the events described and all audio-recordings were transcribed as soon after they were made as possible. All data were filed according to the families or groups that had provided them.

Making sense of the research process and data

As this study was complex, with a number of distinct, yet interrelated research processes taking place in succession and/or concurrently, it was a challenge to keep an overview of the project as a whole and of the way in which the different processes affected each other. Apart from writing regular reflective notes, I used a number of specific strategies to manage this process, i.e. using conference presentations, drawing the participants into my reflections, and creating a thinking wall in my study at home.

Using conference presentations

The PhD process can be quite an isolating experience. Supervision was extremely helpful and essential, but was also infrequent. As I learn best through dialogue in which I can express my ideas in words and invite others to respond to them, I actively looked for opportunities to attend conferences and study days which focused on similar issues, research approaches, and / or populations as I did in my study. At ten of these events I presented aspects of my study that were of interest to the audience. See the table on page IX for an overview of the events I attended, and appendix I for the presentations made.

I found this process very beneficial, as it forced me to reflect on my findings and to decide on which aspect needed to be presented to the given audience in which way. Both positive and negative feedback were helpful in further advancing my study or its analysis.

Critical feedback was never really 'negative', but always thought-provoking, and offered an opportunity to either explain more clearly why I had made the choices I did, or to reconsider the wisdom of those choices. A clear example of how the audience's input developed my thinking further is the article that was published based on the presentation at the Inclusion and Exclusion: 2007 Conference (Kramer-Roy, 2007; see appendices I and Q). It makes explicit which additional ideas were contributed by the audience.

The final, collaborative, presentation at the Inclusion and Exclusion: 2008 Conference gave me an opportunity to engage the research participants in this learning process (see appendix L).

Reflecting with the participants

The action research cycle revolves around reflection as well as planning and action, and the participants responded well to my frequent invitations to reflect on the actions they had taken and their outcomes. The feedback meetings held after the fieldwork, during thesis writing, were a continuation of that process of reflection.

The thinking wall

At the end of the fieldwork I was left with an enormous amount of transcriptions of audio-recorded interview and meetings, reflective notes, photographs and artefacts produced by the participants. Although all this data was filed away according to the groups and the families who had yielded it, each section was still quite substantial. For the chapter about the exploratory phase (3.2), coding the emerging themes and indicating them with different coloured post-it notes was sufficient. For the chapters describing the different group processes (3.3 to 3.6) however, an additional strategy was needed. This was because teasing out the process from the content-related findings was difficult. I therefore covered the walls of my study in blank paper and started writing out the process for each group chronologically at first, allowing space for different processes that

occurred concurrently or intermittently. After making these lists I coded stages and decisions to indicate which of the 'moments' of the action research cycle (observe, reflect, plan and act) they represented. The final stage of the thinking wall process was to then represent these 'moments' visually as action research spirals. These figures in turn were the starting point for writing each chapter.

Timelines of the project

Due to the time limits for completing my PhD studies set by the university, the time available for the active research project was also limited. The time available for the action research groups was further reduced because of the difficulties I experienced in identifying families to participate. The actual timeline was as follows:

April / May 2007	Intensifying the contact with the Mosques, which I had initiated during the first year of my studies
May 2007	Proposal submission and ethical approval
June 2007	Announcement and posters in the Mosques; information meeting arranged but not attended by anyone
June / July 2007	Reconsidering avenues for inviting families to participate; starting to contact special schools and carers' projects
August 2007	School holidays – impossible to make progress with the special schools, but some initial contact made with other services and projects
September 2007 - January 2008	Contacting a wide range of agencies and projects repeatedly to get their cooperation in inviting families; they send letters home with Pakistani children or send them to

Pakistani families on their mailing lists. When that brings little result I request them to make phone calls.

September / October 2007	6 families sign consent forms; start of exploratory phase at families' homes; first holiday club for the children's group.
October 2007	One family withdraws
December 2007	First meetings of women's and men's groups; women decide to meet once every 2 weeks during term-time and men once every 3 weeks on Saturdays
January 2008	One more family signs consent forms
April 2008	Final meetings and family visits.
May 2008	Closing party
July and October 2008	Presentation of my thesis / findings for feedback and approval by the participants and planning for conference presentation
November 2009	Collaborative presentation at Inclusion and Exclusion 2009 Conference
Autumn 2009	Dissemination event

See appendix J for a complete overview of home visits and group meetings and family composition.

Chapter summary

This chapter has given an overview of the design of the study, including its purpose, research questions and ethical issues considered. Furthermore it has described briefly what methods were used to identify participant families and facilitate them to take on an active role in the project.

The next part of the thesis describes what actually happened during the project and reflects on the findings from six distinct but interrelated research processes, which are: access and identifying participant families; the exploration phase with each family; the women's group; the men's group; the children's group; and bringing families together to exchange their experiences from the different groups.

PART 3: LEARNING IN ACTION: THE FINDINGS

Introduction to Part 3:

Learning in action: the findings

Part 1 of this thesis has familiarised the reader with a theoretical background to the study through literature reviews around Pakistani families with disabled children, occupational science and models of disability

Part 2 presented the rationale for choosing a critical social paradigm of research and within that participatory action research, as well as the actual design and methods used.

This third part of the thesis presents the findings of the study. Because of the nature of participatory action research, the findings are concerned with the research process as much as the insight gained into the support needs of Pakistani families with disabled children. For this reason each of the following chapters start with a detailed description of what we actually did and what happened before presenting the findings that have emerged from that process. As the focus of all activities that formed the process was the exploration of the participant families' support needs and finding ways to meet them better, the findings inevitably relate to both the process as well as the 'content'. In other words for the purposes of writing the thesis the process is not just a means to an end (a way to produce content or data), but also an end in its own right (a different type of content in itself).

This relationship between process and content was already made evident in the research question:

How can Pakistani families with disabled children *be facilitated to* identify their support needs and ensure they are met, within the family, in their communities and through the service system?

Please refer to the previous chapter on the design and methods for the subsidiary questions and the processes they relate to most directly.

In order to answer the research questions six distinct processes, and the findings resulting from them, will be presented in the following chapters:

- 3.1. Gaining access to the community and identifying participant families
- 3.2. Getting to know the families: the exploratory phase
- 3.3. The women's group: windows into different realities
- 3.4. The men's group: Islam and disability
- 3.5. The children's group: understanding their siblings' virtual world
- 3.6. Making connections: bringing the families and group processes together

Due to the participatory and emergent nature of the research design, it is inevitable that some of the interpretation of the data is presented with its description. Without that it would be difficult to make sense of the sequence of decisions and events that took place. However in-depth critical reflections on the findings will be presented in Part 4 of the thesis, which contains the analysis and discussion chapters, which are organised thematically in order to be able to bring together the findings from the six distinct research processes presented in the following six chapters.

**Chapter 3.1:
Gaining Access to the Community and Identifying
Participant Families**



3.1: Gaining access to the community and identifying participant families

This first 'findings chapter' will present the findings that relate to the "complex social process of gaining access to the community itself" (Sixsmith et al, 2003) and to the potential participant families within that. This chapter comes first in the sequence of the seven findings chapters, not only because it was chronologically the first stage of the research process, but also because it provides an important backdrop for the processes that occurred later, when the families were being visited and the groups started meeting.

No research without access

McLean and Campbell (2003, p41) point out that "recruitment of (participants) can 'make or break' social research projects, yet this has received little research attention". This process was particularly slow and problematic, and therefore yielded many new insights about recruiting and engaging families in communities that are regularly identified as seldom heard voices.

Reason (2007) observes that

before we can engage with anyone in cycles of action and reflection we need to have the ability to establish relations with an appropriate grouping of people, which means we must either have some access to the community or we need to develop legitimacy and the capacity to convene that goes along with it.

In conducting research with members of a minority ethnic community, where the researcher does not share the same ethnic background, gaining access and developing this legitimacy is a particularly delicate process and a

challenging array of barriers needs to be crossed. Hornsby-Smith (1995) suggests that access to communities, which is generally regarded as 'open access' can become 'closed' when working across ethnic and class differences, which proved true in this study in which it has been remarkably difficult to identify a sample of just six families willing to participate in a participatory action research project. The characteristics of Pakistani families with disabled children living in the UK, as described in the literature review, mean that this is an extremely hard-to-reach group and the process of gaining access has been more time-consuming and complicated than anticipated.

The process of identifying and inviting families to participate

This was a long and delicate process, consisting of three stages of making initial contact with the community, attempting to identify participant families by using the proposed strategy, and diversifying strategies.

Initial contact with the community

During the first year of my study whilst I reviewed the literature relevant to my research interests and prepared my research proposal, I also started to make contacts in the local area where I was planning to carry out my research project. This involved speaking to local service providers, particularly those providing health and social services for disabled children, and non-statutory projects providing support to disabled children and their carers. I also made contact with general community centres and Mosques.

Choosing the best way in

As I was seeking to recruit Muslim families and as I considered it essential that the fathers of the families would be active participants in the study, my initial recruitment strategy was to invite people through the local Mosques. The Mosques are well attended, particularly on Friday afternoons when the main prayer gathering takes place during which the weekly sermon is given. This, I

expected, would give a large number of local families the opportunity to hear about the research project. Apart from the Mosque being a trusted source of information, I also expected it would be an advantage for a 'critical' research project about families' support needs if they were not approached through their current service providers, as this could inhibit them in expressing any negative experiences they may have had with these services. In retrospect I can say that neither did any of the participant families hear about the project through this process, nor were they particularly concerned about expressing any views about the services they receive.

Getting introduced to key gatekeepers

My first step towards achieving the goal of having announcements made in the local Mosques was to get in contact with the leadership of these Mosques. Having lived in Pakistan, I knew it would be important to introduce myself in a way that was acceptable to them and would gain their respect and trust. Just walking in the door would not have been the best way for a non-Muslim, Western woman to achieve this. The best way would have been to be introduced by a Pakistani Muslim man, but being new to the area, I did not know any suitable candidate. I therefore asked the vicar of my church, who has built up good relationships with religious leaders of other faith groups in the area and is well respected, to introduce me. This worked well because it helped the Mosque leadership to 'place' me in a community context; I was not 'just' a researcher floating into the area, but a person who was part of a well-recognised and acceptable local community (that is the Church). The disadvantage was that being introduced by the vicar might give the impression that this was a project initiated by the church, possibly with evangelistic intent. Being aware of this sensitive issue, we clarified explicitly that this was a project endorsed by Brunel University, which sought to explore the support needs of Pakistani families with disabled children and therefore had purely secular objectives. Although this introduction gave me an initial commitment that they would support the project, it still took several months of visits and phone calls to reinforce and put that commitment into action.

Gaining trust

In both Mosques it was apparent that the governing board had more decision power than the Imam, who leads the congregation in the prayers and delivers the sermons. In one Mosque the chairman of the board soon delegated the responsibility for facilitating the project to the Imam, telling him to make the announcements and provide meeting space whenever I needed it. In the other Mosque there was a more complicated power structure and the chairman remained the main line of contact. Here concerns over status and decision power were felt strongly and when the project was discussed at the board meeting, objections were raised. One member in particular resisted the project, suggesting that I could be an informant for the Home Office with intentions to spy on Pakistani families with regards to immigration status. This led to the Mosque withdrawing all support initially, but when I repeated my offer (made many times before) of explaining the purpose of the project and expectations from the Mosque to the whole governing board, they agreed. Wearing shawl or kameez (Pakistani dress), sitting on the floor with them rather than on the chair they offered and explaining my intentions in Urdu, all contributed to the reversal of their decision and they assured me that they would provide their cooperation.

Both Silverman (2005) and Kauffman (1994) discuss the importance of giving the right 'impression' to gatekeepers and potential participants, particularly when working across cultural and social differences. This is a delicate process in which it is essential to be transparent and genuine about your intentions in carrying out the research, whilst at the same time being aware of the community's cultural and social expectations around behaviour and interactions and being willing to adapt to these. This process was greatly helped by my experience of living in Pakistan for nine years and therefore having relatively good knowledge of the Pakistani culture, Islam and Urdu. Having a Pakistani husband, wearing Pakistani dress during visits to families' homes and using the local Mosque as a venue also helped participants to trust me once we met.

The first attempt to identify families

Once I secured ethical approval for my study, the Mosques made announcements at the end of the Friday prayers, which is the time that the largest number of people are present at the Mosque (more than four thousand in total, the majority being Pakistani). The announcement was made on two consecutive Fridays. Around 700 flyers with the invitation written in English and Urdu (see appendix G) were also handed out to interested members of the congregation and remained available throughout the week. At the same time larger versions of the flyers were put up as posters in the Mosques, as well as in three local Islamic bookshops and three community projects. This should have made a significant proportion of the Pakistani population aware of the project. However, nobody attended the information meeting mentioned in the announcements, posters and flyers, and nobody contacted me on the telephone number provided. After visiting all the contact persons who had conveyed the invitation again, just one family contacted me, who initially decided to participate, but dropped out before the reconnaissance stage was completed.

Reflecting on reasons for the lack of response

This was obviously a very disappointing outcome and I reflected on what the reasons for such a lack of response could be. These reflections were informed by the views of the contact persons who had supported the advertising as well as the research literature that describes problems with accessing communities.

Most community members said they did not think that there are disabled children in the area. Or if they did, they did not dare to broach the subject with families they knew had disabled children. For example one person told me someone he knew well had never mentioned his disabled child to him, and therefore he feared telling him about the project might jeopardise their relationship. The strong stigma associated with impairments may lead to blame (often of the mother), shame and rejection, fuelled by a strong community

problem of gossip (Campbell and McLean, 2003). This may lead to families being reluctant to participate in a community level project.

Secondly, several community members suggested that it can be very difficult to motivate Pakistani people to get involved in any voluntary community activities. Unless the benefit for themselves is immediately obvious, or unless food is offered, the Mosque leadership also has difficulty motivating people. This is also an issue I experienced in community work in Pakistan, but I had not expected this to be as much of a problem in this context. Campbell and McLean (2003) describe how participants in that study stated that Pakistan has no tradition of widespread involvement in community networks, and that community members who do get involved may be criticised for 'acting white' (p256). This issue was also brought up in the men's and women' groups later on in the project when they were considering how to continue their group activities beyond the end the of the project.

Thirdly, it may have been difficult for families to take the initiative to attend the meeting or phone me. Five of the six families who participated were approached by someone in person or by telephone and did therefore not need to take the initiative to respond to a written invitation only. This indicates that people are more likely to respond if they get a personal recommendation about the researcher.

In addition to the difficulty in taking initiative, the venue and timing of the meeting may not have been ideal. The Mosque at which it was held was the more conservative one, which families, especially women, may have found too imposing to walk into. The meeting time was on a Sunday afternoon, which the Imam had suggested would be a time most families are free, but I later realised it is also a time that most (planned and impromptu) family visits take place. As visitors will always get the priority over everything else in Pakistani culture, this could well have interfered with families' plans to attend the meeting.

Emmel et al (2007) suggest that there is often a lack of trust between gatekeepers and potential participants in communities. This may well be an issue in this area, although the gatekeepers themselves did not indicate this, as was to be expected. However once I met with the families, it was evident that most of them had very little contact with the Mosque leadership, even if the men of the family attended the Mosque for their prayers regularly. The exception to this was one Shia Muslim family, who were associated with a much smaller Mosque outside the area, which had more of a community function. However, the general impression throughout the project was that the families did not receive, or indeed expect to receive, any type of social support from the Mosque. In addition when problems arose around accessing the Mosques for meetings, they were clearly critical and irritated by the way the Mosques are run (see chapter 3.4). This again is reflected in Campbell and McLean's study where some of the participants described having become alienated from the local Mosque as it had been mired in a series of on-going political and financial controversies and power struggles (2003, p252).

It was also suggested that the poster may not have been attractive enough or that people may not have seen the poster or flyer. Although this seemed unlikely at the time as 700 flyers had gone out into the community, I found out later that none of the participant families had indeed seen a poster or flyer distributed through the Mosques. Sixsmith et al (2003) also note that advertising may not be successful in a socially deprived area, as community members may not be sure whether it applies to them, or be unwilling or unable to proactively pursue the opportunity.

The flyers and posters invited families with children with any type of impairment, but aged up to around 12 years. This age restriction limited the potential number of families who could have responded, and was later changed to 18 years.

Apart from the more general recruitment issues described above, the nature of the project may also have appeared overwhelming to families. Participation in

an intensive, time-consuming project could be seen as an extra burden for already overburdened families. This did appear to be a factor in about half of the families I made contact with but who did not choose to participate in the project.

Diversifying approaches

After this unsuccessful start I reconsidered my approach and went back to the literature to learn from other researchers. The difficulties I was experiencing caused me to think about 'recruitment' and 'sampling' in a new way and I searched the literature again, using new search terms, such as 'access' to communities and marginalised people, 'community participation' and 'opening communicative space'. This yielded some interesting articles and book chapters, which helped me to re-evaluate my difficulties in identifying participant families. I refer to the most significant of these texts throughout this chapter. I found that other researchers had experienced similar problems and the realisation that the access process was part of the overall study reduced my apprehension and increased my ability to step back and learn from it. The presentation I made at a PhD students conference about this process whilst this all happened can be found in appendix I.

Sixsmith et al (2003) emphasise the need for a variety of complementary approaches to find research participants in a community setting. With this changed understanding of community dynamics involved in identifying participant families, especially cross-culturally, I decided there was no option but to approach families through their current services. This strategy got off to a difficult start because by now it was July and the school holidays were about to begin, so people were difficult to contact and not eager to take on extra work. However I did make contact with some statutory and voluntary services before summer and many more in the months following the holidays. I was then able to make contact with two families who received an invitation through the special school attended by their child and one family through an informal social contact before the summer holidays.

The importance of a personal invitation

In total I contacted six special schools, three specialist units in primary schools, the children with disabilities team of the social services department and eight charities / voluntary sector projects (the latter include specialist schools and carer / family support projects). This was not at all a straightforward process as it took many phone calls to get hold of the right person, and personal visits and reminders to each school and project contacted. As the response to the initial strategy of sending invitation letters to the families in their children's schoolbags was not very fruitful, I then requested contacts in these projects to speak to the parents by phone or face-to-face, which gave a better result, though still only just enough to be able to conduct the study.

The fruits of my labour: families signing up

By October I had made contact with a total of 14 families, six of whom had formally consented to participating in the full study (although one dropped out soon after that), the mothers of four more families agreed to a one-off interview, and four decided not to participate once they understood the nature of the project, mostly because they did not think their child should be classed as disabled (e.g. they had mild intellectual impairment, or problems evident at birth had been resolved). Therefore contact with all projects and schools was maintained and new opportunities looked for throughout the rest of 2007. I was also interviewed on a live programme for the Pakistani community on the local radio. By the end of the project I had been in touch with a total of 18 families, six of which participated in the full project, of another six the mothers told me their life stories (either during an introductory visit, or during an interview for which formal consent was obtained), and six decided not to participate at all.

Additional reflections

This section draws the attention to a number of key issues encountered in accessing the local Pakistani community and potential participant families.

Word of mouth

Significantly, most participating families have responded to a verbal invitation by a person whose judgment of me as a person and of the usefulness of the project they trusted. However, invitation by word of mouth of one family to another, described as 'snowball sampling' in the research literature (e.g. Patton, 2002, p237), did not have as much scope as expected and only one family was recruited in this way. One reason for this is that the families are quite isolated and do not tend to know other Pakistani families with disabled children through school or neighbourhood. Secondly, if they did know other families, they often felt they would be too busy, probably due to feeling overwhelmed with the problems and pressures faced in raising a disabled child.

Insha'Allah

I was able to adjust to the speed and method of organizing things in the Pakistani community, recognizing the "Insha'Allah culture" (Insha'Allah means "God willing"), which often leads to promises not being followed up and can also conceal obstruction by apparent cooperation if the promised action does not take place (on time or ever). Assuming that it was not in God's will can be a convenient answer.

The insider-outsider balance

Although my long history of living and working with Pakistanis in Pakistan and Britain may have made me a semi-insider, I was also an outsider, which had the advantage of not being part of the social hierarchy and not being a potential part of the gossip circuit, which helped (potential) participants to feel 'safe' with me (see Kauffman, 1994). Even with a good mixture of being insider and

outsider, I was constantly conscious of the impression I was making and detecting any undercurrents. 'Being there', by living in the neighbourhood where the Mosques are, and therefore being visible and available for gatekeepers, other contacts and (potential) participants to observe me, appraise me and lose any prejudice or mistrust they might have, has also helped to confirm the insider part of my status.

Bolognani (2007) describes a very similar process of gaining access to the Pakistani community in Bradford as an outsider researcher for her study on cultural agency related to crime. Her study, like mine, did not seek to focus on religious aspects, but she points out that many people contacted were conscious that her reporting on the research could contribute to how Muslims and Islam are perceived by people outside their community. She points out that participants in her study experienced increasingly more Islamophobia after the events of 11 September 2001 in the USA and 7 July 2005 in London, as opposed to racism on account of being Pakistani. Bolognani emphasises the need for outsider researchers to be willing to be known in and by the community and to be open to scrutiny, in order to earn their trust in terms of reporting the findings to the outside world fairly. Participants in this study, whilst recognising the issues arising from Islamophobia, did not raise concerns about my reporting of the findings explicitly, but did ask me questions about societal issues beyond the scope of the project. This may well have been a conscious strategy to test my trustworthiness.

Despite all efforts to exploit the advantages of this insider-outsider balance to the fullest extent possible, it is difficult to say in what way the research process and outcomes would have been different if I had been an insider in the community. As a Pakistani woman I might have had easier initial access into the community and therefore might have been able to identify a larger number of potential participant families, although it is difficult to say whether they would have been more or less likely to consent to participating in the project.

I also might have had a better understanding of the deeper reasons for negative attitudes towards disability, or the realities of marriage in a Pakistani context, and therefore been able to identify and explore key aspects more deeply. However I might have had more hindrance from participants' worries about possible gossip into the community.

In terms of engaging the male participants there are no apparent disadvantages to my insider-outsider balance, and attempting to do the same as a Pakistani woman would have been much more difficult in view of social expectations around interactions between men and women within the Pakistani community.

Inclusion criteria's influence on the choice to participate

It is interesting to note that of the participating families five of the six have relatively supportive fathers/husbands, which does not reflect the findings of earlier research that suggest that Pakistani mothers of disabled children are the least likely to receive their husbands' or other relatives' support (Chamba et al, 1999, see lit review). The parents of the other family are divorced and the father is not supportive at all and is not in the study. However out of an additional six families (including the one family that dropped out of the study early on) who were contacted and of which the mothers gave a one-off interview, four reported that their husband did not provide significant emotional and practical support in raising their disabled child, or even made it worse. This indicates that the disadvantage of seeking whole families to participate is that a number of potential participant-families ended up not participating because the fathers were not interested or willing. In light of previous studies and the fact that several families were unable to participate due to the father's refusal this means the sample may not represent the population accurately. However it is very difficult to have a fully representative sample with such a small sample size in any case and generalization of the results is not a primary objective in an action research project. The main focus of the research is to explore the processes involved in facilitating Pakistani families with disabled children to

gain more insight in and control over their support needs and how they are met. The participating fathers were aware of the fact that their support is not taken for granted and that their findings could be important for other, less supportive, fathers to hear, which affected their choice of topic, which was to explore the reasons for negative community attitudes and finding ways of influencing them.

Issues of gate-keeping

One culturally influenced problem I did not recognize soon enough, which led to delays in recruitment, was that a project that serves Asian families with disabled children in the area was not comfortable with my plans to conduct this research project in their area. The staff members are second generation Pakistanis themselves and appeared to be very interested in and supportive of my ideas when I met with them early on in the proposal development stage. However as time went on it gradually transpired that they were not in favour of this research project and used delaying and distracting tactics to obstruct its progress, while all the time remaining polite and friendly on the surface. For example they suggested I should write to their head office to gain permission for conducting the research with their support and offered to pass on the letter themselves. When no response was received for many months I contacted head office directly and it appeared the letter had not been passed on and some internal politics were used to obstruct the communication and approval.

This became all the more obvious when I contacted a sister project in an adjacent area (which serves more ethnically diverse families of which only a few were Pakistani) at a later stage. They considered it part of their role to share information and therefore did not indicate they needed central permission for doing so. It was disappointing to find out that the personal pride and possessiveness of local knowledge and information that can make collaboration in development work in Pakistan so slow and frustrating, was still so strongly present in people of Pakistani origin born and brought up in the West. Several service providers and participating families have subsequently

provided negative feedback about this project, without being prompted by me to do so, which confirms my own assessment of the situation that this was not a personal problem with me as a person, but rather a general resistance against collaboration with others, who might threaten the sole recognition they seek for their work.

Not being able to use their network to invite families to participate in the research through targeted invitations was not only one of the reasons why I had to put in so many efforts into recruiting through a wide range of services, but also left me looking for ways to restore the relationship with this project as the outcomes of my study could be important for them and collaboration could be very constructive for both parties. However, the positive outcome of this problem was that I had to contact all relevant services personally which has helped me to network widely and thus publicize the research project. Although not all services were able to lead me to families willing to participate, contact persons showed much interest in the research and confirmed there was an urgent need for it. Establishing contact with a wide range of services and projects during the project is also likely to facilitate the dissemination process later on.

Conclusion: key meanings arising from the process

So what "valuable data" (McLean and Campbell, 2003) did this "complex social process of gaining access to this community" (Sixsmith et al, 2003) provide? Both my own reflections and the feedback gained from gatekeepers, contact persons and families contacted have increased my understanding of issues involved in recruiting participants in social research in general, but more significantly from the Pakistani community. I will summarise the most important findings here:

Recruitment strategies

To recruit participants for a community project for marginalised populations, varied and flexible sampling strategies need to be used. In addition, each strategy requires sustained effort to keep gatekeepers and contact persons interested in the project and committed to supporting the researcher to gain access to prospective participants. The recruitment phase is an important part of the research process as a whole and researchers need to allocate a significant proportion of their time and efforts to it in their proposal.

Understanding cultural expectations

An equally important factor is the researcher's understanding of the community's cultural and social characteristics and the willingness and ability to behave accordingly. Some things – like wearing the right type of clothes and taking time for drinking tea and chatting – are much easier to deal with than others – like remaining polite yet persistent in the face of the Insha'Allah culture, or accepting gracefully that it is not your place to challenge local status and power issues.

The need for more flexible inclusion criteria

My original intention was to work with families with *younger* children (up to 12 years of age) with severe impairments and my choice of research approach required the participation of *whole* families in a relatively *long and intensive* process compared to survey or single-interview research. Although it was neither desirable nor practical (in terms of re-writing the whole proposal and re-submitting it for approval) to change my research approach, I did need to relax the criteria on the children's age and the nature of their impairments. This taught me that in recruiting participants from small marginalised population groups for a time consuming research project, there is a need for more flexible inclusion criteria.

Cultural understanding versus assumptions

Although it would have been much more difficult to access families in this area without prior personal experience of the Pakistani culture and language, and although many things went as I had expected, some assumptions I made did not prove to be quite accurate and slowed down the recruitment process. Examples of this were my assumption that the majority of families would be covered by advertising through the Mosques, and that participants might feel restricted in expressing negative views on the services through which they were recruited. Both of these assumptions influenced my initial decision to recruit through the Mosques only. This issue highlights the need for researchers to use their previous knowledge of communities, but remain conscious of and challenge their assumptions continuously.

Implications for engaging the participants in the research process

The recruitment process was helped by my previous experience of living and working in Pakistan to an extent, but I found myself on a steep learning curve about how the Pakistani culture as experienced in Pakistan manifests itself in the Pakistani community in Britain nevertheless. These new insights proved to be very important in maintaining a good relationship with the Mosque leadership to ensure we could continue to use the venue and to develop their interest in the outcomes of the project. In addition, what I learned during the recruitment process helped me in facilitating the groups in their action research cycles, especially when considering possible lines of action (see McLean and Campbell, 2003). Before entering the community I had not expected the recruitment process to be such an intensive learning process and it took a while before I realized it was unhelpful to feel all this was a 'waste of time'. I now understand why Silverman (2005) asks: "how should you respond to the challenges you will find (in the field) – are they just irritating troubles or can they be valuable sources of data?" Shifting the answer from the former to the latter option he offers has shifted the focus of my attention towards observing and reflecting the communicative and social processes, rather than remaining too focused on the technicalities of the PAR process alone.

Chapter Summary

This chapter has presented the challenges I faced in recruiting participant families from the local Pakistani community, and what I learned from these challenges. The next chapter discusses the next phase of 'access', by describing how I initiated my interactions with the families once they contacted me to express their interest to participate in the project.

Chapter 3.2:
The exploratory phase: Getting to know the families



Aliya's picture of Dawood and herself

3.2: The exploratory phase: Getting to know the families

This chapter continues the story of gaining access to the community, but the focus now shifts to how I continued to build up a relationship of trust with the families who had decided to participate in the study. During the exploratory phase I was aware that I as the 'observer' was also 'being observed' (Patton, 2002, p331) and that everything I said and did had the potential of building up or breaking down the trust relationship which was so essential for participants being able to respond to me and my questions openly.

The second purpose of the exploratory phase was to give all individual participants the opportunity to express their initial ideas about the issues they faced and support needs they had in view of having a disabled family member. The issues identified by the men, women and children respectively formed the starting point for their action research groups which were formed after the exploratory phase was completed.

This chapter describes the families, the research methods used and the findings resulting from this phase. Whilst the purpose of the exploratory phase was not to construct a complete and exhaustive case study of the participant families, the description of the issues discussed provide the reader with a broad overview of the situation the families found themselves in, and thus the starting point for their action research groups.

The families

The participant families were mostly nuclear families consisting of parents and their children only. Of one family the parents were divorced and the children lived with their mother. Only in one family was the paternal grandmother living with them. Even of the remaining 12 families I contacted I know eight were also

nuclear families, of two I don't have that information, and two families live with the paternal grandparents. In none of the families did the father's brother(s) live in the same household, as is frequently the case in extended families in Pakistan. This is in line with other research studies, which also found that Pakistani families can not be assumed to live in extended families and have plenty of people to help look after the child so that they need less respite and other support (see Chamba, 1999, p17; Fazil et al, 2002, p249).

Family composition

Each of the six participant families had one disabled child. Two of these children had severe intellectual impairment and autism, three had moderate intellectual impairment and one had a mild physical impairment. The nature of impairment given is based on parents' report and presentation of the child rather than formal diagnosis obtained directly from the children's doctors. As this study is rooted in a social model of disability, the focus is on the barriers faced by the disabled children and their families, rather than the exact nature of their impairments. Table 3.2.1 gives an overview of the family composition of the families. The names given are all pseudonyms.

Family background and characteristics

All but one of the parents were born in Pakistan. Noor was born in the UK, although her ex-husband was born in Pakistan. Five families had their roots in the Punjab province, all from different towns. The remaining family originated from Karachi in the Sindh province. Four of the families had lived in the UK for many years, one family was here temporarily for study, and of one family the wife and children had recently joined the father who had arrived in the UK a few years earlier. Five of the fathers were employed and one was a full-time post-graduate student. The level of education of the parents ranged from having completed primary education in Pakistan (Urdu medium) to post-graduate degrees. Four families, including the student household, were on a low income and three lived in unsuitable accommodation due to their low

Family	Adults	Disabled child – gender, age and impairment	Other children and ages	Total number of children
F1	Haider (F) Tahira (M) Murad (B, 22) Zafar (B, 19)	Tariq, boy, 14, intellectual impairment	Zohaib (B, 11)	4
F2	Mahboob (F) Sadaf (M)	Imran, boy, 10, severe intellectual impairment and autism	Jamil (B, 12) Inam (S, 8)	3
F3	Noor (M)	Dawood, boy, 11, severe autism and intellectual impairment	Aliya (S, 13)	2
F4	Sarwar (F) Maryam (M)	Erum, girl, 3, physical impairment	-	1
F5	Gulzar (F) Nadia (M)	Sultan, boy, 14, intellectual impairment	Maheen (S, 13) Abid (B, 9) Haroon (B, 6)	4
F6	Imtiaz (F) Iffat (M) Naaz (G)	Afia, girl, 9, intellectual impairment	Azra (S, 12) Hamid (B, 7)	3

F = Father; M = Mother; G = Grandmother; B = Brother; S = Sister

Table 3.2.1: The participant families (all names are pseudonyms)

income. Only one of the families was on benefits other than those related to their children's impairments (which are not means tested). At home the families mainly spoke Urdu and/or Punjabi, combined to a greater or lesser extent with English. Three women and one man spoke very limited English, and although the level of English of the remaining participants was good, Urdu was used frequently, even if those with limited English were absent.

At the start of project the main roles of all mothers were those of mother and housewife. Two worked part-time (a few hours per week), one took up full time work after the start of the project, and two took up higher education studies. Only two mothers did not study or work outside the home at all. All children over the age of four, including the two older (adult) brothers of one of the disabled children were in full time education. Three-year old Erum attended Nursery.

Although the contact and/or interviews with the other 12 families, who decided not to participate in the full project, have informed and broadened my insight into the issues faced by Pakistani families with disabled children in the UK, all direct quotes and anecdotes in this chapter have been taken from the six participant families.

Research methods used

The research methods I used in this phase have been described in chapter 2.2. In summary I interviewed each person individually (see appendix B for the interview guides), the children also made drawings and timelines, and we looked at photographs, both those in existing family albums and pictures taken with the cameras I provided. These activities were set within the home environment and each visit provided ample opportunity to observe the family as a whole, the atmosphere and their interactions.

The participants at the heart of the study

Interviewing and otherwise obtaining the views of the disabled children themselves was challenging, as one child was very young and all others had intellectual impairments and/or communication difficulties. Overall three children could not respond to verbal questions about disability issues at all, whilst the remaining three could to a limited extent, for example "Why do you go to a different school than your brothers and sisters?". I therefore used alternative, non-verbal methods to give them the opportunity to express their views.

Drawing

Drawing pictures of themselves, their families and favourite activities was helpful, not only because of what they drew, but also because they were then keen to talk about what they drew.

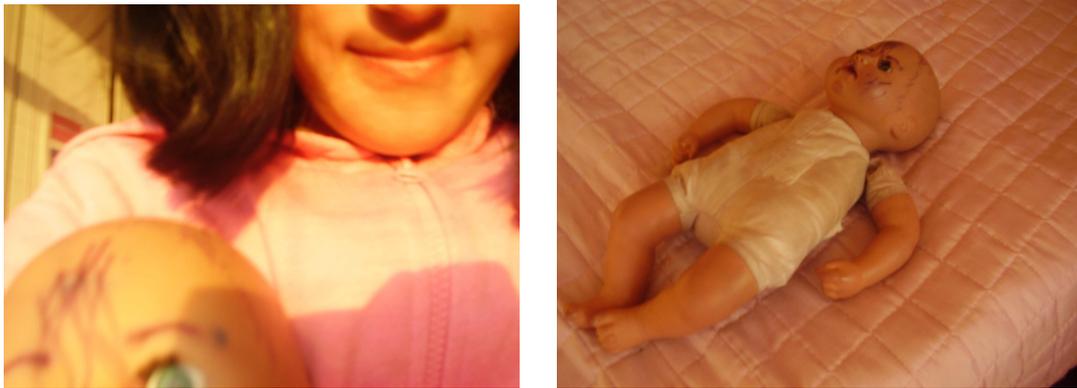


Figure 8.2: Afia's (9) photographs

The following sections describe what I learned about the main issues faced by the families, and about the influence the process had on the action research phase of the project. I will start with the latter.

Getting started: inviting the participants to embark on the action research project

The home-based exploratory phase was very important, as this was the time the families got to know and trust me. Receiving people into your home is a great honour and joy in Pakistani culture, which greatly facilitated this process.

Background of the researcher

The person I am, partially shaped by living in Pakistan for many years, was extremely important in the way I carried out this research. This was expressed by the participants (particularly the adults) often and in different ways, both during the exploratory phase and beyond: they spontaneously spoke about it, they showed it by telling me many personal things on the very first visit before they had even signed their consent forms, and they discussed it in evaluation meetings. Important aspects of this were:

- the fact that behaving within Pakistani cultural norms has become second nature to me (e.g. wearing shalwar kameez, taking shoes off by the front

door, drinking tea and chatting about our families leisurely): **"It is like one of our own is sitting with us"** (Tahira, meeting 2).

- my knowledge about how the Pakistani society works, and about Islam and how it is practiced in Pakistan, meant they did not need to explain this general 'backdrop' to their stories. For example Mahboob said: **"I wouldn't have told you this if you hadn't lived in Pakistan, as you wouldn't have understood"** (Mahboob - Urdu). The same was true in relation to what family members expect and accept from each other: **"you know what happens in Pakistani families, the daughter-in-law has to sacrifice a lot"** (Tahira).
- the fact that I speak Urdu: **"when I heard that you speak Urdu I wanted to participate"** (Sadaf, Urdu).
- the respect I have for Pakistani people and their way of life, and my evident enjoyment in spending time with them.

Valuing each participant's experience and views

The fact that I spent time with each person, and sought to know their personal perspective and feelings about having a disabled family member was key:

"you made everyone feel as if they were the most important person in the project" (Maryam) and

nobody had ever asked about ME before. Other professionals just look at your child's problem, or even just part of the problem, never at the mother raising that child (Maryam, evaluation interview).

This was the first time many participants were invited to reflect on and talk about their experience, and mostly they had not expressed their own thoughts and feelings much before. The mothers very clearly welcomed this opportunity, as reflected in the last quote above. Some of the fathers seemed slightly taken aback by it, although overall they were remarkably open about their views and often their feelings as well. The children were the least open at this stage,

giving me mainly positive answers and drawings. The factors influencing this reticence will be discussed in further depth in chapter 3.5, but the main two aspects of interest at this stage are firstly the children's very strong sense of loyalty to the family unit which brings along with it a worry of discrediting the family by saying the 'wrong' thing, and secondly the fact that they were unaccustomed to being asked about their views and opinions, which appeared to make it difficult for them to verbalise their ideas.

Four ways of knowing

Out of the 'four ways of knowing' (see chapter 2.1), experiential knowing played the greatest part in this phase, when I specifically asked each participant to remember, reflect on and verbalise their experiences in relation to having a disabled child in the family. Becoming aware that their own experiences provide a level of knowledge that is essential for understanding their support needs and looking for ways to improve their situation, was an important factor in remaining motivated to continue to be part of this study for the action research phase.

Communicative space

This important discovery of how their own knowledge would be an important resource in the action research process can be described as an early and decisive part of 'opening communicative space'; without this discovery it would have been difficult for individual participants to actively participate in their groups later. Reason (2006, p193) argues that the formation of communicative space may well be the most important thing we can choose to do in certain situations, as it entails the opening and encouraging of new and better forums of communication and dialogue about pertinent issues which were not being discussed in the particular context so far. As it was apparent that the parents of most of the families did not communicate with each other in deep or satisfactory ways (see the section on support within the

family below), the experience of a positive communicative space was important within the homes as well as in the research groups.

Key issues faced by the families

This section will give an overview of the situation the families who participated in this study found themselves in. From the individual interviews, activities and observations each family's unique story began to emerge, yet they had many things in common. Rather than focusing on complete family stories, this section presents the themes that cut across the families. Quotes from individual participants are used to illustrate these themes.

Diagnosis and initial feelings

In most families it had taken a number of years before a clear diagnosis was given by the doctors. Only in one case was the diagnosis clear from birth. Another child was given the wrong diagnosis at birth and the mother argued with the doctors for ten years to have the diagnosis changed on the child's records. This was important as the wrong diagnosis implied it was an hereditary disorder, which the child's father blamed on the mother (this is the couple that was divorced). Parents spoke of the confusion and uncertainty before the diagnosis was given as the realisation that the child might have permanent impairments became clear only gradually. They found the term "developmental delay" unhelpful as it is vague and seems to imply the child will grow out of it: **"the thing is, it's so open, it can mean anything"** (Haider). Both before and after diagnosis the explanation and guidance given by doctors was felt to be inadequate.

When asked for their initial reaction to hearing the diagnosis, mothers spoke of feelings of grief, trauma, shame and shock -**"my heart just stopped. If he won't be able to speak, what is the point?"** (Sadaf, Urdu). These feelings were intense and Sadaf even talked of how she became physically ill with grief and

developed diabetes at that time. Fathers used words like pain, regret (**"In my heart was pain and regret: why was my child like this?"** – Mahboob, Urdu) and denial (**"It was difficult, in the beginning you have a denial that your child is like this"** - Haider), and talked about the fact that it was difficult to accept an impairment that is not visible. Some fathers told themselves that **"instead of crying it would be better to look for solutions"** (Sarwar).

Negative reactions from relatives and community members

All families talked about the overwhelmingly negative reactions they received from people in their extended family and community in the early days when it became known that the child had impairments. All parents talked about being blamed for the child's impairments. Sometimes the blame was put on both parents, but more commonly on the mother only. People also told them at this early stage that the child would be a burden and would cause them loss and disrespect. In the two cases where the impairment was obvious at birth the mother was told by her family-in-law to cover the child up when guests came so they would not see: Maryam knew her mother-in-law was disappointed because **"the problem is she is a girl AND has a deformity, so it will be harder to find a husband in future"**. Similarly Noor was told to cover her child up so relatives would not see the problem and say **"What a freak!"**.

Additional attitudes became more apparent as the child grew up and are faced by the families continuously. They spoke of people making fun of the child, name calling and using derogatory terms like **"pagal"** (mad) and **"langri"** (lame). They also said that people tended to show an apparent expression of pity and sympathy that was never accompanied by an offer of practical help. Ignorance and superstition was also a recurrent theme, for example Mahboob was told by his relatives: **"don't bring him to the house, because his shadow may fall on the newborn baby"** (Urdu). They felt that children were generally more accepting than adults. Noor felt that the **"Pakistani community is in denial about**

disability", as they think that English people have more impairments and it is no problem for their own community. Noor suggested that this is because in Pakistan disabled children are often 'invisible' as very few attend school or come out of the house for other reasons. The mothers also indicated that their own initial reactions were influenced by community perceptions and that it took time to realise that their feelings of guilt and shame were not justified (see under).

Sometimes parents are confronted with extreme situations and the following story told by Sadaf is worth relating at length:

When I was out shopping one day a Pakistani woman who I know vaguely stopped me for a chat. She asked me why I did not realise my child was disabled during pregnancy, because these days they check it with machines. She told me I should have had him aborted. May God have mercy! How could I commit such a sin? If you have a miscarriage you can't help it, but abortion for me is out of the question, regardless of whether the child might be disabled! The woman doesn't even have children of her own, so how could she say such a thing? She should understand... People say things - it's easy talking for them! Some Pakistanis say people purposely don't get disabled children aborted because they will get a lot of money in benefits, but they have no idea what the financial implications are. My husband has had to change to working only morning shifts in order to support me at home in the afternoon, so he can not do overtime and has no options for better employment (Urdu).

Sadaf was very indignant about the woman's impertinence of questioning her about such personal matters in the first place, but also about the brazenly stated opinion that her child would have been better off dead. She was also shocked about the astonishing perception that it could be financially

beneficial to have a disabled child. Apart from expressing her personal feelings about this incident she also demonstrated that she could relate it to general perceptions towards disability (propositional knowledge).

Isolation

In light of the community attitudes described above, the families were very isolated. Especially if their children had communication and behavioural problems the families had lost contact with many relatives and friends, and felt they were not welcome at weddings and mosque events either. As this kind of socialising is the major leisure activity for Pakistani families this really isolated them. Tahira talked about how she felt she could not take her son out, as he had hyperactivity and behaviour problems when he was younger:

I couldn't take him anywhere, wherever he went, there was trouble... Nobody was coming to our house and if we wanted to go somewhere they would make excuses...people weren't comfortable. It was hard for me to see their faces, it was better to stay at home... Because people think he is not a normal child, even if it is not his fault, but they would always give that impression... I preferred to stay at home... I just locked the doors and stayed in the room with him.

When I asked her if she got any support from the Pakistani community, beyond her family, she said **"No, no, no.... I don't ask for help. I like to stay in my own home"**. This illustrates how difficult it is to deal with people's rejection of the child, which takes away the desire to go out and makes it extremely hard to ask for support.

More surprising was the fact that the families did not have any significant contact with other Pakistani families with disabled children before this study, even though they had sometimes seen them at school functions. Once the

families met each other, several participants commented that they did not realise there were so many Pakistani families with disabled children in the area. The importance of meeting and mutually supporting each other will become evident in the following three chapters which focus on the three groups' research processes.

Faith: from 'punishment' to 'blessing'

Despite this isolation, and despite the fact that they were often told by Pakistani relatives and community members that their child's disability was a punishment from God, it is significant that all parents spoke (with varying intensity) of their child as a blessing. They now perceived the 'tests' that God gave them not in a punitive way, but as an opportunity for developing a stronger personality and faith. For these families faith had a strong positive influence on how they were able to accept their disabled child and look for the positive side of things. Tahira expressed this clearly:

Maybe deep down I think he is God gifted. I pray a lot for him, especially when his behaviour is difficult. My belief is strong. I don't think it is because I have done anything wrong... The way he loves me and his brothers, he is very caring, he doesn't want to see anybody in pain. How God views him? Whatever my good deeds are, just give the reward to him, make it better. This is my responsibility and maybe in this way God is testing me as well - how patient I am (laughs). Our belief is that God tests those who are good people. This is positive as well as difficult... My prayers are all for him, I don't worry as much about the others...

When I asked Noor how she thought God relates to disabled people she said:

Disabled people aren't here to be judged. We're judged for looking after them. So they teach us, it's very interesting, how we learn more from them

than we can teach them... But many people think with blinkers on, like horses, you can't see anything else, like materialism. If you take those blinkers off you can see beyond materialism and see things spiritually.

This is an example of the dual sense of recognising personal spiritual growth that enriched their own lives on the one hand, and of seeing a lack of insight in people around them who had not had the same experience or had been unable to work through it in a positive way. Other mothers expressed this too, both during initial interviews and in group sessions.

Another aspect of faith relates to the idea that everything that happens in life is by God's will. Imtiaz talked about how his attitude towards this idea had changed:

Now I say, don't just say 'God is great' and do nothing, but make sure she gets the right treatment and everything. God doesn't say 'leave it all to me', there is also our responsibility.

Sarwar emphasised that God supports him in taking on that responsibility:

If it was up to anybody they would prefer not to have a child with abnormalities. We have not introduced this, and the One who has introduced it will also take care of it... We will do all we can do, but we also believe that God will help us solve the problem.

The final aspect of faith relates to healing. Many participants, both adults and children said they hoped God would heal the child, often specifying how God might or might not do that. For example Mahboob said: "My prayer to God is that He would make him normal" (Urdu). Sadaf gave an actual example of having taken Imran to a faith healer in Pakistan, who recited verses of the Qur'an and gave him a tonic to drink, after which his fits stopped. However

Noor said she decided not to follow her friend's advice to take Dawood to a certain shrine in the Middle East in the hope he would be healed because

I think there's a reason why He gave me a disabled child. If Allah wanted him to be better, he would have made him better. There wouldn't have been anything on this planet that could have made him better.

All parents spoke about their faith and its impact on how they viewed their disabled child spontaneously and freely; the interview guides did not include direct questions about faith. For many parents the birth of their disabled child and the negative reactions given by family and community members had initially challenged their faith and it had taken time for them to reconsider their beliefs about God's will and the meaning of 'testing'. Most indicated their faith had become more important and more personal since the birth of their disabled child.

The last three sections have shown that the negative community attitudes described in the literature (e.g. Hatton et al, 2004), were indeed commonly encountered by the families. At the same time, this last section has also provided an insight into how the participants responded when a disabled child was born into their family and how their faith was strengthened and played a key role in developing positive perceptions and attitudes towards disability. Croot et al. (2008, p4-6) also describe this contrast between attitudes observed in the general Pakistani community and those in the families.

Ideas about causes of impairments

When asked about the cause of their child's impairment, participants talked of a variety of causes.

Bio-medical versus religious explanations

Some talked more about bio-medical causes, while others focused more on the spiritual dimension, but mostly both perspectives were combined. Gulzar explained how the two perspectives relate in this way:

How should I explain? Mmmm... there is definitely the medical explanation, but without the wish of God there is nothing. Maybe it was in our fate, very frankly, but again, it is all...., there is a medical system in what God has developed. Allah is the big superpower, we can't avoid anything.

Croot (2008, p6) reports that the Pakistani parents in her study also “used both theological and biomedical explanations for disability, demonstrating that these are not mutually exclusive” and suggests that they often used the latter to dispel unhelpful suggestions from other people in their community about the cause or appropriate actions to take when a child has a disability (p5). Similarly Yamey and Greenwood (2004) who interviewed participants from six major religions found that all expressed beliefs that resonate with aspects of the medical rehabilitation model and had some faith in modern medical intervention (p460).

Most participants told me about the medical diagnosis doctors had given them. In four of the six children this diagnosis did not provide clarity on the cause of the impairments, as the cause for the intellectual impairments and autism were not known. Only one parent was told his son's intellectual impairments were due to a chromosomal abnormality. The parents of the child with physical impairment were told this was due to a rare genetic mutation.

Cousin marriage

Several parents mentioned consanguinity, either because the doctor had asked whether they were related, or because they were indeed cousins (three of the six couples). However only one family had been told that this was a likely

cause of their child's disability. As the issue of cousin marriage has been debated in the media even during this study, the men's group was very interested to find out more of the 'facts' and arguments, so this issue will be given some more thought in chapter 3.4.

Magic and superstition

In one family both parents believed that the child's disability was caused by black magic, saying that a relative who had not approved of their marriage had put a curse on the mother whilst she was pregnant and given her something harmful to eat. Although they talked about how the doctors told them about their child's impairments, they did not believe the cause was medical: "if they (*relatives*) would not have put that (*in my wife's food*), my child would have never become like this" (Mahboob, Urdu). In addition Maryam talked about superstitions in the family. For example, people told her that she must have slept on her stomach during pregnancy, or used a knife during the lunar eclipse. Her mother-in-law also told her after the child's birth that she had had a bad omen on the day they got married (a piece of clothing went missing). Finally her own mother had dreamt the day before the child was born that she gave the baby a box with lovely marbles, but when she opened the box there was one missing: "A very naïve resemblance, but then I do believe that sometimes dreams give a message" (Maryam). She said that she does not believe in these superstitious beliefs herself, but even so she initially started thinking that maybe she had done something wrong:

But then I realised I should not take this as a punishment, it is not a punishment, I did settle that thing in my mind. It is the first acceptance phase in which you think all these things (Maryam).

Maryam's story illustrates how much the cultural perceptions of people around you can influence your ideas and emotions even if you do not believe they are all true.

Parents' relationship with the disabled child

Most parents indicated that their disabled child was extra precious to them due to their constant and intense worry about them. They mainly worried about safety now and provision of care in future, after their own death. Their deep affection was obvious from the way they talked about their child, for example "I am very close to him. He is my life; his pain is my pain" (Mahboob, Urdu) and "We are not complete without him. He is the heart of this house, you can say.... In my family everything is for Tariq" (Tahira).

Practical care for the child

In five of the six families the mothers provided most of the practical care for the disabled child. In one family the father provided most of the practical care, by working early shifts on weekdays only, so that he could be at home when the child came home from school. The other four fathers were involved to varying extents, for example by making sure all medical and school appointments were attended, helping the child with schoolwork, taking them out, etc. Overall the five married mothers were satisfied with the level of practical support their husbands were willing and able to give. Only one father indicated that he could do more and that his wife would also appreciate this, but his wife did not talk about this herself. The mother who was divorced was the sole carer for her disabled child. Her ex-husband did agree to 'baby-sit' the child at times, but as he refused to change soiled nappies – making the child play outside in the garden to avoid the smell instead – she was unable to leave him there for any length of time.

Both mothers and fathers talked about the intensity of the care their child needed and how little time they had for themselves. All mothers talked about the need to work or study, or to have a hobby to 'distract' them from their daily worries, to maintain contact with outside world, and to have a different role. Tahira said she enjoyed her part-time job because

it gives me peace of mind, I don't want to stay inside all day long doing the same routine... at work you see the world... you learn new things... and at home there are no ladies, but at work it is all ladies, which gives a social life.

Maryam also looked at the future and said: "I am really happy to have started my studies and find these personal goals for fulfilment very important."

The children in the families accepted that they needed to support their disabled sibling and parents and took on practical care roles too. This mostly involved playing with him or her, but in two families they also helped with dressing and feeding their sibling.

Although five of the disabled children needed much extra care and attention, they received very little respite care out of school hours. Three children attended after school clubs a couple of days per week and went to a holiday play scheme during school holidays, again for a couple of days per week. None of the children went for overnight respite care at the time of interview, although one started doing this for one day a week later. Mahboob said they don't send Imran for respite care

because he won't be happy, he will play up. Or if they are strict with him, he'll become quiet, it will damage him. He can't stay overnight, because we know better what our son's habits are... He won't sleep alone and even if someone stayed with him in the room, he might hit them.

This mix of worries expresses a strong sense of responsibility for his well-being and safety at all times. In later conversations they also expressed a fear that once they accepted respite care, maybe the services would try to take their son from them altogether. Similarly Noor said:

he is very vulnerable. In residential care you don't know what happens. I'm his mum... I don't want him to get hurt. He's got a good memory, and if someone would hurt him he remembers and then, whoever he loves, he takes it out on them.

Emotional support within the nuclear family

Despite the satisfactory level of practical support most of the fathers were able to give their wives, it did transpire in the group sessions in the action research phase that this did not necessarily imply a good level of moral support and communication between spouses. I mention this here as this issue did not form a major focus in the research process, but did give a more complete picture of issues faced by the families.

The issues described here, played a role in all families, but the extent to which this was so varied greatly. The divorced mother reported she had had an extremely traumatic marriage in which she suffered much emotional and physical abuse even before her disabled child was born. After his birth her ex-husband blamed her for his impairments and eventually the marriage broke down. None of the other couples reported having such fundamental problems. However, they did talk of some significant problems, which both the men and the women mainly ascribed to difficulties in communication and conflict resolution, rather than actual hostility or indifference.

Although they acknowledged that to an extent these are universal problems related to how men and women communicate and express themselves differently, the women, in particular, felt that there are cultural expectations and customs that make this especially problematic in Pakistani families.

One issue is that traditionally the marriage is seen as a contract between the two families primarily and a supportive, intimate relationship between husband and wife is not necessarily expected. Instead, the daughter-in-law's most

important responsibility is to keep the family running smoothly and not doing anything that might blight their honour and respect in the community. Building up a good relationship with her mother- and sisters-in-law is vital in achieving this difficult task. Tahira put it this way:

The Pakistani husband will say: ' This is now your house', and then you have to keep his family happy and together - then he will be happy... and they never notice all the positive things you do, but if anything goes wrong they make a big thing of it.

However, when couples live in a nuclear family setting, the relationship between husband and wife becomes the main focus and women reasonably expect more support from their husbands. Tensions which arose in this process included husbands' strong sense of responsibility for their own family at the expense of their wife and children even when living separately, and the difficulty they had in managing conflict and making up afterwards.

Another major worry the women spoke about was that their husbands very rarely expressed positive or negative feelings, which made them feel deserted and lonely within the relationship.

Several mothers also spoke of the emotional support they received from their other children. This was not only expressed verbally, but was also evident in their understanding for and acceptance of the fact that their parents had to give more attention to their disabled sibling than to them.

Relationships within the extended family

The relationships with the extended family varied considerably, both within and between participant families. The main factor in this was whether extended family members had been able to accept the disabled child and whether their perceptions of disability were, or had become more positive. One mother had

lost all support from both sides of the family, another had lost all support from the husband's family, but had good support from her own family, and in the remaining four families there was a modest degree of support from both sides of the family, which had generally grown over the years as the disabled child had become more accepted.

Sources of professional support

The service that all parents were positive about was the Special School their child attended. This was the most important professional support received, not only because they could clearly see that their child benefited in terms of their overall development and behaviour, but also because it provided regular respite for the mothers, giving them some time to do the housework and other jobs, and some time to relax. However, the schools did not always provide enough advice and parents struggled to implement the same strategies at home. This gives too much contrast between expectations of the child at school and at home, leading to difficulties in daily transitions:

At school it is heavy duty all day: boom, boom, boom, boom! And then they get home and WE get the boom, boom, boom, boom! The children build up the tension at school, but don't show it until they get home and they get us pressured. (Noor)

Parents talked of many negative experiences with doctors and other health and social care providers. The first problem encountered was finding out what services will help their child and they were entitled to. Sarwar talked at length about the difficulties they had in getting a referral organised to the appropriate specialist service: **"We're not entirely happy with the medical help; I don't mean the actual care, but the management of the medical treatment, that is the problem"**. A big frustration for the families was that professionals did not communicate clearly. For example, Sadaf felt she was kept poorly informed in the early assessment stages, whilst she observed different services did inform

each other: "they passed their notes to each other" (Urdu). As described above, the long time it took in most families to get a clear diagnosis was also unsettling.

Despite their struggles to get access to the services they needed, the participants were well aware that their children would have received a lot less in terms of medical, social and educational services if they had lived in Pakistan and appreciated that the government provides free schooling and care in the UK. Mahboob remarked: "He only comes home to sleep. After he comes home he is awake for three, four hours and then goes to bed". In Pakistan only a tiny minority of disabled children attend school at all, whether it be special or mainstream school (accurate statistics are not available, but UNESCO estimates that "more than 90% of children with disabilities in developing countries do NOT attend schools", UNESCO, current website). Gulzar talked about their struggle to find appropriate education for Sultan when they were still living in Pakistan:

He stayed in a Special Education Centre for 2 $\frac{1}{2}$ years, but there was no improvement... The children there were much, much below what he was. In Pakistan education is poor, especially in the government sector. Don't ask about that... If you can afford private education it's OK, but in the public sector they are just killing time. I did not see any improvement, except that they were punctual in picking him up from home!

Special school versus inclusion in mainstream education

A number of parents talked about the time the education authority had discussed the most appropriate school setting for their child. Two of the children had such severe intellectual impairments and communication difficulties that the parents did not even mention the possibility of them being included in mainstream education. Two of the other children with intellectual

impairment had attended mainstream pre-school education and had transferred to special education from there. The parents of both these children spoke of finding it difficult to accept that their child was deemed to need special education, partly because it forced them to accept that the child had impairments. For example Iffat said: **"Afia is a slow learner, she just needs practice. But still we had to have her admitted in a special school"** (Urdu). Her husband Imtiaz said:

They do give a choice. Many friends said 'no, don't put her in a special school', but when I saw the school I was very happy as the classes are very small and have two teachers... After a year we saw the results as well.

Haider had similar concerns when they were advised that his son Tariq would do better in a special school: **"In the beginning I said no, he should go to a normal school. It's not fair."** A visit to the special school helped them to accept that it would be the right setting for Tariq, although **"we felt it was the only option we had... It was either here or mainstream, but he wouldn't have coped"**. Sultan, who failed to receive appropriate education in Pakistan (see the previous section above), was unable to read or write when he arrived in England aged 14. Although this would have made it impossible to fit into mainstream secondary education, it took the family nine months to secure a place in a special school, where he is now thriving. The remaining child has no intellectual impairment and is walking well despite her physical impairment, and is therefore expected to do well in mainstream education.

Getting a place in an appropriate school

Although all parents were satisfied with the current education provision for their child, three families had experienced difficulties in obtaining it. In addition to Sultan having to wait for a school placement for nine months after arriving in the country, Noor had had to negotiate long and hard with the local authority

to agree to fund Dawood's placement in a specialist school in the private sector, and Imran's transfer from primary to secondary school went wrong so he spent two months at home, which not only affected his development and well-being, but was also very difficult for his parents to cope with in view of his behavioural difficulties.

Financial issues

A number of financial implications of having a disabled child were brought up by the parents. Although healthcare is free, the families found that having to take the child to many different appointments, sometimes even outside the local borough, became very expensive in terms of transport and parking costs.

Another issue was that it was difficult to find out what benefits they were entitled to, for example Mahboob also pointed out that **"for a long time we had no idea that we could ask for income support and other benefits"** (Urdu).

Two fathers also mentioned they had had to adjust their working pattern in order to be able to support the family. As mentioned above Mahboob only works morning shifts in order to be at home when his son comes home from school, which means he cannot work overtime or move up the career ladder. Imtiaz also stopped working overtime for the sake of his daughter:

I was doing too much overtime with shift work and I realised Afia started to ignore me. She was about 3 or 4 at the time. She would not come to me. So my wife pointed out it was because I was never here. Now I don't do so much overtime and she is happy and fine, as I have more time to spend with her. Giving things or toys or McDonalds doesn't work, you need to spend time.

Imtiaz has learned that supporting his family by being available is more valuable than earning more money, but this choice has clear financial implications.

The disabled children's own perspective

Although the above has given various insights into how the disabled children themselves might be affected by having impairments and by the reactions to their impairment from various people in their families and communities, I was committed to obtaining their views directly (see appendix B for the interview guide). Perhaps more significantly this gave the children an opportunity, often for the first time, to express their views. Due to the children's limited ability to explain their ideas verbally, all other interactions I had with them and all observations of their activities and interactions with family members were important ways of finding out their views about their impairments, their family lives and their experiences at school and in the community.

Drawing: expressing ideas and showing what they can do

Giving the children an opportunity to draw did not lead to more factual information, but clearly helped them in giving their view on the world, as it gave them more time to think about answers to my questions whilst they drew. In addition, in some cases it made the parents realise that their child was much better at drawing than they realised. For example, Sultan drew the two pictures on the next page. The first is of him and his brother playing football, and the other is of a house, drawn at his own initiative, using a ruler. Both his parents and his sister responded with surprise that he was able to do this.

Other non-verbal communication

All children were able to express their wants, likes and practical needs in their own way, either through talking, through using gestures and signs or through actions such as walking away, hitting and pulling the other person towards places (e.g. the fridge).

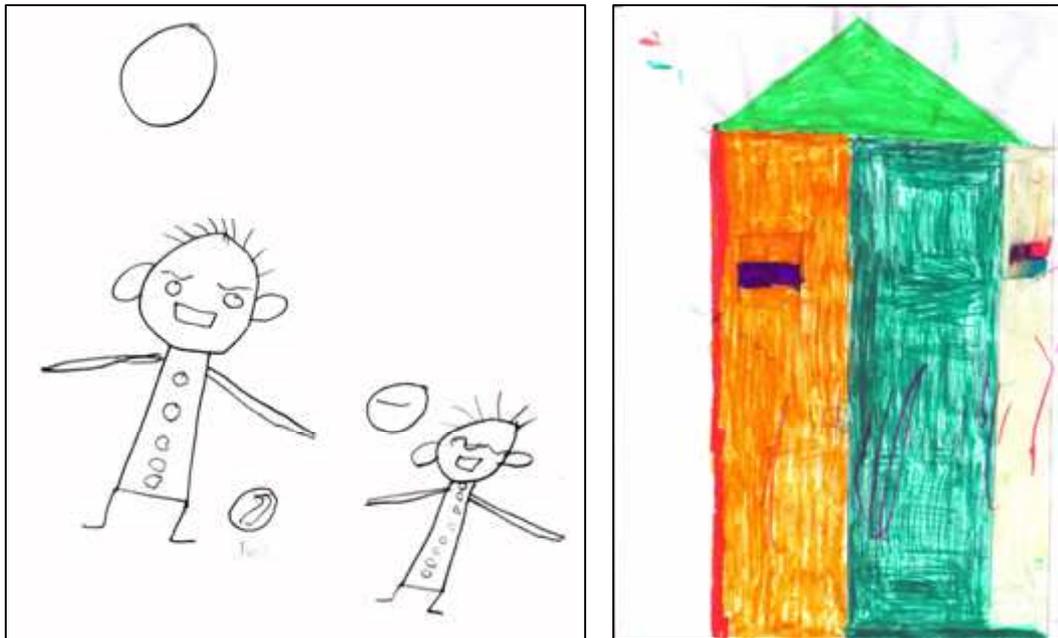


Figure 3.1.3: Sultan's pictures

Boredom

The most noticeable problem the children expressed was boredom, partly because of a lack of appropriate toys and activities at home, and partly because of restrictions in freedom. The children were not allowed to go out on their own and their siblings or parents were not always available to take them out when they wished to. This led to regular arguments for the children who were able to speak, and to 'temper tantrums' or aggression (hitting) for the children who were unable to speak.

Different?

It was difficult to ascertain to what extent the children were aware that they were 'different' from their siblings. This is not a question that was appropriate to ask directly, but the children did not indicate this awareness when answering the question why they did not go to the same school as their siblings.

Feeling excluded

Only one child expressed disappointment about the fact that his siblings did not tend to include him in their play, although the parents of one other child indicated that this was a problem for her too. In the remaining three families the siblings did spend time playing with their disabled sibling.

Sibling issues

Some sibling issues have already been mentioned in the preceding sections, e.g. their loyalty to the family unit, which meant they were willing to support their parents by helping, minding and playing with their disabled sibling, and understanding that their parents could not always give them as much attention as they would like.

Giving a positive expression

This strong loyalty, however, also meant that the children appeared reluctant to think and talk about any negative implications of their sibling's impairment, which led to an all-positive impression of family life. This is clearly expressed in Jamil's (12) picture of his family in figure 3.1.4. His brother Imran, who has severe intellectual impairment and very challenging behaviour problems, is depicted almost identical to himself, with all family members looking very content. The person at the bottom is his little sister **"who is hiding behind the table because she is shy because someone is taking a picture."** (Jamil, 12). This impression that the children's view was unbalanced was confirmed later in the children's action research group, when they began to feel able to express the challenging aspects of having a disabled sibling as well.

Spending time with their disabled sibling

The timelines gave better scope to get a more balanced picture of family life, as it allowed me to ask for details of how a typical day was spent. From this it became clear that siblings tended to spend a significant amount of time with



Figure 3.1.4: Jamil's (12) picture of his family

the disabled child. They reported that they did this willingly and enjoyed their time together, but also indicated that it limited the amount of time or permission they had to go out and play with their friends.

"Special school is more funner"

An interesting sense of jealousy was expressed in three families, where siblings said that the special school was easier and **"more funner"** (Inam) (e.g. more

swimming, less math, trips to Pizza hut, cooking classes, etc.), which they thought was not fair. This indicates that it may be difficult for children to understand the present or future implications of attending special school with regards issues like developmental potential and social inclusion.

Admiration

Most children spoke about their disabled siblings with much affection and admiration for their persistence to learn and achieve new skills. For example Jamil (12) talked of how happy and excited he felt when he played with his brother Imran, because he could see how joyful he was then. At this stage they did not express negative characteristics of their disabled siblings.

Different and the same

Some children also mentioned negative feelings and frustrations, but this tended to be very cursory. For example Aliya (13) talked about her brother eating the food off her plate sometimes. She added that this was annoying, but she did usually get angry, because he was her brother and she understood that he is autistic. Most other children found it quite difficult to explain what was different about their disabled sibling. For example Zohaib (11) initially could not manage to explain what was different, apart from "his writing is a bit like... all over the place and he can only spell a few words, but he likes school". When he told me his brother went to a "disabled school", I asked him what disabled means and he said "Uhh, like they're not like us. Like he's 13, but his more like seven or eight". Later in the interview we had the following exchange:

D: do you know WHY Tariq has special needs?

Z: no.

D: have you ever thought about it?

Z: no, I don't really think about it, I see him as a normal person.

D: yeah..... IS he a normal person?

Z: no, but I SEE him as a normal person, but I don't know if inside he's a normal person or not.

D: what do you think is a normal person?

Z: like someone like..... me and you, and stuff like that, but he is disabled. But he's just learning disabled, he can do everything well. Like running, in his school he came first with running, he got a medal, he got three medals!

D: mmm, he's strong!

Z: uhhh, he goes to football after school, he goes to cricket after school, he goes to a lot of clubs.

D: so he does a lot of normal things doesn't he?

Z: yeah,

D: so what's the difference then between a 'normal' person and a 'disabled' person, is there a real difference?

Z: just a tiny bit, just like, they don't learn properly . It's hard for him to learn.

D: do you think there are more things that are the same about him, or are there more things that are different?

Z: same.

D: mmm, what kind of things are the same then?

Z: like football, cricket, a bit of reading, he knows a lot of stuff on the computer, if you put something in the wrong position he looks for it. He doesn't give up, he never gives up.

D: mmm, that's excellent!

This exchange indicates that Zohaib (11) had probably never tried to explain his brother's impairment before. It also appears that, although he sees him as a 'normal person', he is aware that others see him as different and he is trying to reconcile the two.

How their disabled sibling might feel

Several children talked about the way they thought their sibling felt about their lives. They said they often seemed to be confused, bored or feeling excluded, and that aggression or temper tantrums were often due to these factors. The siblings of the children with severe intellectual impairment, in particular, talked of how they seemed to be in their own, different or 'virtual' world, which they would love to understand better (see figure 3.5.7 on page 274 for Jamil's picture).

Wishing s/he was better

Some children also said they wished their sibling would get better, for example when I asked Inam whether there was anything she could not do because of her brother's impairments she said: **"I don't know... I wish he was better, yeah, and afterwards we would get a bigger house and I can play and run."**

Feeling guilty

Because the children knew that their sibling was not to blame for their impairments, they said they sometimes felt guilty about getting angry when they disturbed their activities or homework or about feeling embarrassed when they did not behave well in front of others.

Growing up faster

Finally, the children indicated how they were learning from the experience of supporting a disabled sibling, as this had fostered their sense of responsibility, made them mature faster and increased their understanding for other people who behave differently. For example, Zafar said:

Having Tariq in the family has made me realise that when other people behave differently, that they might not be normal, they may have the same

issue as Tariq, or worse. I approach them differently... I would have taken everyone else as normal, I wouldn't have known about it.

Chapter summary

This chapter has presented how I engaged the participant families in interviews and activities to explore the issues they faced in relation to having a disabled child.

The way I went about this initial exploratory phase of the project was an important preparation for the action research groups. The fact that it took place in the families' homes meant that they had an opportunity to observe and get to know me in a situation in which they felt comfortable. Most participants clearly welcomed the opportunity to reflect on and talk about their personal experiences.

A broad range of issues was explored pertaining to the difficult initial process of accepting that the child had impairments in view of negative cultural perceptions; the importance of their faith in developing a good relationship with their disabled child; the way caring responsibilities were divided in the family; and the difficulties in gaining access to appropriate health and social care or to benefits, particularly where levels of English and knowledge of the service system were low.

Whereas for this chapter I have used all participants' views collectively to describe the families' situation which formed the starting point for the action research groups, I did not do this in the groups. Instead only the key issues raised by the men in their individual interviews were presented as a mind-map on a flipchart to the men's group, and the same procedure was followed for the women's and children's groups. The following three chapters will describe how each group considered this overview of issues common to all of them, and how they chose which issue / topic to focus on in their own research.

Chapter 3.3

The Women's Group: Windows into different realities



"Forgotten" by Noor.

3.3: The Women's Group: Windows into different realities

This chapter describes the findings arising from the women's group. I will give an overview of what they actually did during and in between meetings, how the phases of the action research cycle might be recognised in this process from my perspective as well as the women's perspective, what the participants and I gained from the process, and general themes / issues that were highlighted through the process.

Overview of activities and interactions

The women's group met seven times during the project. They also participated in two parties for all families together: the Eid party organised by the children's group, which took place before the first women's meeting, and the closing party at the end of the project. In addition two feedback meetings were held after the project whilst I was writing my thesis in order to make sure the findings arising from their group process, which I present in the thesis, are in line with the women's perspective on the process they went through and on the issues they discussed.

Inviting the participants

I sent a written invitation a few days in advance of each meeting, in which I indicated what we would do and focus on in the meeting and how that linked to what we had achieved in the previous meeting. I also phoned each member the day before and/or the morning of the meeting. Unfortunately this thorough invitation process did not guarantee attendance or punctuality and as the participants had to leave on time to collect their children from school or meet other commitments, several meetings were much shorter than the two hours I had planned for.

The influence of the venue on the research process

The meetings were held at the home of one of the families, which was an environment where the women felt very comfortable. Maryam remarked that **"we are used to this kind of environment in the home, which makes it a whole lot easier to be with each other"** (meeting 3). The hostess was very happy to show the group hospitality, as this is a highly valued occupation in Pakistani culture. The tea and snacks also helped the participants to feel relaxed and open up to each other. However it did take rather a lot of time to prepare the snacks, so the hostess missed parts of the conversation at times. Maryam recognised that this could be a problem in terms of my data collection, saying that **"by the time we get here, we have so many things to say to each other... Half the time is gone with getting here, having tea and snacks. In a way I feel guilty about this towards you"** (meeting 3). I reassured her that I considered the whole process of coming together, relating to each other in a way that is culturally familiar and comfortable for them, and engaging in the research process at their own pace, to be an important aspect of my data because it highlights considerations to be made by any researcher or professional seeking to work with Pakistani women in a group setting.

An overview of meetings and activities

Once the exploratory phase was completed the women's group met approximately once every three weeks. The meetings took place during school hours, so that they did not need to organise child care. Erum, who was not in school yet, came to the meetings with her mother, which worked fine as it enhanced the comfort level of being in a home: in Pakistani homes small children tend to be warmly welcomed and included in all family activities.

Table 3.3.1 presents an overview of the meetings and other activities the women attended. Activities given in italics were carried out between meetings.

Event	Number of women present	Activities
Eid Party for all families	4	Party organised by the children's group - the choice of activities and snacks aimed to include the disabled children fully.
Meeting 1	4	Introduction to each other and the principles of action research. Drawings and poetry, expressing an allegory to introduce their disabled child to each other.
Meeting 2	5	Worksheet to explore and tell each other about their skills and resources. Reviewing common issues arising from the exploratory phase.
Meeting 3	2	Discussion on issues faced in family and marital relationships (unplanned). (Did not choose an issue to focus on as planned, due to low numbers).
Meeting 4	2	Choosing a focus: setting up a support group for Pakistani mothers of disabled children. More discussion on family relationship issues. (Did not do activity on occupation as planned).
Meeting 5	2	Defining the purpose and format of the support group. Designing a leaflet to invite mothers. Planning how and where to distribute the leaflets.
Leaflets	1	<i>Making the leaflet in English and Urdu (back to back)</i>
<i>Meena Bazar (women's fair at a Mosque)</i>	1	<i>Approaching women with leaflets and explaining who it was for and what the purpose was.</i>
Meeting 6	2	Activity on occupation. Further plans and strategies for setting up the support group.
Meeting 7	3	Evaluation. Planning for the closing party. Planning for the future and how to continue the process after the project.
<i>Fun and information day at Special School</i>	1	<i>Approaching women with leaflets and explaining who it was for and what the purpose was.</i>
Closing party for all families	4	Sharing and discussing their own art work. Looking at and judging children's art competition. Eating together – each woman had brought a dish.
Feedback meeting 1	3	Feedback on preliminary findings and research question.
Feedback meeting 2	3	Deciding what messages to give at the conference. Supporting one participant whose son was not currently in school.

Table 3.3.1: Meetings and activities of the women's group

Attendance issues

A total of seven women could have attended from meeting three onwards, when the final family had joined the project. However the mother and grandmother of this family never attended. Of the remaining five women two attended all meetings and three participated less regularly. The Eid party and the first two meetings were well attended and greatly enjoyed by the women as expressed in their spontaneous feedback. For example Maryam said she regretted not meeting each other before as **"it is like a family.... we can express ourselves freely, our problems are the same and we have gone through the same things... we're forming bonds here already"** (meeting 2). Similarly Noor said that she had found it really uplifting because they had such important issues in common and did not need to justify themselves, so they could relax in each others' presence.

This unanimous positive feedback at this early stage made it both surprising and disappointing that only two women (the same each time) attended the next four meetings. Two of the other women had practical reasons for not attending, such as being ill or on holiday or having started a job in order to survive financially. The other two women's reasons for not attending were less clear cut; both of them struggled with anxiety and depression and although they did not verbalise this very explicitly, they appeared to find it difficult to engage in the personal communication in the groups (see section below on mental well-being). Despite this poor attendance, none of the women provided negative feedback about the research process per se, and the reasons for not attending were always given as external factors, like needing to attend to other responsibilities, or not having transport to reach the venue.

I spoke to all absent participants on the phone after each meeting, to tell them about what we did or decided in the meetings and to encourage them to join us for the next meeting. Occasionally I also visited them at home to make sure they felt included in the project and to get their perspective on ideas raised in the meetings.

The effect of this poor attendance on the action research process will become evident in the section about the phases of the action research cycles below.

Use of creative activities

The use of creative activities designed to help the participants to reflect on and express their ideas was important throughout the project, but most crucially during the first few group meetings. Although this way of working was new to most of the women, and although some of them found it difficult to get started with the activities, the richness of the discussion following their sharing of their work led to a level of mutual understanding that was highly appreciated. There were four activities that facilitated the research process in this way:

- During the first meeting I asked the women to make a drawing of an metaphor to represent their disabled child or their relationship with him or her. I chose metaphors, as they gave the possibility to focus on certain aspects they were comfortable sharing at an initial meeting. Thinking of metaphors tends to bring out the essence of the topic too and can therefore be a way of expressing concepts that are difficult to explain otherwise. Images included a beautiful but incomplete rainbow lighting up her parents' life; a sun providing an overwhelming source of energy, yet breaking her heart because of the anguish of looking after him (see figure 3.3.1 on the next page); an open book; an angel; and an island in the sea. Some of the images emerged through bouncing off ideas off each others' tentative thoughts. For example Nadia initially had difficulty thinking of an allegory, but her description of her son as being alone in his own world struggling to connect with others, led to an image of an island in the sea, unable to reach the mainland. Nadia immediately liked the idea, and when the idea further developed into the image of a small boat, rather than an island she was able to explain that the island was more appropriate, because **"there is water on all sides, and how will it ever join the main land? A boat would keep moving and eventually merge with the mainland"** (Meeting 1, Urdu). This

negotiation process thus gave the women a first experience of sharing and comparing their personal views and ideas.

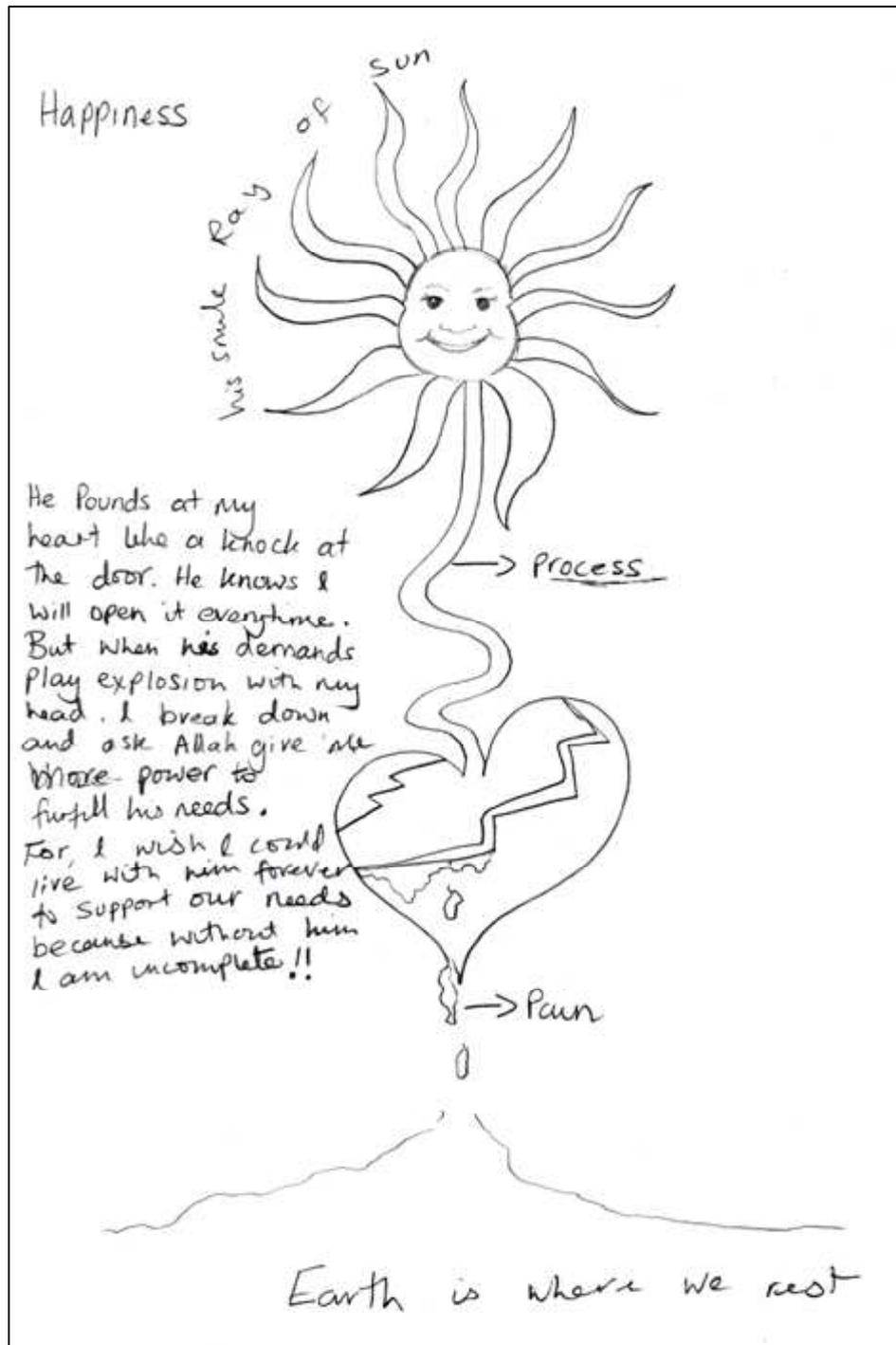


Figure 3.3.1: Noor's metaphor of her relationship with Dawood

- During the second meeting I gave the participants a worksheet (see figure 3.3.2 on the next page) on which they could write what kind of skills and resources they had that could be useful for the research process. There was a large flower with each petal asking for different types of skills, e.g. social, creative, language, vision etc. Though this was a new way of looking at themselves, which needed some explaining, the women were surprised by the number of things they were able to write and this boosted their confidence in themselves and in their 'usefulness' in this study.

- In the sixth meeting I offered an activity around occupational science concepts. This involved manipulating a pile of four coloured paper circles, each cut along one radius, so they could be made to overlap in order to make a 'pie-chart' indicating the relative importance of doing, being, becoming and belonging in their lives. They then did the same again, thinking about this from their disabled child's perspective. The act of physically shuffling the circles was very helpful in trying to grasp this concept and the activity made them aware of the occupational injustice in their lives. See the section on the theme of occupational injustice below for the outcome of this activity.

- After the last group meeting I asked the participants to make a picture in the style of a Pakistani tapestry, showing important, interesting or surprising things they had thought, talked and learned about during the project. I provided them with art materials and they worked on this artwork at home. Five women returned five very different pictures, according to what they chose to focus on: their child, their life, or the research process itself. They showed each other their pictures and talked about them during the closing party. The positive feedback they gave each other was very affirming and satisfying. See the section on evaluation below for details.

In each case the creative activities led the participants to discover and / or express aspects of their experience that were difficult to express in words. In addition holding a tangible product of their ideas in their hands gave a natural focus point for the others to look at, putting both the speaker and the listeners at ease. In the last feedback meeting Noor reflected on the need for pictorial, visual things to trigger discussion, pointing out that this is a particularly effective way to include women with lower levels of education and / or English in the group discussions and to help them realise that **"they have a lot to say"**.

The action research process

In view of the nature of participatory action research, I only made a plan for the first two sessions in order to give the participants the opportunity to find a starting point for their research process. The following meetings were then a continuation of the process, so that each meeting was planned according to what had happened in the previous meeting. My aims for the first two sessions were for the women to get to know each other in a safe, non-threatening way; to explain what the purpose and method of action research are; and to present the common issues and themes they had talked about in the exploratory phase on a flip chart so they could choose a topic for their research from this.

This worked well although no decision was made about which of these issues to work on. The participants agreed to reflect on the issues before the next (third) meeting so that they could decide and move on. However, for the next four meetings only two women attended. As everyone had been so enthusiastic at the end of the second meeting we initially assumed attendance would be better next time and one participant took the opportunity of this more intimate meeting to talk about the difficulties she faced in her marriage. When it became likely that attendance might remain poor, we decided to continue the process with just the three of us, remaining open to the others to join in at any time:

As far as I am concerned I would like to continue meeting and working on the process of setting up a group, but at the same time the others would be highly welcomed if they attend! (Maryam, meeting 5).

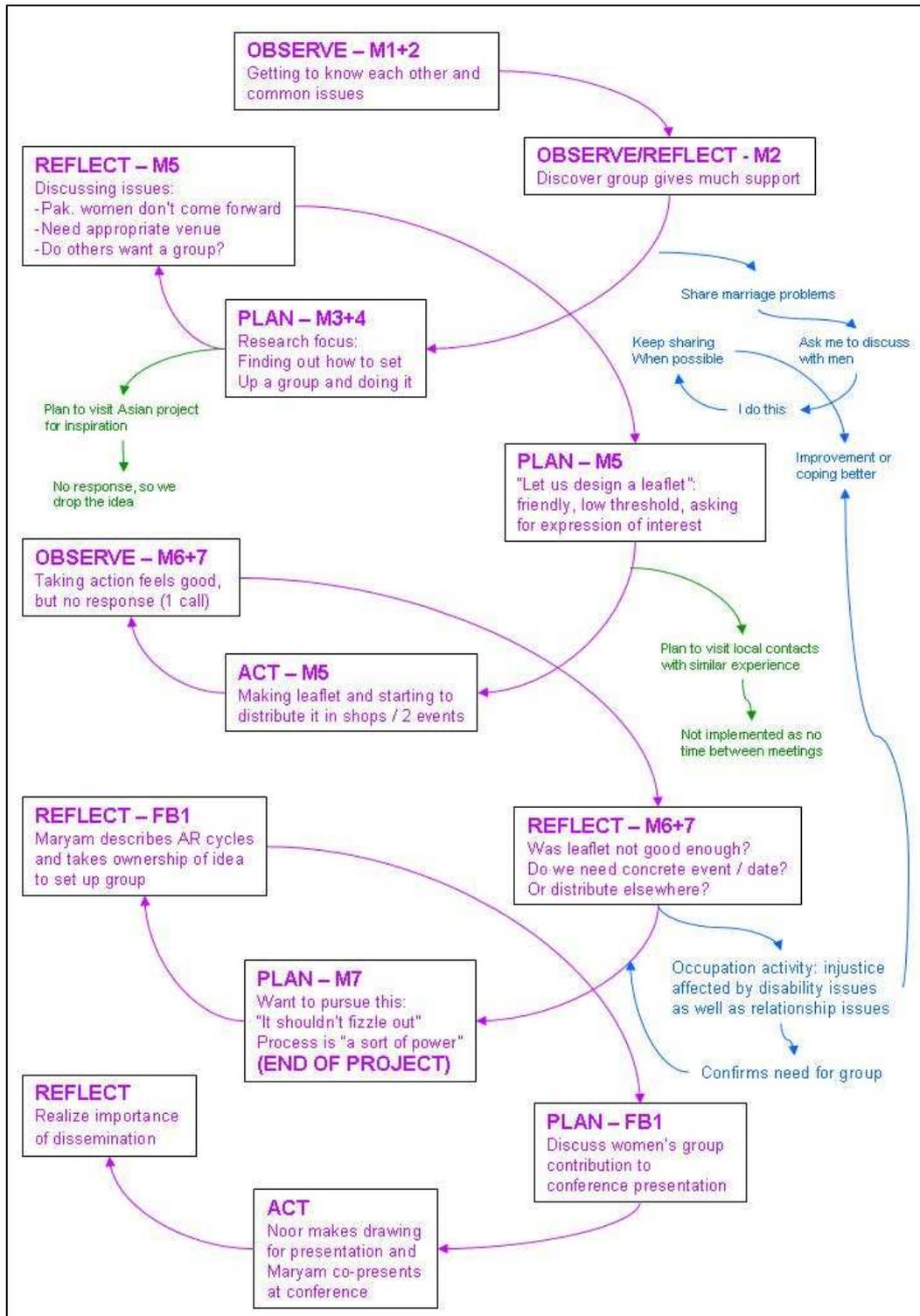
Unfortunately this did not happen until meeting 7, when three women attended, but as this was the last meeting it was mainly taken up with evaluation of the actions undertaken and the project as a whole. With only two of the women attending the four meetings in which the research focus was chosen and plans for action were made and implemented, the findings from this process can not be attributed to the women's group as a whole. Not only was the process slowed down by waiting for the others initially, but it was also demotivating to realise that the support group they sought to set up might also be affected by poor attendance. The problem of not knowing whether the other group members would agree with their plans and actions was partly resolved by both the women and me keeping them up to date with the process in between meetings.

The women's main action research cycles

The core of the main process followed by the women was summed up accurately by Maryam as follows:

Decide to invite others - make leaflets - hand out the leaflets at Meena Bazar and local bookshops - no response - hand out more at the Fun Day - no response - that's where we're at... (feedback meeting 1).

Although this sums up the essence of what they did very well, it belies the complexity and depth of reflection that was involved. Figure 3.3.3 on the next page visualises all the action research cycles, with their various off-shoots, which the participants and I went through. I will describe the main cycle (given in pink in figure 3.3.1) first, before introducing the off-shoots and their effect on the main cycle.



Key: OBSERVE, REFLECT, PLAN, ACT: refers to stages in action research cycles;

M = meeting, FB = feedback meeting; Pink depicts main action research cycles, green depicts off-shoots, blue depicts opportunist actions.

Figure 3.3.3: The women's group's action research cycles

As described above, the first two meetings were used to get to know and trust each other, gain an overview of the disability related issues they had in common and understand what the action research process is about. By the end of the third meeting the women talked about the support and inspiration they drew from these meetings, both in terms of disability issues and relationship issues. This led to a suggestion by one of the women not to concentrate on one single issue arising from the exploratory phase, but rather on finding out how they could set up a support group to continue beyond the project timescale and which would be open to any Pakistani mothers of disabled children. In the next meeting they discussed how they might invite other Pakistani mothers, and what barriers they might face in this.

Key issues discussed at this point were that **"Pakistani women don't come forward"** (Tahira, meeting 4); the need for a suitable venue as the current hostess could not be expected to provide all hospitality for an ongoing group; and the problem of finding out what exactly the other mothers would want from a support group.

Keeping all this in mind they decided to make a very simple and attractive leaflet (see appendix K) in English and Urdu, asking Pakistani mothers of children with special needs to get in touch if they would be interested in attending a group that could offer help and friendship. Maryam distributed leaflets in local shops, and Tahira handed them out to women at the Meena Bazar (women's fair) at her Mosque. In addition I sent them to the women I had been in contact with for the project, but whose families had decided not to participate. Acting on their plans motivated the women, but all this action resulted in only one phone-call. It was then decided to hand out more leaflets at a "Fun Day" for all local families with disabled children organised at one of the special schools. This task was undertaken by Sadaf, who had been brought up to date with the research process in meeting 7. Although some mothers showed interest at the time, no-one contacted the women on the phone numbers given.

Despite this disappointing outcome, the women were able to step back and reflect on possible reasons for this: in addition to the barriers they had anticipated beforehand, they considered that maybe the leaflet was not attractive enough, and that it might work better to have an actual date and time for a first event printed on the leaflet. They were also very definite that they wanted to continue to pursue this process, but unfortunately we had run out of time for the project and initiative for any further action would now have to come from them rather than me. At the first feedback meeting their intention to continue the process remained strong, but it was decided that summer holidays were not a good time of year to invite people. In addition the Ramadan (the Muslim holy month of fasting) started straight after the summer holidays and it would be best to wait until after that.

When the opportunity arose to make a presentation at a conference (see chapter 3.6 for details and appendix L for the PowerPoint presentation) the participants decided during feedback meeting two what messages they wished to include about the women's group and how to use Noor's drawing (see title page of the thesis) which she made especially for the presentation, to encourage active participation by the audience. Maryam was one of the co-presenters at the conference and was encouraged by the positive feedback received, which made her realise the importance of disseminating the findings as they evidently were significant for a wider audience.

Off-shoots that were not pursued

Other strategies were considered as well (indicated in green in figure 3.3.3). In meeting 4 I told them about an Asian support project for disabled people in a neighbouring borough and we decided it would be good to visit and learn from them about how to initiate a support project. However it was difficult to get through to the right person and we gave up on this idea in the end. One of the women also knew of a Pakistani woman in the area who runs holiday clubs for Muslim schoolchildren, who might have ideas about getting support from the council. She decided to contact her, but as she was out of the country at that time, this did not work out either. Finally I suggested they might learn from

the local community resource centre, which supports a lot of local voluntary projects. They were willing to do this without me – to avoid the impression that I was 'in charge' of the project – but did not get around to doing this.

The participants' difficulty in following through their plans in between meetings underlined the fact that these mothers of disabled children are very busy in their families, that they are not accustomed to taking initiative and action, and that it would be wise to start any group or initiative very small. It also showed that although these suggestions were sensible and recognised as useful, two of the three were MY suggestions and therefore not a result of the women's own research process, which underlines the importance of facilitators following the pace and direction of the participants' processes, rather than trying to steer the process by making too many concrete suggestions.

Opportunist actions

Two opportunist actions (given in blue in figure 9.3), one initiated by the participants and one by me, were not as unrelated to the main research focus of setting up a group as we first thought.

The first was one of the participants taking the opportunity to talk about the relationship problems she was having with her husband, during the first occasion that only two women were present. Although the other participant's relationship problems were not by far as complex and distressing as hers, she was working to resolve them nevertheless. In addition they knew that some of the absent women were also facing problems, and indeed that this was all too common in Pakistani families. Once these problems were out in the open, they kept being discussed or mentioned in later meetings as well and it became clear that they had an impact on mothers' ability to cope with caring for their disabled child, even if there was not necessarily a direct causal link between the two issues. This then became a confirmation of the need that existed to organise a mutual support group for Pakistani mothers of disabled children. The conversations also helped the participants to work on their relationship with

their husbands, or at least cope with the existing problems better by understanding the dynamics involved in them (see the section on marital problems on page 213 for more detail).

Finally the women asked me to address this issue with the men's group in the hope that it might help them to change. I explained to them that this would not be an appropriate thing to do because it would interfere with the men's own research process and because it would have felt like a breach of confidentiality. However it did mean that I was aware of the problem, so that I was able to encourage a discussion about communication problems at home to develop when one of the men brought this issue up in one of the activities. I could obviously not feed back to the women what their husbands had said because of confidentiality concerns, but I did reassure them that they appeared more aware of and disturbed by the problem than they had assumed, giving them the possibility to start addressing it more openly in their own homes.

The second opportunist action was taken by me, when I offered the interactive activity to explore occupational science concepts as they were played out in their lives. I did not expect this to have much impact on the women's research process, and mainly did it to clarify in my own mind how the issues faced by the families could be interpreted from an occupational science perspective. However it became very clear during this activity that the occupational injustices they faced (mainly in the form of occupational imbalance and lack of true belonging) were closely interlinked with the relationship problems they had been discussing (see section on occupational science below for details).

Both these actions together showed how important the 'secondary' theme of relationship problems was, and that being able to talk about them in a supportive group setting was very helpful in being able to handle and improve these issues in their daily lives.

Phases and parallel themes

Teasing out the group's actions and reflections shows there are two distinct phases to their process. The first three meetings were mainly concerned with getting to know and trust each other, which led to the realisation that the group in itself met some major unmet needs for support for them: this was the exploratory phase of the action research process for this group. Their decision to try and set up a support group that would continue beyond the project, so that more Pakistani mothers of disabled children could benefit from this kind of support, was the start of their action phase, which continued to the end of the project. Although the main focus for this phase was the setting up of a group, a very clear parallel theme around relationship problems and belongingness emerged as well, which we soon realised was not actually an entirely separate theme. The first phase was planned and led by me, but as soon as the suggestion - and then the decision - was made to focus on setting up their own support group, the decision making, planning and action process started to be taken on by the participants. I was still there to facilitate the group and to make sure the meetings took place, but we started to work collaboratively and all key decisions were taken by the participants.

Getting going, keeping going

Throughout the project I was aware that time would be a challenge in different ways. Firstly I realised that committing oneself to a participatory research project was a major commitment for the participants, and that possibly it was difficult for them to estimate beforehand how much time it would take.

Secondly there were less than five months available for the groups, which made me want to do as much as possible in the time available. At the same time I was well aware that the group needed time to get to know each other and to start to understand what action research was all about, before I could expect them to start taking decisions or action.

After the first two meetings I could see the participants were ready to start taking the decision about what issue(s) to focus on, which made it very hard for the two women that continued to attend to know what to do: they were ready to launch into the action research cycles, but felt they could not move on without the other group members. This slowed down the action research cycle for two more meetings after which they decided they should not continue to wait. Once that decision was made they were able to move quite fast on implementing their plans, reflecting on the outcomes and readjusting their plans.

Another time aspect that played a part here is more positive: as the two women felt they could not use the meetings to move on with the task in hand, we were left with some time, which one of the women decided to use to talk about her relationship problems. This eventually turned out to be a major factor in many Pakistani mothers' lives and therefore fed back into the discussions about the purpose of the support group they were trying to set up. For me as a researcher it was very important to let go of my anxiety about losing time, and to allow the participants to fill in the research process in a way that was useful for them.

The final aspect of time pressure was the frustration of the participants that due to the minimal response they had received to their leaflets, they felt not much tangible result had been achieved and they were sorry we had run out of time. The motivation to continue the process without my facilitation was great, but once again, they knew that this would take effort and – most of all – time, which they do not have much of. The short time I had with the groups made me very optimistic that a participatory approach can work very well with Pakistani families, but that it needs much more time for ideas to grow, for initiative to be sparked and acted upon, and to complete any actions embarked on.

General themes and issues highlighted through the process

In the course of the action research process, a number of themes emerged that give some insight into the lives of these women and an indication of what the nature of their support needs may be.

Understanding the social model of disability

The participants often talked about the barriers they came up against in bringing up and trying to ensure the best level of care for their disabled children. The most commonly discussed issues are presented here.

Community attitudes

They frequently indicated that the most difficult aspects of having a disabled child were related to the attitudes and responses encountered in the Pakistani community. For example Nadia reflected

Why does a mother cry? It is not for herself. It is not because of her disabled child, but because of the time and society we live in. What will they do to our child? What God has given me has never caused me pain, but the society... (meeting 1, Urdu).

Noor added that she is often shown pity because of her child's severe impairment, but

I don't like it at all if people look at me in pity. Society needs to change that view, people get confused with saying 'bechara' (literally: 'helpless one') and acceptance - they are two different things. With saying 'bechara' they don't accept that, because it is hard to face and quite shameful (meeting 1).

Maryam responded by saying that her husband says he just ignores what people say, but she believes that

you can only pretend it doesn't affect you for so long. You can't pretend you're cold and unaffected by the world. The child is going to grow up and will need to face it too (meeting 1).

This aspect was expressed in another way in Nadia's allegory of her son as an "island in the sea", in which she suggested he is unable to connect with society (the "mainland") and that very few people try to connect with him.

Issues in obtaining professional services

Finally the frustrations the women express about their dealings with professional service providers are also around getting access to services and people's attitudes, rather than in the actual care provided. For example Noor talked about how difficult it is to get the right type and level of care:

Like, you know, I am still struggling about getting Dawood's respite care. Through fighting - it's really sad that without a fight you don't get anything (telephone conversation).

Financial support is also difficult to obtain and the women found that unless you asked – and knew what to ask – you were unlikely to find out what you were entitled to (feedback meeting 1).

Once access to care was achieved, there were often problems in communication with health or social care professionals. For example Maryam found that a surgeon they consulted was very insensitive to the feelings of parents when discussing options for surgery: the way he talked about the possibility of amputation "was really horrible! Perhaps he was just doing his job and being 'professional', but a bit more concern would be very useful!" (individual

feedback). This unhelpful attitude was not only encountered in individual consultations, but also in groups that bring families with disabled children together. Maryam described the problem in those settings by comparing it to the way I had worked with them as a group:

Debbie is committed, genuinely listens and absorbs: it's about being listened to. In (other groups) this is not the case. I don't open up to them, I don't talk deeply, they're not interested (meeting 7).

This section indicates that the women and their families experience a number of distressing barriers, which appear to be more difficult to deal with than their children's impairments in themselves. When I reflected this back to them in feedback meeting one, they debated it for a while: although they agreed that people's attitudes and other barriers were extremely frustrating, they made it very clear that this did not mean that the impairment in itself did not matter at all, because they would love their child to be 'normal' and in their hearts the hope for healing is never gone.

Doing, being, becoming and belonging: an occupational science perspective

As mentioned above one dedicated activity during meeting 6 helped the two women present to look at their lives from a fresh perspective. This was very helpful as it gave new ways of reflecting on and talking about the difficulties they faced, and they referred back to it regularly afterwards. In addition, many things they said before this activity, and all other participants at any given time in the process, had already indicated they had an awareness of concepts like occupational balance. This section gives an overview of the women's experience from this perspective.

The four-circle activity

After a brief explanation of occupational science I gave the women the set of four colored circles each. I then asked them to think about their lives and

decide which of these four aspects played greater and smaller roles. Although this took some deep thinking and repeated re-shuffling, their final 'pie charts' were quite revealing to both themselves and to me. The visual expression of their ideas made the occupational imbalance in their lives very obvious.

The circle in figure 3.3.4 shows Tahira's result, who felt very strongly that

there is no place for becoming, there is no time for that... there is no choice for you, you have to do things, you have to be there... if I'm not in the house, it will fall down.

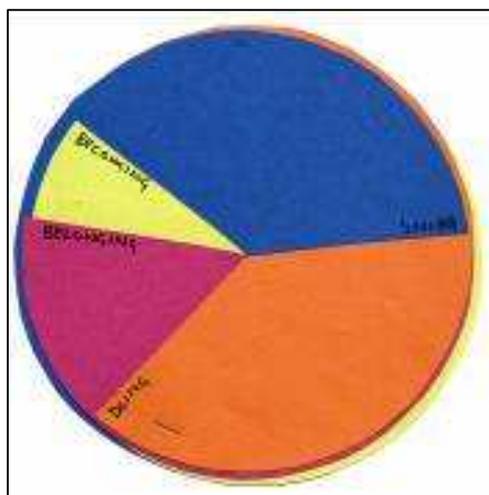


Figure 3.3.4: Tahira's circle activity

Key:

Orange: doing

Blue: being

Yellow: becoming

Pink: belonging

Later she added that in a way any thoughts about becoming centred around her children:

In my thinking, it is all for my children, they are more important than anything else.... Like when they achieve something, like pass an exam, I can see my shadow in there, it makes me grateful to see that what I'm doing, it is not wasted.

The idea of belonging was quite ambiguous for Tahira, and tied in with the things she was expected to do as a mother. She said:

it makes me feel both ways, isn't it? Good, and bad as well. Good is, you are special for someone. Like belonging, I am the centre of everyone.... they all come to me... But you can't do something for yourself.... I mean, there is no choice.... You can say it is cultural as well. For the running of the family, for the children, it is a cycle, a natural thing.

In one way the role she was expected to fulfil gave her a sense of belonging, but on the other hand she felt this was not true belonging, as it did not consider her individual needs. Doing subsequently took on a very large portion of the circle. In view of this strong imbalance she recognised between becoming, belonging and doing, it was remarkable how strong her sense of being remained. This was very important to her and had been influenced by her strengthened faith and resilience through raising her disabled child and having a difficult marital relationship.

Maryam's circle (see figure 3.3.5) showed more balance, which was indeed the first thing she said. However, she recognised aspects that were not so balanced too.



Figure 3.3.5 Maryam's circle activity

Maryam talked of "certain goals in my life that I have not been able to achieve, they upset me, they affect me in the way I am today". This was due to getting married and having a child, but also due to moving abroad. She maintains high personal and professional goals for herself and says "what happened in the past affects who I am today and provides motivation for becoming". This very strong sense of becoming helped her to study for an online post-graduate course despite her very busy life as the mother of a disabled child who requires many medical appointments and interventions. For Maryam

the belonging aspect is a really well-balanced part of my life; I have a very good sense of belonging with my mother, my father, my husband, my family, myself, my daughter. The ups and downs of my life don't affect my sense of belonging with my family.

As the two women compared their stories Tahira reflected on the injustice in the lives of many Pakistani women, saying that

when your children are born, you are losing your respect, your identity... the more time you spend with your in-laws and your husband, and when difficulties come, all the pressure comes on the woman.... In Pakistani families, you can't get justice. Even if you know it is unfair, you have to keep quiet. If you speak up, your house will break up... the children will end up crying.... You don't want your children to blame you by saying 'you should have been more patient' (Urdu).

The women also used the circles to think about occupational balance in their disabled children's lives. The most striking thing here was that both emphasised how essential the concept of belonging was. Maryam said that her daughter

has a real strong sense of belonging, she feels special in the positive sense.... I feel it is really important for her to know she is fully loved and supported... we want her to know she is accepted for who she is... we are trying to let her live her life at her own pace and we give her as many positive experiences as possible.

Tahira pointed out the contrast between home and elsewhere:

belonging-wise, he knows - he loves his family, his brothers. He is more comfortable at home, when he's away from home he's not happy.... With us he is complete, he is safe.

Other indications of the importance of occupation

Awareness of aspects of occupation was evident at other times too. For example the first two meetings' impact on the women was so significant because it gave them a very strong sense of belonging, through having their difficulties recognised, and being fully accepted. This was expressed at the time, but also was the first thing to be brought up in the group evaluation: "we got recognition - we can't talk like this with friends and family" (Tahira, meeting 7) and

it was non-judgmental, we had similar concerns, we were able to communicate effectively as we were on the same frequency. Being all Pakistani was the main reason for this strong bonding (Maryam, meeting 7).

Both of these statements underline the idea that belonging is an essential aspect of or precondition for engaging in occupation, in this case participating in a research process.

Another reason for the effectiveness of this research group was the fact that it involved activities (i.e. doing) as well as talk:

obviously that is what made us share, those activities. The way you presented them, that was nice. That has never happened at (*another group*): there we're just all there at a specific time, have some tea, the children play, and we go... (individual feedback).

Another aspect that came up several times was the need for occupational balance, something other than caring for their (disabled) children. For example Sadaf said: "If my child was well, I would love to go and watch films or visit friends. I would also like to work so I can learn things and meet others" (meeting 2). When Noor told me she had finally managed to arrange for some respite care, she said: "It will make so much difference to have that one night a week, to have some rest, to be a bit different...." (telephone conversation).

Finally concepts of being and becoming were highlighted most clearly whenever the women talked about the way their faith had changed and grown over the years, which will be described in the next section.

Different religious views

Chapter 3.2 has already described how faith plays a role in the women's lives, but during the group meetings some more aspects were highlighted. Right from the first meeting the role religious views and personal faith played in their lives was shared and discussed. Although they viewed many key concepts in the same way, there was also debate about them. For example when Tahira said that "we can accept that God has given us this duty to look after this child", Noor responded by saying

But I don't see myself as being hard up.... Allah gives us whatever problem and sees how we deal with it. And the reason He does it is so that we learn,

and you develop and teach others. What I find with our people is, that they say 'oh, I have a disabled child, I can't do anything, you know, God has punished me', but it is not about that (meeting 1).

This difference was further emphasised after Noor shared her extremely difficult life story and the others sought to encourage her by saying "you're paving your way to Heaven" (Maryam), but Noor disagreed:

No, I say no, because that is not the truth and if you start to claim that, you start to think you're invincible and you should never, never say that! It's not about me going to heaven or hell, that judgment is up to Allah (meeting 1).

In later meetings others also talked about the support they experienced from their faith (as opposed to the sense of future reward or punishment), for example "when I'm upset, God gives me power" (Tahira, meeting 3).

A different aspect of faith was mentioned when they discussed the importance of all being Pakistani for the openness in the group. Maryam explained that

as Pakistanis we are more prone to making links with people from the same religion and background; we have been brought up that way, so it comes from the roots (meeting 7).

This is indeed something that is evident in Pakistani society, and although all women were in principle very open to associating with people from other religious or cultural backgrounds, they clearly felt more comfortable to talk about their faith and difficulties in this all-Pakistani group.

Marital relationships and mental well-being

As I have already mentioned above a strong parallel theme related to relationship problems and mental well-being emerged in this group. In almost all cases these two aspects were closely related, although in some cases the mental well-being issues were more strongly related to having a disabled child, rather than having a difficult marital relationship as well.

While this issue was not included explicitly in the initial interview guides, many women alluded to or openly spoke about their relationship problems or mental health issues in response to my questions about how caring responsibilities were divided in the family, how they and their family members reacted to being told that their child had impairments, and who gives them support in looking after the child.

Based on this data, it appears that of the 13 mothers I spoke to in depth, there was only one who indicated she had good, problem-free relationships with her husband and in-laws and was well supported and mentally well. One other was also doing well, but verbalised a number of past and present issues. Three women were showing considerable strength after having gone through very significant difficulties (some ongoing), and evidently considered themselves currently mentally well. The remaining eight had had and continued to have major relationship problems and/or struggled with current mental health problems. Some of the latter did have a good relationship with their husband, but this did not necessarily translate into him providing practical support in looking after his disabled child(ren).

Although this high incidence of mental health needs is sobering, it is not a surprising finding in view of what earlier, larger, studies report (e.g. Fazil et al, 2002; Hatton et al, 2004; and Emerson et al, 2003; see chapter 1.2). When these issues were discussed in the group sessions, the women also suggested that **"sadly this is the story of many families in Pakistan"** (Maryam, meeting 3). Nadia also felt these problems are common and that one reason was that **"men are**

not given guidance by their parents" about how to treat their wives (individual feedback). General issues relating to marriage relationships, including expectations from each other in the cultural context, have already been described in chapter 3.2). However Maryam did point out that parenting a disabled child can influence the mother's mental health and marital relationship by saying that "all the extra stress that comes with having a disabled child comes into it and brings depression" (meeting 5). Tahira added to this that part of the problem is that

the men go to work in the morning and we take on all the care. Especially when the child is on holiday the mother has to look after the child all day. And when the mood is not good, the men have no idea what is happening in the house and what a hard day his wife has had and they start to ask why this is in a mess or that hasn't happened (meeting 5).

Whilst it was helpful for the participants to be able to talk about their relationship issues in a safe environment, they also felt uneasy to paint a negative picture of their husbands, whom I knew and worked with in the men's group. This, combined with the realisation that some of their stories revealed that their husbands did support them in other ways, led to some apologetic comments, for example Tahira said some time after she had been talking about her struggles: "did you notice that my husband is actually quite close to my son? He cares for him so much" (meeting 4).

Evaluation

The outcomes of the project were evaluated both in terms of the research process and in terms of the research focus.

Benefitting from participation in the research project

The participants spontaneously told me what they thought of the research process throughout the project. Much of this feedback is reflected in this

chapter already. In addition a more structured evaluation took place at the end of the process, when I asked them to fill in an evaluation form (see appendix M), and when we discussed what they liked best and least about the project in the last meeting (meeting 7).

They found the questions on the form about what they learned and whether anything had changed due to their participation very difficult to answer and mostly left them blank. However, when I asked the same questions in a different way during feedback meeting 1, they articulated this well. This 'thought bubbles' activity involved passing around 5 sheets, with one statement each, and adding their ideas to them. The statements read:

1. "Things I know now that I did not know before the project",
2. "Things I did during the project which I had not done before",
3. "Things I think about differently now because of the project",
4. "Things that changed in my family relationships because of the project"
and
5. "Things I have decided to do or change in the near future as a result of the project".

The following is an overview of the most frequently and/or emphatically stated benefits (no quotations from the data are given if they have already been given above).

The group itself

The most frequently mentioned benefit of being part of the project is that it brought together a group of Pakistani women, who had much in common. Meeting other mothers of disabled children from the same cultural, religious and linguistic background enabled the women to open up to each other and share their problems without having to defend themselves. This mutual recognition brought them much relief and catharsis.

Opening up

Several women talked about how it was not only good to be listened to and truly heard, but also to learn to listen to other mothers' stories. Both of these helped them to open up. For example: **"I learned to come out of my personal space and embrace others with bigger problems than mine"** (Maryam, evaluation form).

Activities and action

Both the structured activities that I offered and the fact that the research process itself required planning and action, were appreciated, because they provided new ways in which to become aware of and express their thoughts and feelings about their lives: **"you got us a lot of things to think about and do... we didn't only use it for your project, we could use ideas generally"** (Noor, evaluation form). The action of planning for their own support group and inviting others provided a way of discovering their own potential: Maryam commented that **"I never knew I would be able to initiate the idea of a support group. I never knew enough about this side of my imagination!"** (feedback meeting 1) and earlier said this whole process was **"a sort of power"** (individual feedback).

New ways of thinking

All women spoke of the fact that their thinking had changed. Sadaf summed it up well: **"it was a very good attempt to make us think more deeply"** (evaluation form). Tahira spoke of being more open-minded, thinking more widely and positively. Maryam said that **"the project has enabled me to open up my views and my opinions and become more receptive and more acknowledging"** (evaluation form).

Concepts of disability

The women talked about the way their concepts of disability had changed through the project. For example: **"I learned that disability is not our fault, it is God's will, so we need to work and take part in this kind of project"** (Sadaf, evaluation form, Urdu). Tahira talked of not seeing the child with special needs as different, but rather as 'normal' and positive. These more positive ideas were also expressed in answer to the question what they wanted the Pakistani community to understand about disability. Tahira answered that they should understand that **"any parent can have a disabled child, it is not a punishment of God"**, whilst Maryam wrote that **"I would ask them to come out of their shell and embrace the children with disability"**.

Impact on relationships at home

One woman expressed very clearly that the project had had a great impact on the communication level with her husband and child, saying that the participation of the men had **"encouraged them to open up and allowed them to come out of their comfort zone and talk"** (Maryam, evaluation form). She was very clear that the fact that both she and her husband took part in the separate groups had enabled her to improve their communication at home. One other woman also said the project had encouraged her to talk about disability issues with her husband and children. The other women recognised that their husbands were more aware of family and disability issues, but were still trying to get more communication with them. However they did indicate that the project had helped them understand the communication problems better, which had helped them to feel less affected by them: **"I try to ignore all the harm feeling, I don't get upset"** (Tahira, feedback meeting 1).

The participants also indicated that their own relationship with their disabled child had improved, for example **"I started giving more time to Tariq and things are better now"** (Tahira, feedback meeting 1). In addition several mothers said

that their other children played and communicated with their disabled sibling more, for example "my other children play more with Imran, like help him draw or play with the ball - he is happier than before" (Sadaf, feedback meeting 1).

Evaluating through art

I asked the women to use their creative skills to express their views on the project in a drawing in tapestry style. All five women who had attended the group meetings honoured this request, and the four women present at the closing party told each other about what they had made. The pictures they had made were very different, in terms of topic and style (see figure 3.3.6).

Tahira showed in her picture how the project had been about creating an optimal environment for disabled children: "an environment that is open, where they can get fresh air, so that they can do what normal people do... and Debbie is here... she is a helping hand for Pakistani mothers" (Urdu).

Nadia made a picture of all the things her son likes: "I made this for the children... they may not understand what they see, but they like what they see" (Urdu).

Sadaf also drew what her son likes and made a picture of a bird sitting on a branch. She said Imran loved to go to Pakistan, where he watched the parrots in the tree opposite their house, especially when they flew away.

Noor drew a picture of flowers, uprooted from a beautiful but complex soil, representing their disabled children: "the world in which we live has forgotten us... so although we live in this world, we can not live in the reality that is seen through the window (in the middle of the picture). There is a distinction between our reality, and the rest of the world's reality" (Urdu).

Despite the fact that the pictures seemed to be so different, Noor pointed out that they had all drawn birds, and that although not everyone may have recognised it **"it's all got to do with freedom, because we feel caged"**. When I commented that the expression of two realities through the idea of a window is very powerful, Noor pointed out that, again, all have shown this in a different way: Tahira used words to **"portray her world as distinct from the world outside"**, Nadia alluded to it by using different boxes, and Sadaf **"has isolated herself"** by making the bird solitary. A final similarity Noor noticed was that everyone had drawn flowers, which she felt represented **"the happiness we have because of our (disabled) children"**.

Maryam, who was not able to attend the closing party, also made a picture and focused on the positive impact of the project on the relationships in the families, through the way the different groups had taken different approaches to the same issue, as appropriate for each group's members.

Whilst each person had chosen a different focus for their artwork, they all showed they had reflected deeply on their child's world, their family life in relation to the world outside and on the way the project had changed the way they viewed their situation more optimistically. Tahira summed this up as follows:

The encouragement and support that you have given us - what you have taught us, what we have learned together... Because before this we were very tense and since we started meeting, we let that pressure out; we became more relaxed (Urdu).

Ongoing mutual support

A final indicator of the impact of the project became evident during the final feedback meeting six months after the closing party. When I invited the women for this meeting, I found out that one of the children had been out of school for two months, as the transition from primary to secondary special school had gone wrong. As Sadaf could not leave the house the two other women who were able to attend and I went to see her. Noor, who has faced difficulties in securing the appropriate education and care package for her own son then took the initiative to help Sadaf, who speaks hardly any English, to follow this up. As schooling was not the only problem, Noor contacted a number of statutory and voluntary agencies over the next week, and encouraged Sadaf to be more assertive in fighting for the family's support. This action was highly appreciated by Sadaf and her family, but at the same time was quite stressful for Noor, who had enough challenges to face in her own life. She felt frustrated about the poor level of service and communication by service providers and said that **"it is like a black hole! I don't know if I want to stay involved in this! This case shows how lack of English makes you very dependent on the goodwill of the system and people working in it"**. Noor pointed out it was fortunate that they had come to know each other through the project, so that she was able to support Sadaf. She added that this kind of mutual support was an important motivation for setting up an ongoing support group for Pakistani mothers of disabled children.

Chapter summary

This chapter has presented how I engaged the women in their research group. Key aspects of their research process and the issues addressed are summarised here.

The research process

For the women the forming of the group was fundamentally important in itself, not only for the strong sense of belonging and mutual support it provided, but also for discovering that the value of reflecting on their own situations and acting to bring about positive change.

The process showed that these Pakistani women were able to engage in reflection, planning, action and evaluation, although their social situations made it difficult to take action outside the home in between meetings.

The use of creative, non-verbal methods to elicit expression of feelings and views, was strongly facilitative in this group. Participants had not experienced this type of interaction in other groups, and felt that it was the main reason why issues could be addressed in much more depth.

The very small number of participants who participated in all the meetings was a concern in practical terms – as it slowed down the group in taking decisions as they were uncertain of the absent members' views – but also in terms of interpreting the outcomes - as it makes any intention to generalise outcomes more contentious. However those who did attend and took decisions and actions found this an empowering experience.

The initial stages of getting to know and trust each other and forming the group, would have benefited from having more time available, as a relationship of trust with each other and the researcher / facilitator, is a precondition for engaging in the action research process together. Even more time – years rather than months – would have been needed for the implementation of the very good ideas they had.

Key issues addressed

Whilst the women were not familiar with the theory around the social model of disability they clearly described the barriers they faced, particularly due to

negative community attitudes and due to difficulties accessing good quality services.

The women also illustrated their understanding of the concept of occupational injustice, and articulated that belongingness was a key issue for themselves as well as their disabled children. Occupational imbalance was also identified as a key problem which impacted on their ability to manage their central task of caring for their disabled child and the rest of the family, in a way that maintained their own wellbeing as well as that of the other family members.

Faith formed a pervasive, mainly positive, influence on the women's sense of identity and purpose as well as on the way they acted. Their faith had grown and become more important to them in the process of accepting their child's impairments and dealing with the social responses to them.

A final crucial discussion the women wove into the group process was around marital and family relationships and the mental wellbeing of Pakistani women in light of those.

This chapter has described the complex story of successes and challenges of facilitating the women's group in their research process. The next chapter will do the same for the men's group.

سُورَةُ الْحُجْرَاتِ

Chapter 3.4:

The Men's Group: Islam and Disability

سُورَةُ الْحُجْرَاتِ
بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ

يَا أَيُّهَا النَّاسُ إِنَّا خَلَقْنَاكُمْ مِنْ ذَكَرٍ وَأُنْثَىٰ
وَجَعَلْنَاكُمْ شُعُوبًا وَقَبَائِلَ لِتَعَارَفُوا
إِنَّ أَكْرَمَكُمْ عِنْدَ اللَّهِ أَتْقَاكُمْ إِنَّ اللَّهَ عَلِيمٌ خَبِيرٌ

"....In God's eyes, the most honoured of you are the ones
most mindful of Him; God is all knowing, all aware
(of people's true worth and the thoughts they harbour)"

The Qur'an, Sura 49 (al-Hujraat), verse 13

3.4: The Men's Group: Islam and Disability

This chapter describes the findings arising from the men's group. It follows a similar structure to the previous chapter on the women's group, giving an overview of activities and interactions first, then describing the action research process, followed by a presentation of the themes and issues highlighted through the process. Differences between the research processes in the women's and men's groups are also discussed, which highlight the advantage of a flexible and participatory approach to research.

Overview of activities and interactions

The men met seven times in their own group, attended two parties for all families during the project period and two feedback meetings (for their own group) to inform thesis writing after the project had finished.

Inviting the participants

The same multi-pronged approach to inviting participants was used as for the women's group. The men had busy lives and free Saturdays were precious to them. Yet they were willing to come and appreciated the opportunity to meet other Pakistani fathers of disabled children, as shall become evident below.

The influence of the venue on the research process

The choice of the small local Mosque, had several reasons. The first reason is cultural: in Pakistani culture meetings between men and women are somewhat restricted and it was therefore important to meet in a venue that was both respectable and public. In Pakistan the Mosque is a freely accessible meeting point for community members and it was on this basis that I asked for permission to use the Mosque. The additional advantage of this was that the Mosque management was repeatedly reminded of disability issues within the Pakistani

community and were thus given the opportunity to extend their support to the participants. The men were indeed very comfortable at this venue and freely shared their views about a range of issues with each other and me.

An overview of meetings and activities

Six men participated in the group meetings, of whom five were fathers and one was the older brother of a disabled child. See the section on 'family background and characteristics' in chapter 3.2 for information on the participants. The group met every three weeks on Saturday mornings according to the availability of the two men who worked in shifts. Each meeting lasted approximately two hours. Table 3.4.1 on the next two pages presents an overview of the meetings the men attended and other actions they undertook in between meetings (the latter are given in italics).

Attendance

There were a total of seven men who could have participated in this group, i.e. five fathers and two older brothers. However one of the brothers did not wish to participate and his brother and father tried to ensure that at least one of them was present at each meeting; they managed this for all but one meeting. One family was recruited in January and therefore one man did not join the group until meeting three, but he then attended every meeting after that. Between three and five men attended each meeting. Because it varied who was absent, all men remained up to date with the process throughout. They also continued their efforts to contact scholars and Imams in between the meetings even if they were unable to attend.

In terms of the family parties, an interesting situation arose. One family had arrived on time and the father was looking after his son. The father of another family had not been able to come. The two remaining fathers (of the fifth family the divorced father did not participate in the project and the sixth family had not been recruited by then) sent a child ahead to find out if other fathers were there. As the

Event	Number of men present	Activities
Eid Party for all families	1	Party organised by children's group - the choice of activities and snacks aimed to include the disabled children fully.
Meeting 1	5	Introduction to each other: sharing a happy and a sad story about their disabled child. Introduction to action research. Reviewing issues arising from the exploratory phase.
Meeting 2	3	Discussing recruitment issues. Choosing an issue as the topic for their action research: Islam and disability.
Friday prayers	1	<i>Sarwar made an announcement and distributed flyers after the Friday prayers at the large local Mosque to invite more families to participate in the research – no result.</i>
Meeting 3	3	Discussing article provided before the meeting Plan: ask Islamic scholars and Imams what the Quran and Hadith teach about disability.
Contacting scholars / Imams	3	<i>Haider asked his Imam – confusing answer. Imtiaz asked his Imam – says the Quran doesn't mention disability. Gulzar sent email to scholar in Pakistan – no reply.</i>
Meeting 4	5	Skills and strengths activity – leads to discussion about relationships and conflict resolution at home. Review action – hearing what one Imam said makes them realise that references to verses in the Quran are necessary.
Contacting scholars / Imams	3	<i>Sarwar tried to contact a blind Imam – no response to messages. Others followed up their contacts.</i>

Table 3.4.1: Overview of men's group activities (part 1)

Meeting 5	3	Reviewing action – difficult to get hold of scholars and imams. Visiting Imam at the large local Mosque together – he promises to find out.
Contacting scholars / Imams	3	Zafar wrote to a scholar in Iraq – no reply. Imtiaz met Imam at a different Mosque – invited to come back with group. Gulzar sent reminder emails – still no reply.
Meeting 6	3	Reviewing action. Refining questions to ask scholars / imams. Considering futures steps. Revisiting Imam at the large local Mosque – says he found out, but lost file – says we can come any evening the following week.
Contacting scholars / Imams	2	Imtiaz and Gulzar visit Imam together and are given witten information. Imam at other local Mosque repeatedly changes meeting day and meeting never happens. I email information gained so far to participants.
Meeting 7	4	Evaluation. Planning for the future and how to continue the process after the project.
Closing party for all families	4	Helping the children to make a large 'snakes and ladders' game on the theme of disability. Looking at and judging children's art competition. Eating together (each family had brought a dish). I provide a print-out of all contacts, information and articles collected during the project.
Feedback meeting 1	3	Feedback on preliminary findings. Again express commitment to follow up action.
Feedback meeting 2	2	Deciding on messages to be included in conference workshop Starting to plan for the powerpoint presentation

Table 3.4.1: Overview of men's group activities (part 2)

one present father was out of the room at that moment, the children reported no men were there, so their fathers went back home. Significantly this party took place before the first men's meeting and was the first opportunity to meet the other families, i.e. at a time that they were still a little uncertain about the purpose of the project. They later reported that when they heard no other men appeared to be present they assumed the party was for women and children only. In Pakistani culture it is quite acceptable for whole families to come together for parties or functions, but the room would often – either formally or informally – be divided into a men's and a women's area with the children moving freely in between, especially on occasions where the families don't know each other well. At the closing party, by which time they knew each other well, four fathers attended, interacting well with the children and sharing a meal with all families together. As the participants were at ease with the project by that time this gender division was not as strongly felt and all participants mingled when the activities required it (see chapter 3.6).

Nature of activity

Throughout the project the men were more comfortable with talking than with doing activities. I invited them to use their creativity on three occasions, with limited, yet significant, success.

For the first activity (in meeting one) I requested the men to bring two photographs of their disabled child, "one that makes you feel happy or proud, and one that makes you feel unhappy or sad". Only one man brought pictures, which he said his wife had given to him as he was leaving the house to come to the meeting, so he had not chosen them. I therefore modified the activity by asking them to tell me two one-minute stories instead. This worked well as it helped them to give a quick, yet vivid introduction to themselves and (their relationship with) their child. For example Haider started with his sad story:

**It is sad what has happened with him, because everyone doesn't understand...
He is different and doesn't know how to behave, so it affects social life...**

When others tell him off, it hurts... When he was small, once in the Mosque... someone called him 'pagal baccha' (mad child). That kind of thing is hard.

His happy story on the other hand expressed much affection: "The innocence... Some of the things he comes out with. It is innocent, other children can't do like that" .

For the second activity (in meeting four, in which all five fathers were present), I invited the men to fill in a worksheet with a line-drawing of a man, with each body part representing certain types of skills or characteristics (see figure 3.4.1 on the next page). For example the shoulders represented responsibilities that weigh heavily, the hands represented practical skills they are good at and the legs represented steps they could undertake to change life for the better. I explained that the purpose of this activity was for them to tell each other about themselves, so that as a group we would know what kind of skills and characteristics each member had that could be useful in taking action later on in the research process. The men appeared bemused by this task, but completed it without questioning it. They did need some clarification on some of the items, especially the eyes, which represented their "vision". Sarwar said during the discussion afterwards

I had to think a bit, I had never even thought about what is my vision about life. It forced me to think.... I want to make life as good as possible for my family. I never thought I had to answer these kinds of questions! .

None of the men alluded to disability when describing their vision (eyes) or steps to change life for the better (legs). Only Mahboob, who takes on a lot of the practical care for his son, referred to their disabled child directly, in the section about responsibilities that weigh heavily (shoulders).

Reflecting on what they had written by the trunk ("how do you maintain balance in your life, in terms of home, work, relaxation and leisure?") Sarwar said

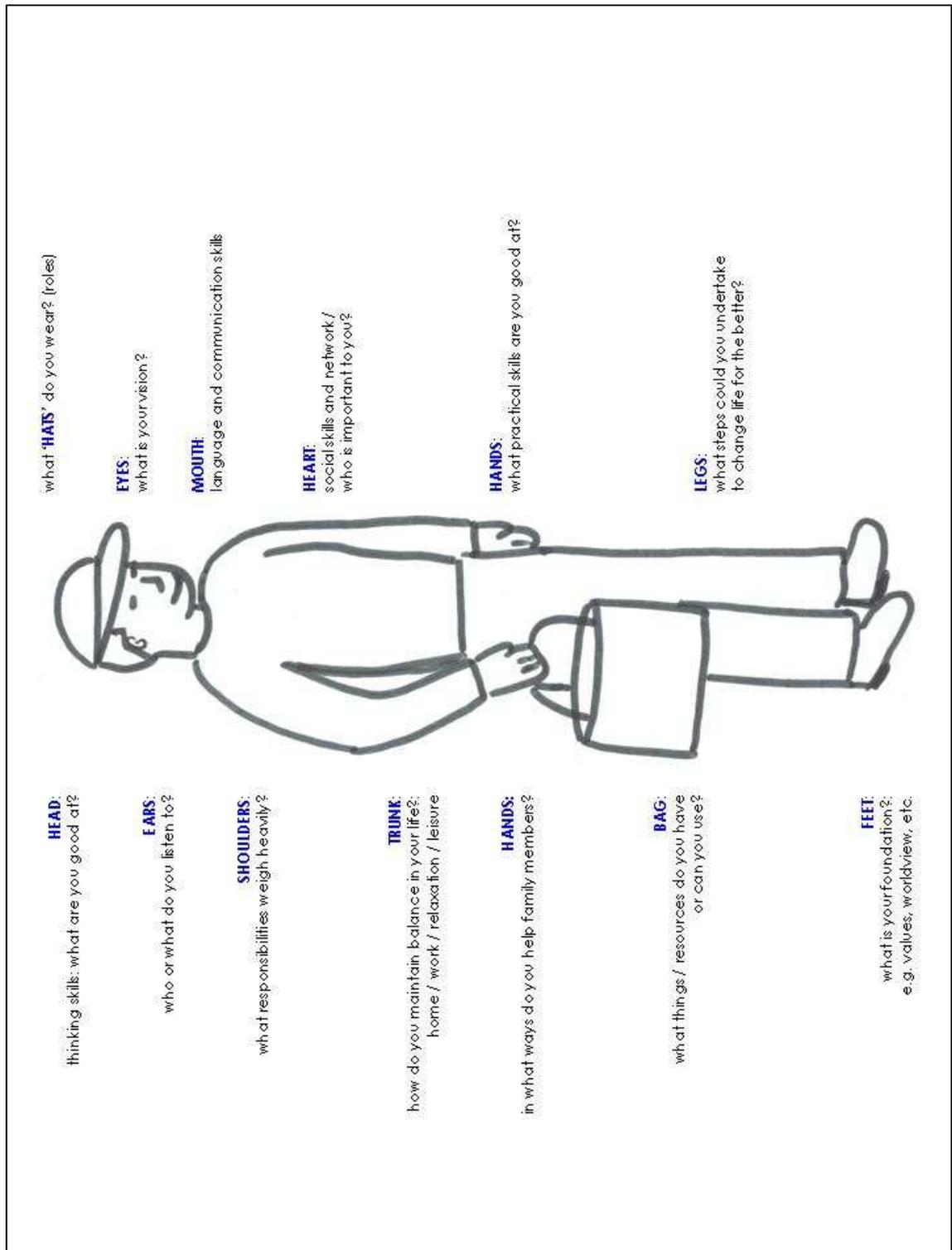


Figure 3.4.1: worksheet used to index views skills and resources

I don't intentionally plan activities to relax, I just feel tired and think of something.... If I'm about to shout at someone, then I know I need to relax.

From this point a long conversation followed about relationships at home and dealing with conflict and anger. Although this was not the main focus of their action research process, I was aware from conversations in the women's group that not all relationships were easy, so I felt it was appropriate to use this opportunity for the men to reflect on their attitudes and strategies for conflict resolution. They were open about their struggles and also shared positive strategies and experiences with each other. I wrote in my notes about the meeting

I was quite impressed with everyone's openness in this meeting... what was very good was that some very positive, constructive things were said, which some of the others definitely needed to hear and reflect on.

Although this conversation was not referred back to explicitly in later meetings, several men referred to it in the evaluation form. For example Haider wrote in response to the question "Has anything changed in the way you say or do things at home?" that

I try to use different methods to see if harmony can be reached, to see if things can be done differently to please all... I try to listen more".

Similarly, Mahboob said: "**In my understanding, when family members talk together more, it has a positive effect"** (evaluation form, Urdu). Some of the women also indicated they noted a change in their husbands. For example Maryam replied to the question "what did you like best about the project?", that

It encouraged the fathers to open up and it allowed them to come out of their comfort zone and talk... my husband has been able to listen to my concerns and worries with a different perspective (evaluation form).

The third activity was part of the evaluation process and for this I asked the men to "write a poem about the most important, interesting or surprising thing (or person) you did or thought about during this project". I chose poetry, as this is a highly valued art form in Pakistani culture, which is enjoyed by men as well as women. I provided high quality textured paper and a calligraphy pen for this task. The initial response from Gulzar was **"you are asking a difficult thing... does it have to be poetry?"** (meeting 7). Imtiaz felt even more strongly: **"you cant' find me next week, I'm going to move with my family!"** (meeting 7). I reassured them that it did not have to be poetry, that a short story would be fine, and that the purpose was to highlight their most important experience of the project, rather than producing a sophisticated piece of writing. However, nobody brought a poem to the closing party, despite the fact that I had assured them they could choose whether or not to read it out to others. After a few reminders, one father eventually wrote a lovely personal ode to his child.

Although the men engaged in these activities a little reluctantly, they provided an opportunity to share some of their personal thoughts and feelings in a non-threatening way. However the majority of interactions consisted of discussions about their chosen focus and other related issues, and consulting Islamic scholars and Imams about their topic.

Apart from the three creative activities mentioned above, which were offered to them directly, the men were also encouraged to engage in two creative activities with their children at the closing party. The first activity, in which everyone present participated, involved providing written feedback and voting for the best entries in the children's art competition. The second activity involved helping the children to complete a giant snakes-and-ladders game. These activities facilitated positive interaction between adults and children and created useful structure in the party (see chapter 3.6 for details on both these activities).

The action research process

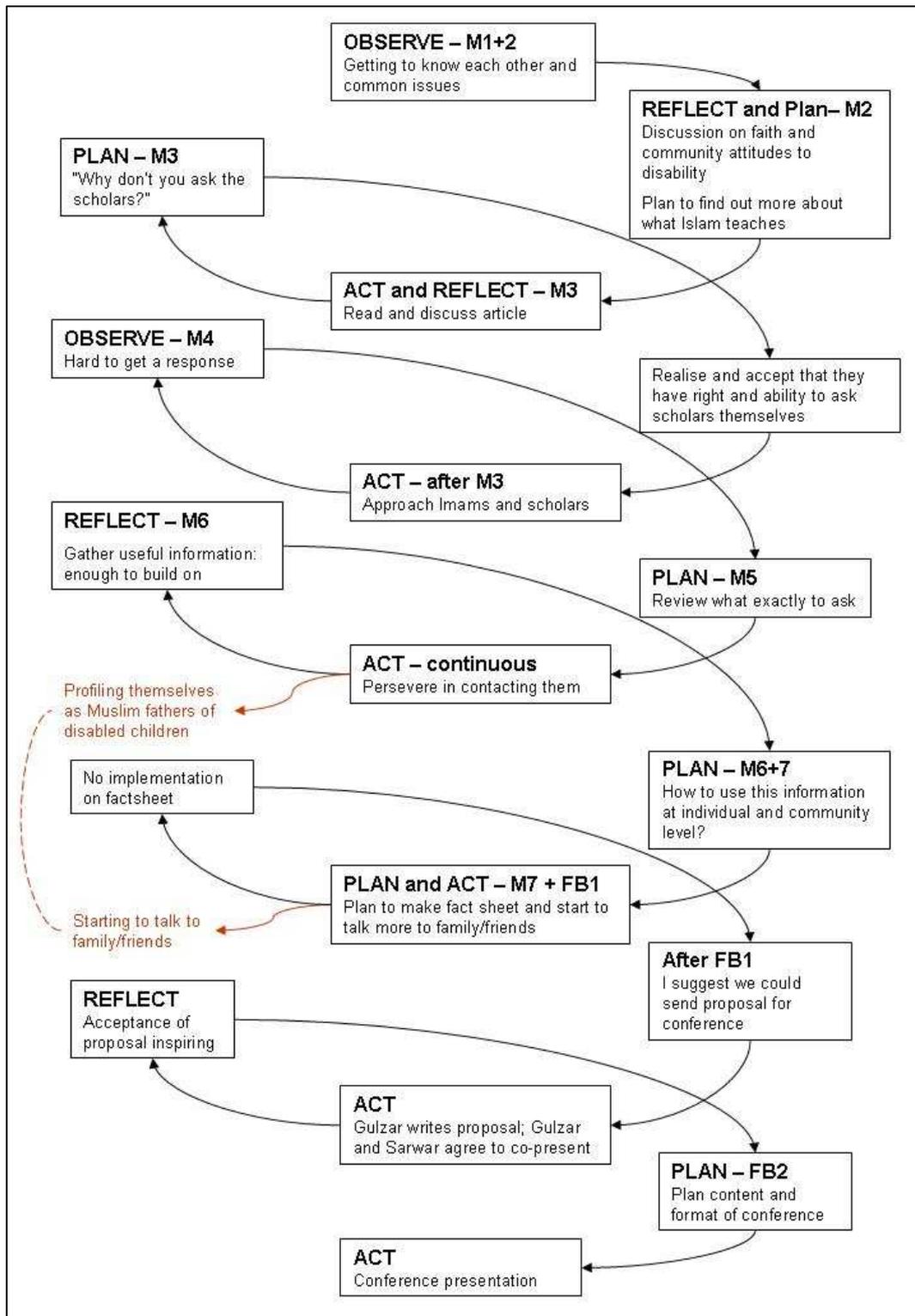
As with the women's group, the purpose of the first two meetings was to get to know each other, to understand the action research process, and to review the common issues identified during the exploratory phase. By the end of the second meeting the men decided they wanted to focus on disability and Islam and from then on they maintained their focus well. The process described homes in on this main topic. Figure 3.4.2 (see next page) visualises the action research cycles the men went through.

Meeting one

As already indicated above, in the first meeting the men introduced themselves to each other through two short stories about their disabled child. This activity gave them control over what and how much they would reveal to each other, whilst on the other hand inviting them to consider their personal, emotional response to their child's impairment and people's reactions to it, rather than a dry, objective description of the impairment. After this introduction I explained what participatory action research is and how it might work for this group. Having explained that the first step would be to identify a suitable focus, we then looked at the flip chart with common themes arising from the individual interviews in the exploratory phase. One issue that had not come up during the interviews, but which they felt had a big impact on their lives, was the financial impact of disability, so that issue was added to the chart. One major theme on the flip chart was 'community attitudes'. They agreed this was a problematic issue, but wondered whether they could have any influence on this. They agreed to reflect on all the different themes before the next meeting, so that they could decide on a focus for their research then.

Meeting two

In the second meeting the men decided to tick off unsuitable themes first. In this process Gulzar suggested that "faith" was not an issue to look at, as he thought only 10 to 15% of Pakistani people might have negative beliefs around the causes



Key: OBSERVE, REFLECT, PLAN, ACT: refers to stages in action research cycles;

M = meeting, FB = feedback meeting; black depicts main action research cycles, brown depicts the effect of the process on the way the men profiled themselves.

Figure 10.2: the men's group's action research cycles

of disability. When I pointed out that all families had talked about negative responses at the birth or diagnosis of their disabled child, they all agreed that this is the case. When one of the men started talking about his belief that his child's disability was caused by someone performing black magic, a long discussion about this topic ensued. At this participant's request this conversation was not recorded, indicating that he realised this is a sensitive and debatable issue. I will therefore refrain from giving details about this conversation. The other men did not share his belief, as they made particularly clear in the next meeting when he was not present.

The most important outcome of this discussion was that it led to the first decision and planning moment in their own action research cycle. The men decided they wanted to find out more about what Islam actually teaches about disability, both its causes and how Muslims are expected to respond to it. As a starting point for doing this I sent them a paper by two Muslim Arabic speaking academics in the field of education who studied the original Arabic Qur'an and Hadith (the sayings and teaching of the Prophet) in order to understand the Islamic position and attitude towards disability (Bazna and Hatab, 2004).

Meeting three

Although not all men were able (because of lack of time or inability to read English) to read the whole article, it formed a good starting point for a discussion on their understanding of the Islamic view on disability in the third meeting. Haider talked about the concept of God testing people, saying that

man is put on earth for God's purpose, to give Him recognition... the tests come on different people at different times in their lives and these tests are what put you in categories when you get to heaven, your status there (meeting 3).

However Gulzar did not believe that God gives punishment in this way, but that life

is a growing process through whatever comes on your path and how you respond to it. It would not be difficult for God to test us in another way, why destroy the life of that child?

When I asked him why, from a spiritual point of view, he thought there was disability in the world, Gulzar answered "maybe God wants to give me something through it. Why not see it as a gift? Maybe through my son I am closer to God!". Imtiaz also added that since his disabled child was born he had seen a lot of blessings in his life: "on my low wages, I still don't understand how we ended up with a comfortable house.... God just gives me blessing, I feel like that." The men did not think that God "planned" disabled children, but that impairments occur randomly. This implied to them that it is in essence not important what happens in life, but how you react to it.

At the end of this interaction, Imtiaz asked why I was discussing this with ordinary people like them, rather than Islamic scholars (learned people who specialise in Muslim theology). Although all three men present at this meeting immediately agreed with me that it would be better if they as Muslim fathers of disabled children would ask their Islamic scholars and Imams, Imtiaz (for whom this was the first group meeting) wanted me to decide what they should ask them. I explained the idea of action research again, emphasising the fact that they were co-researchers who needed to take an active role in the project. After this the following interaction took place:

Imtiaz: I see! You want to step back, so we can do it ourselves.... (Urdu). But if you go with us to see the scholars, you are better than us in explaining

Debbie: No, I am not a Muslim, nor do I have a disabled child. You are a Muslim and have the full right to go to your scholars and ask about an issue affecting your life, don't you?

Haider: Oh, yes, we do!

Imtiaz: OK, I'll do it for you

Debbie: No, no, don't do it for me!

- Imtiaz: Alright, for myself then!
- Debbie: So what's the next step for all of you then?
- Imtiaz: I'm going to find out from the scholars, but first I am going to talk at home, to my mum and my wife, as she has better knowledge because she grew up in (an Arabic speaking country) and speaks Arabic very well. Then I'll go to different scholars
- Haider: I'll try and find out... no, not try, I will!

This conversation was very important for the participants in taking on the role of researcher, and as a group they moved forward from this point onwards. However Imtiaz, who verbalised first his doubts and then his understanding so well, repeated his request for me to go with him/them in almost every meeting, expressing doubt that he was able to talk to the scholars on his own. Nevertheless, he approached and gained information from two scholars and searched the internet as well.

Taking action in between meetings

From meeting three until the end of the project all men took action to approach local scholars and imams (men with basic training in Islamic theology, who lead the prayers in the Mosque and preach the weekly sermon on Fridays) through their own Mosques and other Mosques in the surrounding area, and well-known scholars in Pakistan and Iraq through email. The latter was not successful as no replies were received even after several reminders. The former strategy was more successful, but again, several visits were required in most cases, and only a few gave any substantial information. Internet searches helped to confirm some of the views given by local scholars. The section on "Disability and the Quran" below describes what the men found out.

Meeting four

In meeting four, which was attended by all five fathers, Haider was the first person to report back that he had talked to the Imam at his own Mosque. This Imam had

explained that disability is not from God. As the view he brought was contested by the other participants - which was an important process for their research - I will quote this view at length here:

I understand it better now. He said it's not from God, as he creates perfect. In the Quran it says your wife is your field - it is how YOU plough it and water it and ... he says it's your fault, it's not sin, but how you cater, how you conceive, how you look after her during pregnancy, that causes disability. Every conception is perfect, but it is *when* you conceive. For example you're not supposed to have sex when there is an eclipse.... It's like a field, if you throw the seed in there and just expect it to grow, it can come out pear-shaped. If you take the time and look after it... Like some of the dates in the month you shouldn't, including woman's cycle, or situations in the atmosphere (Haider, meeting 4).

Sarwar responded by saying that "somehow it puts the blame on my wife!" and by explaining that "the scientific fact is that if a woman is having her period she can't conceive". Imtiaz was doubtful too, saying "so if we sleep with our wife in this situation our child will be disabled? I don't believe these things!".

Importantly this discussion also led to the question whether the scholar told Haider that his view was based on the Quran and/or Hadith, or whether it was a personal opinion:

Haider: It isn't in the Quran... but the Hadith explains..

Sarwar: So did he quote the Hadith?

Haider: No, I just asked him

Debbie: I would like to know what it actually says

Sarwar: It is a fair point that not everything is in the Quran, so we need to see how the prophet did it. Some people will go beyond that, but I

personally draw a line after the Hadith, after that it is humans who can err... We need to find out from the sources. I think if we can find a scholar who can answer the questions and quote scriptures...

...

Gulzar: But the Quran only gives the basics

Sarwar: ... when it comes to this we expect others, scholars, to tell us. I now think about studying the Quran about this myself... because I want to be sure that if a scholar tells me it's mine or my wife's fault, I'll be able to tell him it is not from the Quran or Hadith. I won't believe him unless he shows me a reference. If they are well-respected scholars, I have some level of belief, that he has actually studied the Quran.

Gulzar: I wrote to someone in Pakistan, but no response. Lots of them do the minimum required studies...

Haider: Why would you trust better known ones more?

Sarwar: Because he will quote the exact sura (chapter) and verse, or which Hadith books, so I can read it and check it out. Anyone who will give me references, it is fine.

This discussion was very important in clarifying that in order to get reliable information, they needed to listen carefully and ask for references that they could check out for themselves whether the scholar's view is really based on the Quran or Hadith. From this time onwards the men were more rigorous in their approach to gaining this information and continued to contact and follow up scholars and Imams, as well as search the internet.

Meeting five

This meeting was not so well attended, with only two fathers, and the one brother. It was a short meeting as one participant arrived rather late. Sarwar clearly explained to Zafar (who had missed the previous three meetings), what we had achieved so far:

We've been trying to find out what the Quran actually says about why people are disabled and how we should behave towards them... we need to find some scholars who can tell us what exactly it says and where in the scriptures... Without that I can't just accept it, we need to know it's not just an opinion... I think if you don't give references it probably means you don't know yourself, or you have given it your own interpretation and they make a long complicated story, which is very much open to interpretation.... So we have not been successful so far. (Sarwar, meeting 5)

Although the men had been able to talk to some Imams in the area, they had not been able to give references. Islamic scholars were much more difficult to identify and contact, mainly by email. I commented that it is hard to come by information, and that that in a way is a finding in itself. Sarwar suggested that **"it often just takes time to establish a contact, once you have that it gets easier.... We'll keep trying"**. After considering who else they could approach, I observed that they had not approached the Imam of the large local Mosque, who had been very helpful to the project in providing a meeting venue for the children's meetings and family parties.

This led to an immediate action by the group as a whole as Sarwar suggested that **"he might be there now. Why don't we just go and see?"**. When we arrived at the other Mosque the Imam was indeed available and the men explained very clearly what information they needed and why, adding that they had not been very successful in obtaining it from other sources. The Imam asked when they needed the information by, as he also needed to find out. The men made sure that they had his contact details and asked if they could get back in touch in a week's time. After this short meeting they were optimistic that the Imam would **"find out for us, I think he will do it for us"** (Imtiaz). However, despite phone calls and a repeat visit after meeting six, when the Imam said he did find some information but did not bring it with him that day, he never shared the information.

At the end of meeting five the men exchanged their telephone numbers and email addresses, after which some email communication took place between meetings. However this consisted mainly of me sharing information brought in by the men, or providing links to relevant web-sites found by either the men or me. Although they often told me they had seen or read my emails, only two of the men occasionally used this mode of communication themselves.

Meeting six

At the sixth meeting it was evident that all men had continued to work on trying to gather information: Zafar and Gulzar were awaiting responses to their emails to scholars in Iraq and Pakistan, Sarwar had had telephone contact with a blind Imam in another part of the country and was waiting for him to phone back, and Imtiaz had visited an Imam at a Mosque in a nearby area who had invited him to come back with the group. Although it was not possible for everyone to go on the visit, it was decided Imtiaz and Gulzar would go back together and we spent some time reviewing what they could ask. Imtiaz was very keen for me to join them, saying "but I want to take you - because we are telling the Imam we are doing some research". However I explained that it was important that they present themselves as researchers and that my presence would probably not be helpful, which he reluctantly accepted.

As we were nearing the end of the project I also posed the question what they might do with the information once they had found out enough. Imtiaz's initial answer was "We will give the answers to you", to which I replied "No, it's your research, I'm just watching - I'm trying to anyway!". But then they came up with some suggestions about how to use this information:

- we will need to educate them (the Pakistani community), through the Imam, or within our families (Imtiaz)
- if we want to spread it at mass level, we need some strategies. If we are looking to spread it in our own circle then word of mouth is OK (Gulzar)

- local TV (Imtiaz)

When I asked whether the Imams could be of any help in this process, they suggested that they could possibly talk about it in the weekly sermon after the Friday prayers.

When Imtiaz and Gulzar went to the Imam as agreed later in the week, he was not available and Imtiaz later went back again on his own. He was given some printed information, which was useful and contained a good number of references to the Quran.

Meeting seven

In meeting seven the discussion about what to do with the information was continued. Imtiaz thought that we needed to do more research, particularly about medical aspects of disability, such as genetics. However Haider suggested it was now about implementation. Gulzar added that

The basic findings are important, especially if it is connected with religion.

Whatever we are doing and thinking about disability is wrong, we need to know that God is not looking at it this way. Any other scholars are going to say the same.

Although the conversation then progressed to adding more ideas about using the information gathered, Imtiaz kept coming back to needing to know the medical reasons for disability and whether cousin marriage caused a higher incidence of disability in the Pakistani community. The rest of the group felt that the priority was on changing community attitudes towards disability, rather than in-depth scientific information, and it was decided that I would send some information on genetics to help them answer any questions from their family and community members. They added the following ideas to their list from meeting six:

- the only way I can say, is the Qutba (*Friday sermon*) (Haider)
- if we had an institutional platform it would be easier - some community organisations are working for the Pakistani community. They can support us (Gulzar)
- we need to keep in touch with each other (Imtiaz)
- we need some material (*written information*) (Imtiaz)
- it is about commitment - we will actually need to do what we believe should be done... not just attending, but actually doing the work (Gulzar).

At the end of the meeting, when I asked them to evaluate the project, the men were more interested in my evaluation of the group and asked me whether I had started writing the thesis and what my findings were. I explained it was too early for findings. After this they asked how I decided to conduct this research and whether it was useful for me, so I summarised some of my observations, for example the contrast they had highlighted between attitudes towards disability in the Pakistani community and within families that have a disabled child themselves, and the positive influence of faith on the way they accept and support their child, which they had reported. When they asked how I might implement my findings, I reminded them that I was hoping to organise a local dissemination event after completing my studies, and that I would need their help in this. This inspired them and Gulzar suggested that we could also contact people in Pakistan, for example people in the ministry of education whom he knows, or that they could set up their own project to draw in more people.

The closing party

At the closing party I gave all men a printed pack of all information gathered and contact details of each other, to enable them to continue the process without my constant facilitation.

Feedback meeting one

At the first feedback meeting in which I presented an overview of what we had done during the research process and what we had achieved, Gulzar observed that in the three months since their last meeting they had not really done anything to continue the process. Imtiaz had contacted another scholar and said he had also "been trying to discuss it in family gatherings, engagement parties and so on".

They then proceeded to make some plans for the next few months, agreeing that they would all look at the information pack I had given them at the end of the project again and to write a draft 'fact sheet', that they could then distribute in Mosques. They felt it would be easier to ask Imams to use the information in their sermons if they had a fact sheet to give him. Although they set themselves a deadline for drafting the factsheet, they did not make any progress with it.

Responding to a call for papers

Some time later I received a call for papers for the "Inclusion and Exclusion Conference 2008", which particularly welcomed joint presentations by participants and researchers. When I forwarded this information to the participants by email, Gulzar offered to draft the proposal, to which I only made minor changes before sending it to the conference (see appendix N). Both Sarwar and Gulzar were willing to co-present at the conference.

Feedback meeting two

The second feedback meeting was used to finalise the content for the presentation. The men talked about what messages they felt needed to be given to the audience and after the meeting Sarwar put those ideas into a PowerPoint presentation, which I sent to all families by email and printed out for the women's group to work on in their meeting.

The conference presentation

Apart from Sarwar and Gulzar one woman (Maryam) and one child (Maheen, 13) co-presented with me at the conference. The men presented the slides about how they had worked as the men's group and what they had found out, as well as the slides about implications for policy and practice. They did this confidently and convincingly, by expanding on what was written on the slides through giving personal examples.

An additional topic: cousin marriage

As already mentioned above, one participant was very interested in the subject of genetic causes of disability and whether cousin marriages raised the risk of these. Imtiaz brought this issue up at the first meeting he attended (meeting 3) and for the next meeting brought in a newspaper article titled "Birth-defect fears over first cousin marriages" from the London edition of the Pakistani newspaper "The News" (11/02/2008), which reported that Member of Parliament Phil Woolas called for a public debate on the issue. The issue was widely reported on in the British media at the time. Imtiaz reported on two different occasions that people in the Pakistani community had told him that the incidence of disability was higher for 'English people' and was concerned that the whole debate had more to do with propaganda than scientific fact: **"But I think the medical side, they try to brainwash us - such babies are born in English families too"** (meeting 6). I explained to him that the risk of genetic disorders did indeed rise in cousin marriage, but the incidence is so low, that in real terms it does not increase the total incidence of disability as much as is often claimed. The other group members did not feel that this issue needed to be explored in depth, as it is still unclear how much effect it has - **"... also we don't have any solid proof, because it is about chances and ratios"** (Gulzar, meeting 7) - and it did not affect their question about Islamic views on disability much - **"we don't need that information, we are looking at disability in general, what we should do is make them aware of disability, not of cousin marriages"** (Gulzar, feedback meeting 1). As this issue was clearly very important to Imtiaz, I provided the group with links to relevant websites and - towards the end of the

project – a scientific article that contained some hard “facts” (Devereux et al., 2004), and an unpublished overview of the incidence of childhood impairments in Bradford which has the highest percentage of Pakistani residents in the UK (Corry, 2007). A brief overview of this issue and varying relevant views on it will be described below. Notwithstanding the general interest in and importance of this issue, its repeated discussion in the groups was not helpful for the research process, as it distracted from the chosen focus and slowed down the progress of their work on that focus, as is evident from Gulzar's comments above.

Challenges in engaging with Mosque leadership

The men encountered two major challenges from a direction they had expected to be more supportive. The first related to using the Mosque as the venue for our meetings. The Mosque management had some difficulty fulfilling their initial commitment to allowing the group to meet there for the duration of the project. The status and power issues described in chapter 3.1 continued throughout and the participants' arguments that the project was for the benefit of the Pakistani Muslim community and that the Mosque should be accessible to them as local Muslims did not convince the chairman to continue to allow any further meetings (meeting 6). Although we were able to arrange for the remaining meetings to take place in the other Mosque, the men were upset about this issue. Gulzar felt there was no specific valid reason for them to say no, whilst Imtiaz said **“It's like a political party!”** (meeting 6).

Secondly, the results of the men's efforts in obtaining information about disability in Islam from Imams and Islamic scholars were limited by the poor response they received. The men were not surprised by the lack of response from scholars abroad, even though some had dedicated websites on which they respond to questions sent in by Muslims around the world. They also understood that their local Imam's might have to look up information on this specific topic, but were frustrated that some of the Imams did not fulfil their promise to do so. Imtiaz said in meeting six that the Imams **“don't want to discuss it because they don't think they**

know enough". Yet, when they were making plans for raising awareness of disability issues in the Pakistani community they still felt the Imams would be the most appropriate persons to present messages to the community. Haider thought that they "could get them to do a talk after the Friday prayers, as part of the sermon, so people become more aware". He explained that "the second part (of the sermon) is more about awareness of what happens in society. Within that he can explain".

This discussion indicated that the men felt that the Mosque was the most appropriate place to start raising awareness in the Pakistani community, and that they were willing to put effort into convincing Imams to support them in this effort.

Themes and issues arising from the process

There were, then, two main topics about which the men became more knowledgeable through the action research process, i.e. 'disability and Islam' and 'cousin marriage and genetic causes of disability'. Although some of the other issues raised in the exploratory phase were talked about at times (for example difficulties in accessing services, and social isolation because of their child's behavioural problems), these did not constitute consistent themes for their action research process.

Disability in the Quran and the Hadith

This section describes what the men themselves found out about disability and Islam through contacting Imams and Islamic scholars, and through searching the internet. This section is based on print material the men received at one Mosque, print-outs of information they found on the internet and an on-line video of an Islamic scholar discussing the issue. The information they found is congruent with and complements the short literature review on this topic given in chapter 1.4. Although the print material they obtained did not have a reference, an almost identical version of it can be found on the internet (Al-Islaah Publications, online).

The Qur'an does not contain many direct references to disability, but much can be inferred from a variety of verses.

God's will

A central Islamic belief is that God, the creator, has absolute power and that what happens in life is subject to God's will: "Nothing on earth or in heaven is hidden from God: it is He who shapes you all in the womb as He pleases" (Quran 3:5-6). This implies that any abilities or disabilities need to be accepted for what they are. Mahboob used the example of Ayub (known as Job in the Bible), who suffered many losses and disease with God's permission (though inflicted by Satan), yet continued to honour and serve God. Mahboob added that "**God always gives enough strength to carry any burden that He gives**" (Urdu, meeting 7).

Removing stigma

Where disability is directly referred to, the verse serves to remove any stigma experienced in society: "No blame will be attached to the blind, the lame the sick. Whether you eat in your own houses, or those of your fathers, or any of your friends' houses, you will not be blamed ... whether you eat in company or separately" (Quran 24:61). Eating together in Arabic culture implied a close association at equal footing and this verse is the clearest indication in the Quran that no moral judgment is applied to disabled people.

Muslim duty to support the 'needy'

Another important principle concerns the Muslim's duty to meet the needs of the disadvantaged: "Be good to your parents, to relatives, to orphans, to the needy, to neighbours near and far, to travelers in need and to your slaves. God does not like arrogant and boastful people, who are miserly and order other people to do the same, hiding the bounty God has given them." (Quran 4:36-37). Although disabled people are not referred to explicitly, they would arguably come under the category of 'the needy' if their impairment prevented them from generating

their own income. This expectation from Muslims to support the disadvantaged, is further underlined by a Hadith in which the Prophet told believers to “show mercy to those on earth, so that God, who is in the heavens, bestow mercy on you” (exact reference not given in the information provided by one of the Mosques), which implies a divine reward can be expected in return for showing mercy.

Testing through ‘calamities’

A central aspect of the spiritual lives of Muslims concerns God's testing and in this context disability is viewed as one of the many ‘calamities’ that might occur: “We shall certainly test you with fear and hunger, and loss of property, lives or crops. But [Prophet], give good news to those who are steadfast, those who say, when afflicted with a calamity, ‘We belong to God and to Him we shall return’. These will be given blessings and mercy from their Lord, and it is they who are rightly guided” (Quran 2:155-157). This verse clearly confirms the view that the ‘tests’ that God gives are not to be considered a punishment, but rather an opportunity for developing a stronger personality and faith linked to rewards in the afterlife, which participants had also talked about in the exploratory phase. In addition Sarwar found an online video of a well-known Islamic scholar explaining the reason why God “creates disabled children” (Naik, online). He argues that God judges people in different ways, depending on their circumstances, for example wealth and poverty, or disability and health. The test is both for the parents, to see if they have faith in God, and for the disabled person themselves, whether they believe in their creator despite their impairment. In the latter case, if God has taken abilities away, He adapts the test criteria. In all cases, the harder the test, the higher the reward in Heaven.

Including and supporting disabled people

The men concluded there is no moral judgment on disabled people in the Qur’an and that Muslims are exhorted to support them and include them. The fundamental issue for Muslims is that “in God's eyes, the most honoured of you are the ones most mindful of Him: God is all knowing, all aware (of people's true worth

and the thoughts they harbour)" (Qur'an 49: 13), as this clearly implies that people's abilities are relatively unimportant in comparison with their faith in God.

Challenging community attitudes

In view of this, the men felt that negative attitudes towards disability in the community may be based on cultural, rather than religious beliefs, and need to be challenged by making people aware of what the Quran and Hadith actually teach.

Cousin marriage and genetic causes of disability

The issue of cousin marriage has indeed been intensely debated over the past few years and been reported on in the media repeatedly. The debate has been heated and problematic because scientific and political aspects of the issue have been confused. Two MPs (Ann Cryer in November 2005 and Phil Woolas in February 2008) have stated their views very strongly, making explicit value judgments about the cultural practice of cousin marriages, for example Phil Woolas is quoted as saying that "levels among the Pakistani population are higher than the general population and everybody knows it's caused by cousin marriage" (emphasis mine) and Ann Cryer is quoted as saying that "this is to do with a medieval culture where you keep wealth within the family" (BBC News, 10/02/2008).

Dr. Aamra Darr of Bradford University argues that

the predominant focus of media attention has been on alarmist presentation of data on the increased prevalence of recessive disorders in the British Pakistani community, with little consideration of other pertinent issues.... Marriage between two individuals who are cousins, in itself, is not the cause of recessive conditions. It simply increases the prevalence of very rare recessive conditions in a population, as cousins are more likely to be carriers of the same recessive gene variant. In the British Pakistani

population a minority of couples are likely to be carriers, while the vast majority of couples do not have any additional risk (Darr, 2005).

Brittles points out that the risk of birth defects rise from about 2% in the general population to 4% when the parents are closely related (quoted in Wilkinson, 2008), emphasising that the risk and the actual numbers are still very small. Nevertheless, Corry emphasises that "genetic disorders can be devastating for the families involved" (quoted in Wilkinson, 2008) and looking for an effective approach to reduce the incidence is important. Recognising the political and scientific importance of this debate Bradford University produced a guide titled "Consanguineous marriage and inherited disorders" (Darr and Modell, 2009), which provides a balanced view on the issue and an appropriate approach to genetic counselling, that concentrates on families known to be at risk, rather than whole communities.

Evaluation

The men filled in an evaluation form after meeting seven. Like the women and children, they too found it difficult to verbalise what they had learned, so I used the same 'thought bubbles' activity in feedback meeting two. These two written methods and their spontaneous feedback throughout the process show that they had benefited from the project, and were able to express that clearly.

Value of meeting each other

The men appreciated the opportunity to meet up and talk to each other as they felt supported by each other and that they should keep meeting (Mahboob, evaluation form). They also spoke of the importance of exchanging ideas and learning to acknowledge that they were all different and needed to be open to differing views (Gulzar, meeting 3).

Awareness of the action research process

The men spoke of the challenges I faced in this project. For example they realised it had been difficult for me to get the group together (Gulzar, meeting 6), and felt that they had not "cooperated" very well (Imtiaz, meeting 4).

They also showed understanding of what involvement in action research required, even if they did not always act on that understanding. For example, the discussion in meeting three about the need for them to go and approach Imams and scholars for information themselves, rather than relying on me to speak for them, shows this understanding. They went on to find out they were able to do this. They also acknowledged how difficult it can be to obtain information from their Imams and Islamic scholars (Sarwar, meeting 4) and expressed frustration that this had meant they did not find out as much as they had hoped (Imtiaz, meeting 6).

Some of the men also valued the joint pursuit of knowledge in itself. They enjoyed the fact that they were collaborating with me to conduct this research and supporting me in writing my thesis. Two offered to proofread my thesis.

Gained knowledge and continuing to find out more

The men also talked about the knowledge they had gained through the research process, mentioning a range of topics, including their disabled child's needs, communication in the family, medical aspects and perceptions of disability in the community. This new learning inspired them to keep finding out more.

Changes in attitude towards the child

Some of the men talked about changes in their relationship with the child. Gulzar said he was "more focused in understanding and providing his needs", while Haider said he tried "to use different methods to see if harmony can be reached". Zafar indicated he was undertaking more activities with his brother and wanted to involve him more in the community (feedback meeting 1).

They also talked about the need for a change in attitude in the whole family (Gulzar, meeting 6) and having started to educate family and friends to achieve this (Imtiaz, meeting 6). Zafar intended **"to try and change other people's perception of disabled children"** (feedback meeting 1).

Commitment to continuing the process

Although all men were involved in thinking about ways to continue the process, in terms of raising awareness of disability issues in the Pakistani community, they found it difficult to put this into practice beyond the project time. Gulzar wrote about the need for setting up a platform to raise awareness in the community and possibly writing some articles for local newspapers (evaluation form).

Imtiaz stated that **"the project clicked on my mind and I am still doing, and getting information"** indicating that the new approach to dealing with his questions and issues around disabilities he had experienced during the project was sustained (feedback meeting 1). Similarly Gulzar expressed his commitment to continuing the process in meeting six and gave evidence of that commitment several months later, by writing the proposal for the conference and co-presenting the workshop there.

Comparing the research processes of the men's and women's groups

When comparing how the men and the women worked together in their respective groups, there are some interesting similarities and differences to note.

There was a high level of openness between the group members in both groups and a willingness to respond to each others areas of interest. Members of both groups were also willing to take action in between meetings in order to keep the research process moving.

Whilst attendance was less than desirable in both groups, there was a significant difference in this respect. In the women's group attendance was very good in the first two meetings, but only two members attended the next four meetings, which meant that the remaining members did not engage with the process for all that time. In the men's group however, attendance was both a little better overall, and it varied who did and did not attend, so that all men were engaged with the research process throughout, and continued their search for information even when they could not attend a group meeting.

Although initially the men showed more anxiety about taking action independently they went ahead in spite of this. For most their confidence grew quickly once they started to take action, though one continued to express his doubts. Whilst less women took action between meetings, they were more explicit in noting how they felt this was an empowering process.

The women appeared to be more conscious of the research process overall and emphasised the importance of the relationships in the group, even to the extent that their research focus became to set up a support group for Pakistani mothers of disabled children. The men appeared less person-centred and chose a more factual topic, which required more rational discussion.

Related to this, the women were very positive about the creative activities I offered to trigger deeper sharing about issues. The men however were not comfortable with this approach, preferring to communicate through talk only.

The participatory and flexible nature of the project meant that the groups had considerable control over how they wished to work together in ways that were meaningful for them and that they felt comfortable with.

Chapter summary

This chapter has presented how I engaged the men in their research group. Key aspects of their research process and the issues addressed are summarised here.

The research process

The men appreciated meeting other Pakistani fathers of disabled children and exchanging ideas and experiences together. They discussed both factual information and more personal stories and feelings.

The men developed a clear understanding of the action research process and the expectation that they would implement their plans themselves. Whilst most of them did take independent action, they found this quite difficult and frequently requested me to accompany them.

Profiling themselves as Muslim fathers of disabled children when they went to speak to their Islamic scholars and Imams, made them more assertive and proactive in challenging negative attitudes towards disability in the community.

Experiencing first hand how difficult it was to gain support from the Imams for raising awareness of disability issues was disappointing. At the same time it made them more convinced that it was important to convince them, as they were in a good position to spread messages in the Pakistani community.

Despite great willingness implementation of action plans was difficult during the process, and even more so after the end of project. The limited time available for the action research groups limited the potential tangible outcomes of the project considerably.

Key issues addressed

The central topic the men's group focused on was what the Quran and Hadith teach about disability. They found that the message is positive, both about the disabled person themselves, and about the need for the Muslim community to support them.

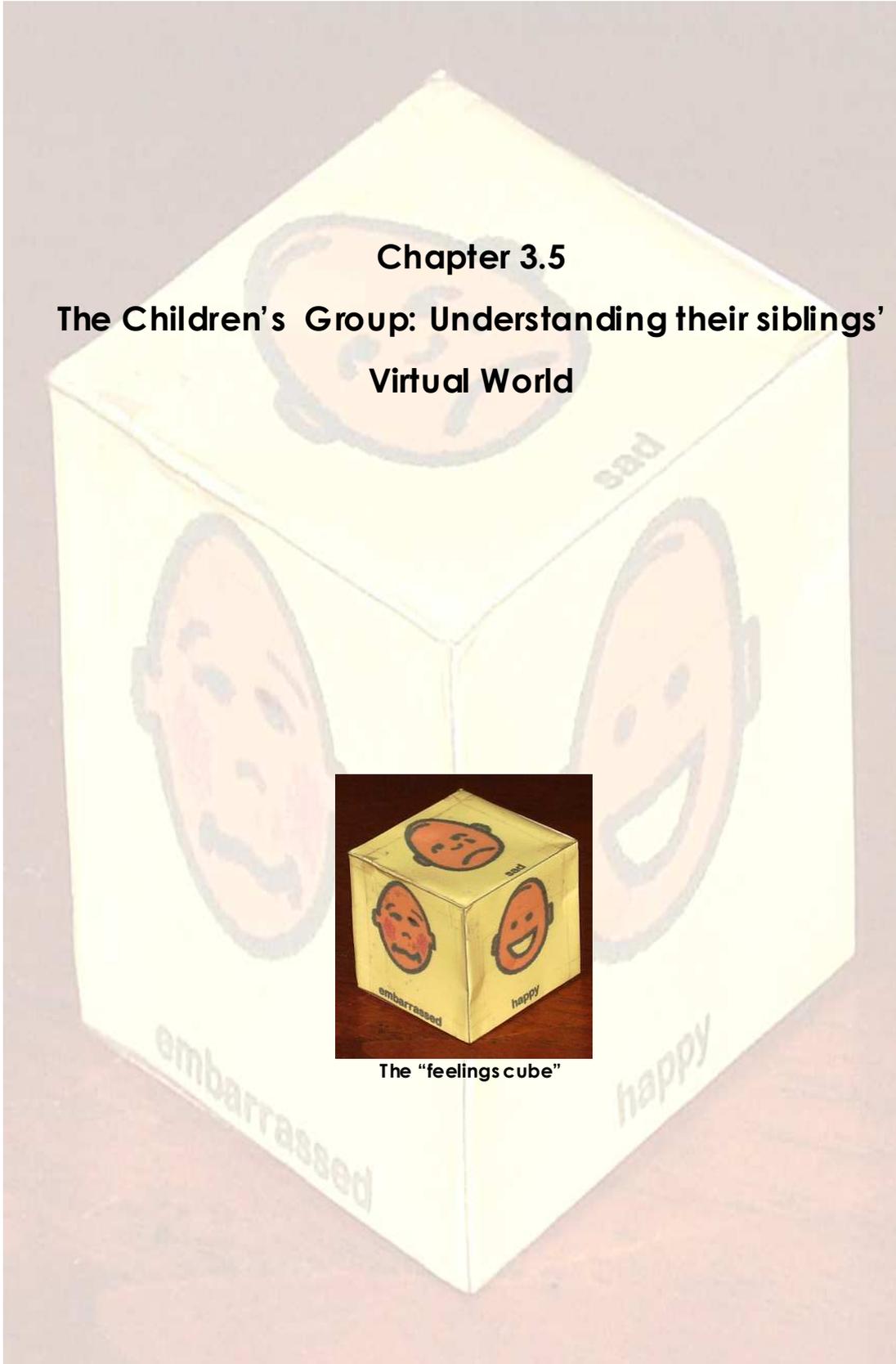
Some men found it very important to have a good understanding of the effect of cousin marriages on the incidence of impairments. They learned that a balanced

view of this issue is very important, i.e. not to deny that there is an influence, but to realise that this is a rather smaller influence than some (political) voices suggest.

The men also learned from each other about how to deal with challenging relationships within the family. Only one extended conversation about this topic took place, but most men indicated at the end of the project that they had put their efforts into improving communication with their wives and/or children.

This chapter has described the complex story of successes and challenges of facilitating the men's group in their research process. The next chapter will do the same for the children's group.

Chapter 3.5
The Children's Group: Understanding their siblings'
Virtual World



The "feelings cube"

3.5: The children's group: Understanding their siblings' virtual world

This chapter describes the findings arising from the children's group, known to the children as the "Kids' Club". The children needed more intensive facilitation of the research process than their parents did and in making the connections between the activities they engaged in. Although they had less ownership of the overall research process, the children were able to clearly indicate what they had learned and otherwise gained from participating in the group.

Overview of activities and interactions

The Kids' Club was the first group to start and met eight times. In addition the children attended two parties for all families together during the project period and two feedback meetings to inform the thesis writing after the project had finished.

Group membership

The Kids' Club was organised for the siblings of the disabled children only. This was not what I had envisaged doing when I wrote the research proposal, as the intention was to include all children. The decision to work with the non-disabled siblings only was taken after an introduction meeting in September 2007, when it became evident that for two children, who were both autistic, the group setting was very upsetting, for three of them I would not be able to guarantee their physical safety, and one was too young (2 ½) years to be part of it. Two children could have potentially managed in the group setting, but I felt it would then be more consistent to offer it as a siblings club, which would have the advantage of observing how their time away from home and their disabled sibling might affect them, and of giving them more space to start reflecting on and expressing their feelings – including negative feelings – about

having a disabled sibling. As will become evident in the description of the children's research process below, every activity (apart from the customary fun games at the start of each meeting) clearly focused on their disabled sibling and their relationship with him.

Inviting the participants

The same multi-pronged approach to inviting the children was used as for the other groups, with written invitations followed by phone calls to remind them. As most of the children were dependent on their parents or older brothers to bring them to the meetings, phone calls in the morning were essential, but still did not result in full attendance.

The venue

The meetings took place in the large local Mosque, which runs a secondary school for girls. Setting the date and time for meetings was a challenge every time, as the Imam was very difficult to get hold of and not good at relaying messages between the Mosque management and me, often delaying the sending out of invitations. The room we were allocated was large (5 x 8m approximately) and empty. There were small tables (120cm long x 30cm wide x 30cm high), which were normally used for Quran and Arabic classes, which we used to make square tables by putting three or four alongside each other. This was a rather unstable construction and leaning on the end of a table would tip it up, which often led to much consternation. As the room was otherwise empty, it was very tempting for the younger children to start running around and I soon learned not to bring in any balls. Although it was useful to have so much space for some activities (e.g. parachute games) it was generally difficult to structure the room in a way that helped the children to concentrate on the task in hand.

The advantage of the room was that it was on the third floor, well away from the Mosque on the ground and first floors, so the children's noise did not disturb

anyone else. The drawback of the room being on the third floor was that on two occasions a child who came alone had difficulty finding the room.

An overview of meetings and activities

Seven children participated in the meetings, five of them (from two families) regularly and two occasionally. The children of the family that was recruited last never attended the Kids' Club, but did participate in the closing party. As some of the children attended daily Quran classes after school, the meetings took place in the school holidays ('holiday clubs') and on one Saturday a month between holidays. Table 3.5.1 on the next page presents an overview of the meetings, how many children attended and what research activities we did.

Group composition and attendance

The ages of the children ranged from 6 to 13 years, and there were both boys and girls. There were also significant differences in characters and family structures / routines. This made for quite a challenge to plan activities that were interesting and enjoyable for all, and at the same time good triggers for thinking about the issues arising from having a disabled sibling.

The youngest group member was almost six years old at the start of the project and he had only recently immigrated from Pakistan with very limited English. Although he very enthusiastically joined in the fun games, and was interested in drawing and working on worksheets, he opted out of almost all discussions and games that required deeper thinking. As he often did this noisily, it was difficult to meet his needs as well as keeping the rest of the group focused on the activity. Another difficulty arose because two of the older children almost constantly provoked each other in a playful, teenage manner to an extent that disrupted the group process considerably. Trying to teach them that there are reasonable limits to stay within was difficult, particularly as they attended the group voluntarily and wanted it to be fun, and I therefore did not want to be strict.

Event	Number of children present	Activities
Meeting 1 (Holiday Club)	7 (4 families)	Getting to know each other: making balloon hats. Worksheet "My brother likes... / is good at..."
Meeting 2 (Holiday Club)	5 (2 families)	Planning for the Eid party: ➤making a welcome banner
Meeting 3 (Holiday Club)	5 (2 families)	Planning for the Eid party: ➤planning games and food suitable for their disabled brothers ➤making an Eid card for their brother, based on their likes and strengths identified in meeting 1
Eid Party for all families	6 (3 families)	Games that included all children Food that all children were allowed to eat Presents and Eid cards
Meeting 4 (Saturday)	5 (2 families)	Starting to talk about negative as well as positive views and feelings: ➤Drawing Mr Men characters to represent themselves and their disabled brother ➤Feelings cube Discussion: "What is research?"
Meeting 5 (Saturday)	6 (3 families)	Looking at common issues from exploratory phase Deciding on research focus: "to understand my brother better in order to make him happier"
Meeting 6 (Saturday)	4 (2 families)	"Views from our shoes" – story reading and discussion
Meeting 7 (Holiday Club)	3 (1 family)	"Two bugs" worksheet (positive and negative aspects of life with a disabled brother) Story writing
Meeting 8 (Holiday Club)	3 (1 family)	Story writing / drawing / decorating
Closing Party	7 (3 families)	Art competition (evaluation activity) Making and playing "Snakes and Ladders" game Prizes and presents
Feedback Meeting 1	6 (3 families)	"Thought bubbles" – what changed occurred as a result of participating in the project Reviewing the research process and what they learned from it
Feedback Meeting 2	5 (2 families)	'Cinquain' poems about their disabled brother and about the research project Making a poster with key messages for the Inclusion and Exclusion conference

Table 3.5.1 Overview of Kids' Club meetings and activities

Three children from one family – **Maheen (13), Abid (9) and Haroon (6)** - attended all meetings. Although they really enjoyed themselves, their behaviour could be very challenging. The main problem was that most of their interactions with each other were very negative, criticising each other's ideas and work and therefore undermining each other's confidence constantly. They also had considerable difficulty concentrating on discussions, but applied themselves well to games and creative activities.

Two more children – **Jamil (12) and his sister Inam (8)** - attended regularly. They were initially calm and cooperative, but within a few meetings a group dynamic developed in which Maheen and Jamil constantly provoked each other and made rude jokes or remarks about each other. This was often combined with the girls teaming up against the boys.

The very noisy and boisterous atmosphere that resulted was difficult for the two children – **Zohaib (11) and Aliya (13)** - who came on their own and were both much more shy and quiet. Although they never stated that this was a reason for rarely attending, I observed that they struggled to fit in.

The two non-disabled children – **Aza (12) and Hamid (7)** - of the family that was recruited last never attended the Kids' Club, although they did participate very well in the Closing Party, which they attended with their whole family.

A final problem in the group dynamics arose from the fact that the children of one family were brought to the meetings by a volunteer who supported the family. She did so very faithfully and I appreciated the fact that she made it possible for the children to participate. I asked her to sign a volunteer agreement which emphasised that everything she said and heard was confidential, and that she should not influence the children's input and ideas during the activities (see appendix O). However, despite her good intentions, she responded to the children's behaviour very differently to me, and the way she tried to encourage them to join in with the activities, or to stop negative behaviour was often insensitive or belittling, making the children feel

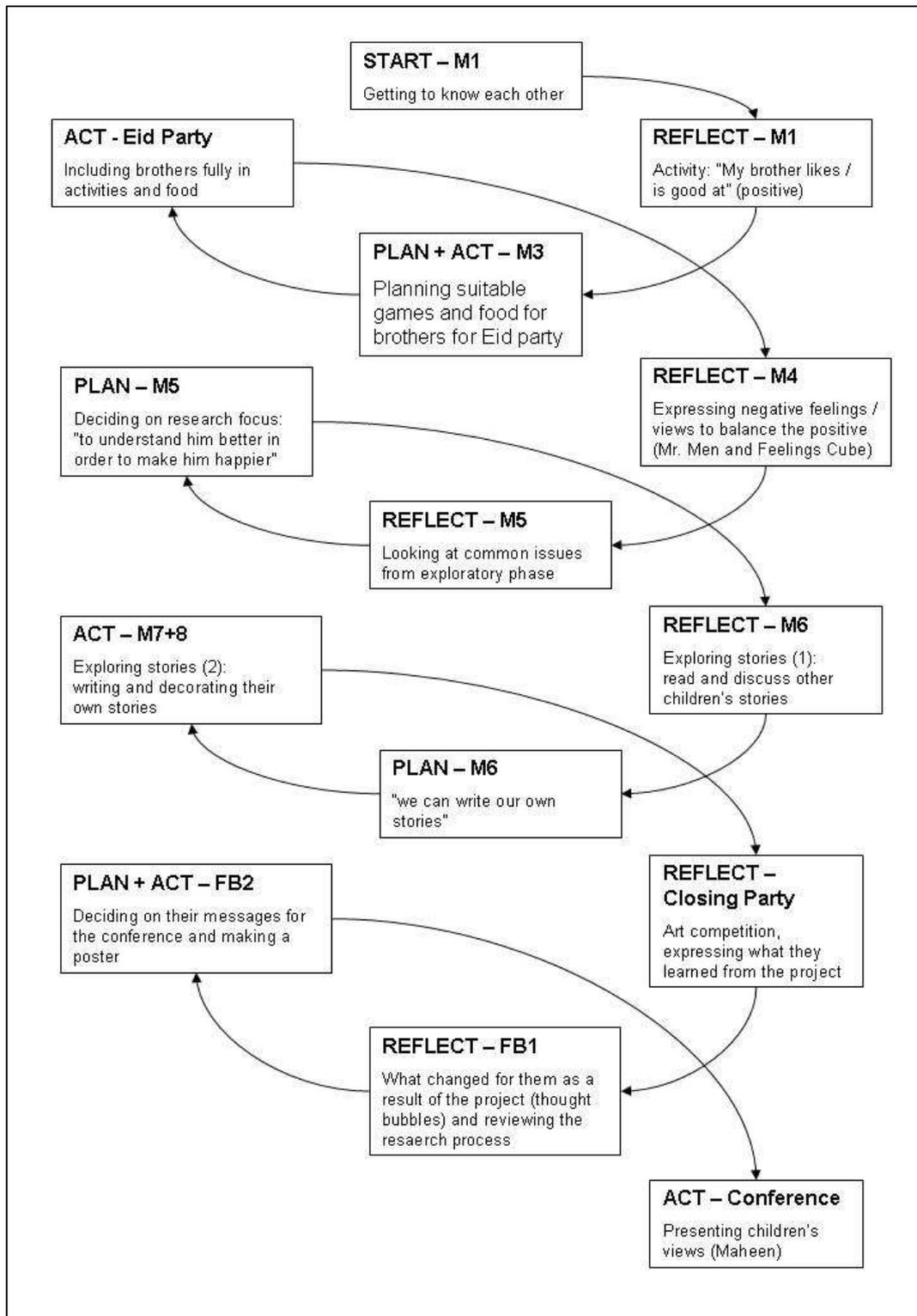
embarrassed. For example she told one girl who was crying in one of the earlier meetings not to act "like a drama queen", and in a later meeting "Come on, say something! Or have you become autistic too?". This type of 'humour' was neither appropriate, nor helpful to either the children's confidence or the group process. Her remarks to the two children who had difficulty fitting in – "why are you so shy, so quiet?" – made them feel very self-conscious and may also have played a role in their poor attendance. I struggled with this problem and tried to address it by modelling a positive approach to the children, and sometimes responding directly, e.g. telling her to give the child the time to recover herself and reassuring the child it is OK to feel sad sometimes. I wrote about it in my notes after listening to the recording of meeting 5, which had been particularly challenging in terms of behaviour, a few months later again:

She was just not being helpful, as the way she was trying to get the children to behave just made them feel worse – small, put in the spotlight. I remember worrying about her ever after; because of her position with the family, and because she was usually the one bringing the children, I did not feel I could say anything about it (personal notes, 30/06/08).

All these issues around behaviour and group dynamics made the children's group rather an exhausting part of the project. However, despite all this, there were some great moments in every meeting when the children were able to express their ideas about and views on the issues they faced related to their siblings' impairments, within the family and in society.

The children's action research process

The following section will focus on the actual research process I facilitated the children to go through. See figure 3.5.1 on the next page for a flowchart giving an overview of the research process the children followed.



Key: OBSERVE, REFLECT, PLAN, ACT: refers to stages in action research cycles;
M = meeting, FB = feedback meeting

Figure 3.5.1: The children's group's action research process

The first 'Holiday Club' (meetings one to three)

The children's meetings started before the men's and women's group meetings, in fact before the exploratory phase was completed. There were two reasons for this. The first was that the children were unable to meet during the school term, because some of them attended Quran classes after school. This made clusters of meetings in the holidays more practical. The second reason was that the Muslim festival of Eid (the celebration at the end of the Ramadan, the holy month of fasting) fell just before the half-term holiday and organising an Eid party for the families would be a very culturally appropriate way to help the children get into a collaborative group process. This did indeed work out well and the children met for three meetings, culminating in the party on the fourth day.

In meeting one the focus was on getting to know each other and starting to talk about their disabled siblings. As the children had been reluctant to express any negative feelings about living with a disabled sibling during the home interviews, I asked them to fill in a worksheet about what they liked and what they was good at (see figure 3.5.2 on the next page). Sharing their pictures was a non-threatening way of introducing their disabled siblings to each other in a positive way. Much later, Abid (9) referred back to this activity saying that it had helped him in starting to understand his brother better (feedback meeting 1).

In meeting two, we started planning for the Eid party, by making a large welcome banner together. This gave the children the opportunity to start working together as a group towards a common goal. Their concentration was taken up by their cutting, pasting and painting so much, that I did not succeed in engaging them in planning for the party. The result was very attractive though and added much atmosphere to the large empty room during the party (see figure 3.6.1 on page 294).



Figure 3.5.2: Jamil's worksheet about Imran's strengths and likes

The next day, in meeting three, the children used their ideas from the drawing activity of meeting one, to think of games that their siblings would enjoy and be able to join in with. They decided on skittles, a game and 'pass the parcel'. They also decided a quiet corner where they could draw and colour would be helpful. Jamil (12) showed good awareness of his brother's needs by cautioning that I should not bring crayons as his brother Imran was likely to eat them. In addition they thought about appropriate snacks, both in terms of their siblings' preferences, and in terms of allergies. For example Tariq was not allowed to eat chocolate as it made him very hyperactive, and the children decided not to have any chocolate at all then, so he would not feel excluded.

The other important activity in meeting three was making an Eid card for their sibling, based on his likes and strengths as identified in meeting one. They really

worked hard on their cards and giving them to their sibling during the party was an important gesture. They wrote positive personal messages inside, for example Haroon (6) wrote "Dear Sultan, you are great because you play with me. Much love from Haroon". Almost a year later, during feedback meeting two, Inam (8) remembered: "Jamil made a card with a (Nintendo DS) game on it and Imran loved it! He thought it was a real game!".

Maheen (13) secretly made the card for me instead of for her brother (for whom she made a card at home in the evening), and wrote inside: "Dear Debbie, you did a lot for us - many thanks, we will miss (you). You are so kind and polite to disabled and us. Thanks. From Maheen, Jamil, Haroon, Abid and Inam". This message expressed an early understanding of the intention and ethos of the project.

The Eid Party

All but one (who was sick) of the participants of the Kids' Club attended the party, along with four of the five disabled children. They all participated in the games well and the non-disabled children ensured that their disabled siblings were getting their turn and helped them to do well. The only disabled child who was not very happy was Imran, who appeared uncomfortable in the new, noisy environment full of strangers and hit two of the younger children. He settled down after he was given his card and present, which was a spiky, sensory ball. The children often talked about the Eid party in subsequent meetings and wrote about it on their evaluation forms, for example "we played, we organised the party and had fun" (Inam, 8). See chapter 3.6 for further details about the Eid Party.

Meeting four

In this meeting I offered two activities to help the children to start expressing negative feelings and ideas. In the first activity the children drew "Mr Men"

characters to represent first themselves, and after that their disabled sibling. They really enjoyed this and there was indeed a mixture of positive and negative pictures made. The following two pictures were made by Jamil (12) and Inam (8) about their brother Imran. Inam emphasised the fact that Imran really enjoys sensory play, like handling a spiky ball, smelling foods before eating them, and stroking and smelling Inam's hair, whilst Jamil emphasised the fact that Imran often hits others when he feels bored or anxious.

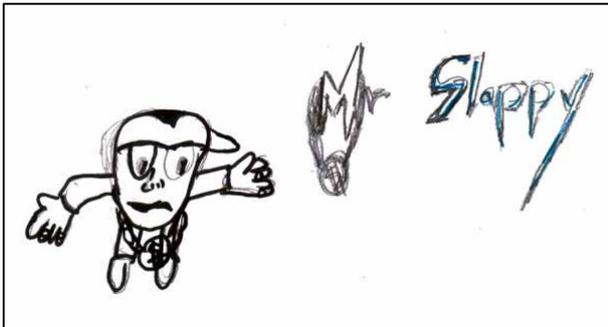


Figure 3.5.3: "Mr Slappy" by Jamil

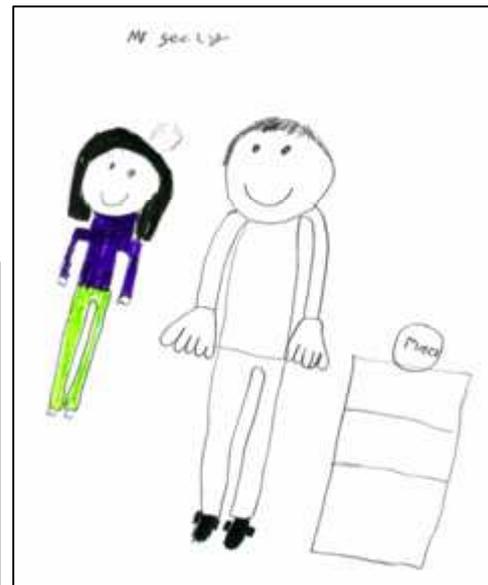


Figure 3.5.4: "Mr Feely" by Inam

The second activity was a group game in which the children took turns to roll a dice with the symbol for a different emotion on each side: happy, sad, excited, angry, proud and embarrassed (see the title page of this chapter). In the first round they told each other any story about when they had felt that way in the past, whilst in the second round it had to be a story about when their disabled sibling had made them feel that way. Inam (8) told this story when she landed on "embarrassed":

When we went to the supermarket and Imran was next to me and he just started shouting, and all the people stared at me. That was SOOO

embarrassing! So I went away from Imran. I solved the problem by taking him to the car and then he stopped shouting and was happy (meeting 4).

At the end of the meeting we also talked about the concept of research. This was an interesting conversation, because of the wide age range in the group. The older children associated research with science and technology and knew some terms like hypothesis and deduction, although they were not able to give a correct definition for these terms. They also gave examples of using research in police investigations and doing their homework. After I clarified that the purpose of research is to find out NEW information, and that in a lot of research the starting point is a research question rather than a hypothesis, the children thought of ways in which new information might be found. From this point onward it was Inam (8), one of the youngest participants, who showed the clearest understanding. She suggested that watching and other forms of observation, such as smelling and listening, could be used, and that talking about the observations would be helpful too. The following conversation followed:

Debbie: Can children do research?

Maheen (13): No, we can't do research, because if we want to research about the moon, we can't go there. We can only *use* research.

Debbie: But sometimes research can be about other things, like our own lives.

Inam (8): Children can do research, because children can watch, observe and ask questions.

Debbie: Yes, all we need to do is think of a NEW question and how to find out information about it.

Inam (8): You might write it down

Debbie: Yes! You think of a question and write it down. Then you find out information and write down everything you do and find, until you find an answer.... So Inam is right when she says that children can

do it - children can observe, ask questions, listen, write things down...

In order to consolidate this understanding I showed them a diagram that visualises the action research process as a staircase (see figure 3.5.5 below). I explained how we had already gathered ideas in the individual interviews and activities at home and in the activities and discussions in the group meetings so far. This meant that we now needed to 'choose an issue', and I suggested I would bring a flip chart with issues raised by them in the exploratory phase for the next meeting. I also suggested they could start thinking about suitable issues before the next meeting.



Figure 3.5.5: The action research process (taken from Gibbs et al, 2002, p13,

After this meeting I sent a letter to the two children who did not attend, to explain what we had done, so that they would be able to join in the process the next time. However one child never attended the meetings again and the other child did not read the letter.

Meeting five

This was by far the most difficult meeting in terms of behaviour and emotions: Jamil and Inam had an argument because Inam accidentally cleaned off Jamil's drawing on the whiteboard, which left Inam sulking for an hour; Abid had a severe toothache, which was aggravated so much by eating chocolate that it made him cry; Jamil and Maheen played their teenage game of provoking each other and name calling; Haroon was wandering around the room refusing to sit down; and the volunteer embarrassed Zohaib by commenting that he was 'very quiet'.

Nevertheless, this was a pivotal meeting because the children chose an issue to focus their research on. I started off by showing them the flip chart with issues arising from the exploratory phase, highlighting the main themes. Then I asked them to take a different colour marker each and put a cross by issues they did not find important or thought were wrong, and to add any things they felt were missing. When we talked about the problems from their disabled siblings' perspective the children mentioned the 'feelings cube game' we played in the previous meeting so I engaged them in another round of the game, this time telling stories about a time their sibling felt that way. This helped the children to express their understanding of their siblings' feelings or communication skills, for example "Embarrassed: when we shout at him, he makes this little tiny sad face and makes the sign for 'sad'" (Jamil, 12), "Excited: when visitors are coming, he gets excited and he behaves well" (Zohaib), and "Angry: when someone takes some food from him" (Abid, 9).

As the bad group dynamics persisted, I tried to make them aware of its impact on what we could achieve. Maheen's (13) response illustrates the mood of the meeting well:

Debbie: If we want to work together over the next few months, it is important that we are...

Maheen (13): a team?

Debbie: Yes, that's right, a team!

Maheen (13): Impossible!

Debbie: No, that's not impossible at all, because you're all actually very good kids, you are just trying to find out where each others buttons are located and you are starting to push them, which is fine, that's what kids do. But we need to learn that there will be times that we will work together and other times that we can play.

After this there were a few minutes of more focused discussion during which the children prioritised issues. Jamil suggested that they could explore the fact that they can't understand the different world their sibling seemed to live in :

Jamil (12): For me it's the virtual world thing

Debbie: Is that the same for you, Maheen and Abid?

Maheen (13): A little bit

Debbie: Is the issue that he is in a different world, or what that does to you? Is the problem with him or with you?

Maheen (13): With us

Debbie: What is the problem with it?

Jamil (12): Our problem is that we can't help him on the journey where he's trying to go

Debbie: But maybe he wants to be in that different world? What do you think, does he want to be there?

Jamil (12) and Maheen (13): NO! (*very definite about this!*)

Jamil (12): He's trying to get out

Debbie: That is a very good issue. You are saying he doesn't understand our social world, but would like to get into it and we could try to help him.

Although a few other issues were discussed – other people not knowing how to behave towards the disabled child; and not being able to bring friends home because they are frightened of the disabled child – they unanimously decided to focus on “understanding our siblings and the different / virtual world they live in better, so that we can make them happier”.

At the end of the project Jamil (12) made a picture (see figure 3.5.7) for the conference presentation, showing how he imagined Imran's virtual world as a computer game.



Figure 3.5.6: Jamil's picture of Imran's virtual world

Jamil (12) explained that

the picture shows Imran in his virtual world. He is in a room, which is filled with water. The arrows show that there is a way out, but the way is blocked. The only way out is the path of stepping stones in the water, but if he steps on them he will be drowned. If he solves the puzzles on the walls, then there will be a safe path. The other two people with him are 'holograms' who try to lead him in the wrong direction. Once he crosses this water, he has achieved 'level one' of his mission and there will be more levels to solve before he can escape from his virtual world.

Meeting six

Only three children attended the whole session, whilst one arrived when we were just about to finish. We read some stories written by other siblings of disabled children from a book called "Views from our Shoes" (Meyer, 1997). Maheen and Abid enjoyed this activity, but Haroon did not join in at all. After the first story (see appendix P) they asked for more, and Abid read one out loud, an important initiative for a boy who had so far been difficult to engage in activities involving speaking. Although Maheen responded well to the stories and the questions I asked about them, she gave constant negative feedback to Abid about his English language skills, about hesitating whilst answering, and about his reading. I pointed out to her what she was doing, and that this was detrimental for Abid's self-esteem. Later when she started to talk about writing a story about her disabled brother Sultan she also said she shouted at him sometimes, so I linked the two problems, suggesting she needs to think about her interaction with her brothers:

Maheen (13): I don't know what happens to him (Sultan) when he gets angry - he breaks my things - I really feel angry, but I love him actually.

Debbie: So when you're angry...

Maheen (13): I say 'you're mad, go!'

- Debbie: But when you say that how does it make him feel?
- Maheen (13): He shouts 'you're mad!' I don't know what's wrong with him...
- Debbie: So how does it make you feel when you shout at him like this?
- Maheen (13): When I'm angry I don't feel anything, but when I am in bed at night, then I start thinking about it.
- Debbie: So how do you think you should respond? Is there any point in getting angry?
- Maheen (13): No, it doesn't help, but when he spoils my things, I can't do anything, I just get very angry.

This conversation showed that Maheen was able to reflect on her own behaviour and understood why it was not constructive, yet she found it difficult to break out of the negative pattern she had built up. Interestingly, her mother Nadia told me at the end of the project that the way the children behaved and included Sultan in their play was always better when they came back from the Kids' Club, even though the effect would wear off again quite soon.

Maheen suggested that she could write her own story before the next meeting, using both the style of the story we had read in the meeting, and the conversation we had had about her relationship with Sultan. While she expressed her frustrations in their relationship, it was also evident that she had started reflecting on the positive sides of having a disabled sibling and sought to emphasise that right at the start of her story. Importantly she also showed an awareness of the fact that Sultan felt excluded at times. The story she wrote is on the next page, in figure 3.5.7 (I changed the names, but used the same font).

The second Holiday Club – meetings seven and eight

This club took place in the February half-term holidays. By this time the last family had joined the project and I was hopeful they would attend. It was disappointing for the three children who did attend and myself that the other

MY LIFE WITH MY BROTHER

My name is Maheen and I have three brothers. My elder brother Sultan is not like other people. He has learning disability, I mean he is a slow learner. I think I am lucky to have a brother like that. He has many good and many annoying things like he helps me to clean the rooms. Cleaning is one of his favourite things. He likes collecting coins and ironing his clothes and many other things.

I sometimes get very angry at him and he replies me with more anger. He sometimes messes up my things, like my books, and my clothes as well.

He doesn't like to go out and if he goes out to the shop he don't know how much money to give. But still sometimes he reacts like he is so clever and he have no disability. Whenever we never give him something he feels like he is not important for any of us.

He usually likes to play with my smallest brother Haroon. He likes to watch films and Power Rangers. He likes to eat everything that we eat, but he likes banana most of all.

*After all these problems I still **love** my dearest brother and I am happy with my brother.*

Figure 3.5.7: Maheen's story

children did not attend due to a variety of reasons, like sickness, other events to attend or, in case of the new family, no-one being able to bring them.

I had prepared two activities. The first one was the "two bug activity" (inspired by Meyer and Vadasy, 2008, p133), for which I gave them one worksheet with a dragonfly to write things that "bug them" about family life with their disabled sibling in the wings, and one with a butterfly, or "love-bug" to write things they

love about it. The children enjoyed this activity, concentrating more on colouring in than on writing their responses. Maheen's bugs (see figure 3.5.8) illustrate that the negative interactions form quite a strong pattern, to the extent that even the 'positives' on the love bug do not describe much harmony.

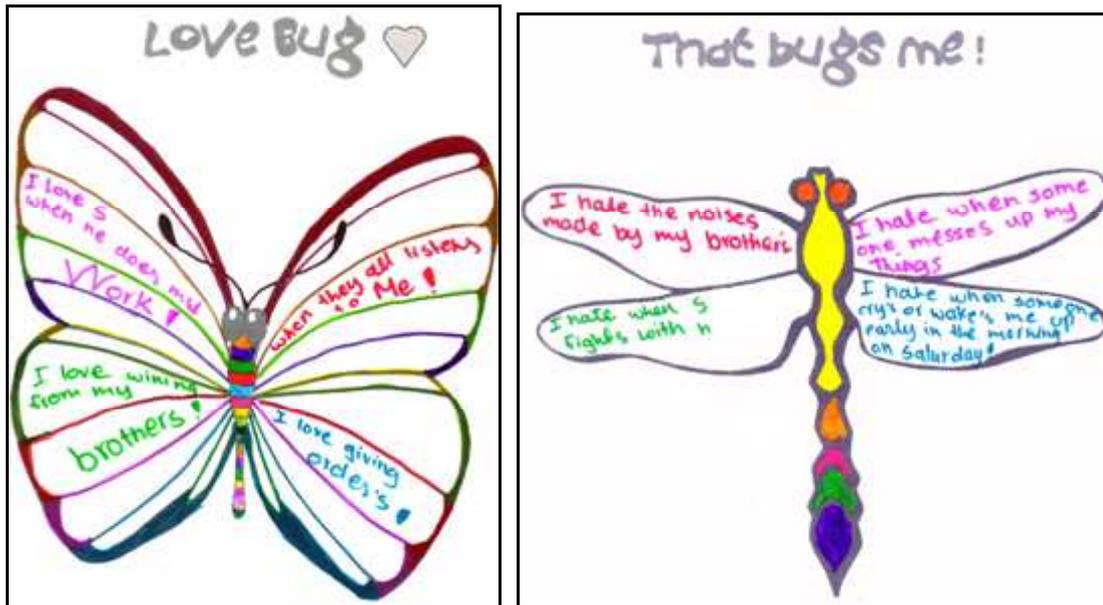


Figure 3.5.8 Maheen's 'two bug activity'

The two bug activity was a preparation for the second activity, which was to write their own story or mini-book about their life with their disabled sibling. To give some structure to this I offered a number of titles that they could use if they wanted to. The suggested titles were:

1. What I would like my friends to understand about my brother / sister.
2. "Flip-sides: three (or six) things I both do and don't like about my brother / sister"
3. "It's not fair!"
4. "Once upon a time my brother/sister....."
5. "WHY?"
6. Questions I have about my brother / sister and their disability.

Abid was not at all willing to try to write a story and spent much time folding a sheet to create a mini-book; so much time that there was no time left to write a story. Haroon (6) was happy to draw a series of pictures and told me verbally (in Urdu) what the story was about. This was one of the very few occasions that Haroon expressed some ideas about his family life.

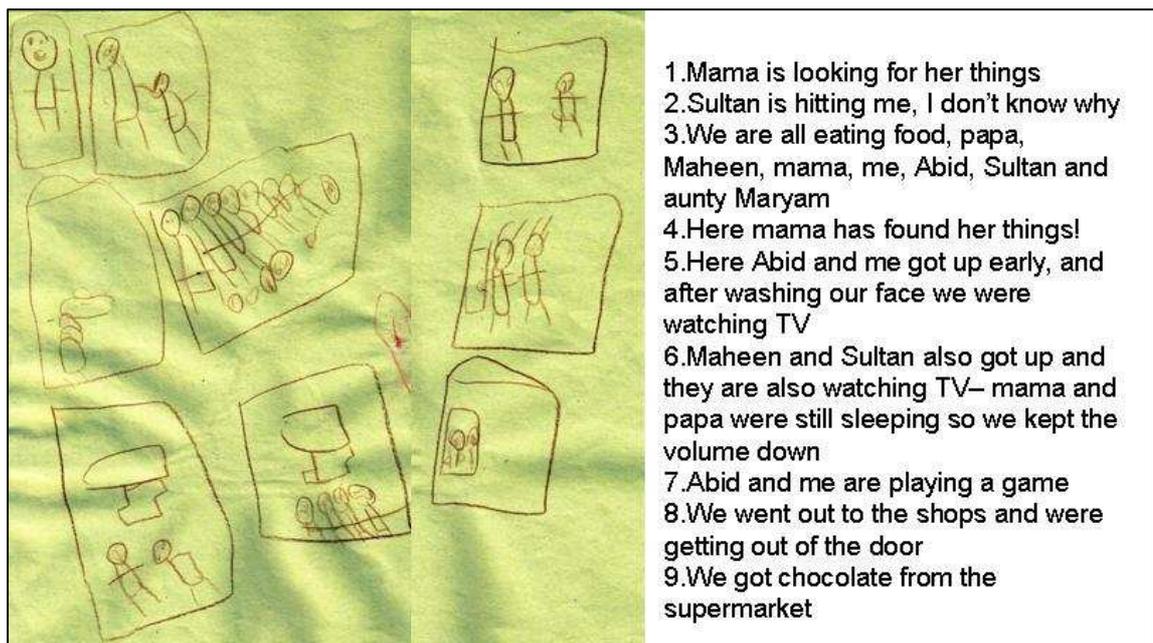


Figure 3.5.9: Haroon's picture story

Maheen had brought in the story she wrote at home and decided to decorate and expand on it. She did not edit the story, but stuck it onto a larger sheet, combining it with the "flip-sides" theme (the speech bubble at the bottom says: "lift this page up to read a story about me and my brother"):

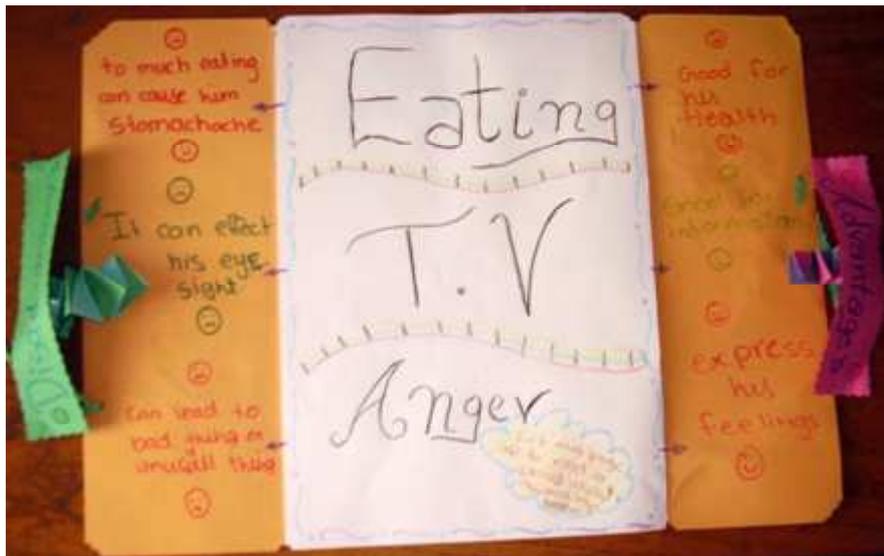
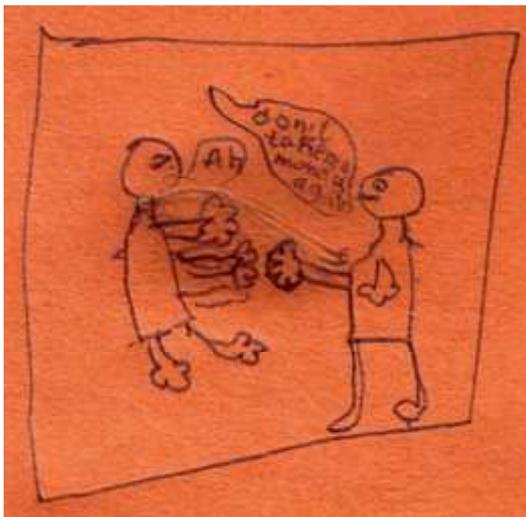


Figure 3.5.10: Maheen's book

The second day of the club again only the same three children came. This time Abid (9) came prepared and wrote a story in the mini-book he folded the day before, with the title "it's not fair", about an incident that had occurred in the morning before they left for the club:



"It's not fair"

Life with my brothers.

This morning, my brothers, sister and me were watching television. My youngest brother Haroon took the money from my eldest brother Sultan's purse and he got very angry and he start fighting with Haroon. My mother slap him and took all his money from him. The End.

Figure 3.5.11: Abid's picture story

After his reluctance to take part in the activity the day before I was pleased he completed a whole story without help.

The other children completed their stories as well, but we were all feeling disappointed nobody had turned up again. In my personal notes I wrote:

I am wondering whether this kids' group is worth all my efforts of organising / designing the activities, putting frustratingly much time and effort into contacting the Imam to book the room and into inviting the children. The only benefit I can see is that the family who do attend get an afternoon of constructive activity and some guidance on their negative interactions with each other – which of course is not a waste of time.... Not sure what to do about the group, as Jamil and Inam (*the other two children who attended regularly*) will be away in Pakistan for six weeks (*including the Easter holidays*). Maybe I could do some home-based activities in each (willing) family? Must think about it... (personal notes after meeting 8).

I did indeed decide not to pursue the children's meetings any further, as the father of the 'new' family also indicated he would not be able to bring his children, although I would be welcome to visit them at home. I visited all families at home once before the closing party. I provided each family with a pack of craft materials to use for the art competition for the closing party (see chapter 3.6). This was part of the evaluation of the project. In addition the participants filled in an evaluation form.

Evaluation and feedback

All children filled in their evaluation forms, although they did not find this easy and some of the answers remained short, superficial or even unanswered. Most children realised that my reason for doing the project was related to Pakistani families with disabled children. Aliya (13) added to this "**for Pakistani siblings to communicate and not feel alone**". The most common answer to the question what they liked best about the project was that we played games and had lots of fun. All children said that they told their parents what they did in the

group. They also answered the question about what they wanted their friends to know about their disabled sibling in some depth. All talked about wanting their friends to respect their sibling. For example Maheen (13) said

I want my friends to understand that if my brother is disabled they shouldn't laugh at him because my brother is a gift from God to me.

Aliya (13) added that she wanted them to know "that having a sibling that is disabled is quite difficult".

The feedback meetings

The questions that related to their learning about the research topic were not answered much at all. Neither did they indicate what had changed in their views or family lives as a result of the project. These questions may have been a bit too abstract for them, but as the answers were important for me, I decided to build in two further evaluation activities into the first feedback meeting in the summer holidays, which was attended by six children. The first activity consisted of 'thought bubbles' on large sheets of paper stuck on the wall on which each child could add their answers. This resulted in more detailed answers, for example:

Things I know now that I did not know before the project:

"how my behaviour should be towards my brother"

"how to deal with him and help him to stop hurting himself"

Things that changed in the way I talk and play with my sibling with special needs:

"always include him"

"I talk to him more nicely"

"I understand my brother more"

A more physical expression of their opinions was required in the second evaluation activity, in which they stood on the four coloured and numbered quarters of a large parachute in response to my question. If they disagreed they stood on the 1, if they fully agreed they stood on the 4, and if they did not feel so strongly about it they used the 2 and 3.

The following answers were interesting:

- “How much did you learn about what research is”: mixed (some 4, some 1)
- “Did we find a good answer to our research question?": yes
- “Did you work as a team?": no (1 and 2)
- “Would you come again”? yes (all 4)

In order to elicit the children's feedback on the thesis writing, I also showed them an overview of what we did (see figure 3.5.14 on the next page, which was printed in very large font and displayed on the wall), asking them to tell me what they remembered about the various activities and discussions, and what they had learned from the process.

All children felt that their understanding of their sibling had improved, and expanded on what they had written on the ‘thought bubbles’ activity with examples of how they were able to include and support their sibling more. For example, Zohaib said

I understand better why and where he wants to go; when he is upset I call over friends and we go over to the park

and Maheen (13) said

I understand what he likes and doesn't like, and why he feels left out sometimes; so I give him what he wants.

Abid (9) also felt able to contribute his views in this discussion, and observed that when his brother Sultan **"has seen a funny TV show he keeps telling the same thing over and over again"**. His sister Maheen (13) added to this that she felt that he **"just wants to be like us; whenever we are watching something, he laughs when we laugh"**. Apart from showing that they were able to understand their sibling better, this interaction was also positive because Abid had the confidence to voice his view and Maheen built on what he said, rather than giving him a negative response.

It was encouraging to see that the children remembered all the things we did and were able to say how they had learned through the process, but it was also evident that they needed the chart of "what we did" (see figure 3.5.12 on the next page) to realise how the activities all linked into each other. It made me realise that in this group all the planning and decision making about what to do in the meetings had been done by me, and that they had been more than happy to follow my lead. This was despite the fact that in both written invitations and during the group meetings, I had repeatedly encouraged them to give me ideas about what they would like to do. However, the key decision about choosing a research topic and phrasing their research question had been taken by them, and they were able to evaluate the outcome of their activities in light of that. In addition their responses during the parachute game showed that they were aware of the fact that their teamwork and behaviour during the meetings had not been ideal, showing an ability to evaluate their own performance.

In the final feedback meeting, which was attended by the most regular five attenders, I told the children that I was going to make a presentation at the Inclusion and Exclusion 2008 Conference with some of their parents and asked



Figure 3.5.12 Overview of activities of the children's group for feedback meeting 1

them to make a poster to display there. I had typed out for them what they had discussed in the previous feedback meeting to help them get started. All children added their drawings and ideas, and told me of which activities they wanted me to print out photographs to add to the poster. As we ran out of time, Maheen offered to finish the poster at home. However when she gave it back she had left off some of the other children's drawings and ideas, so I had to explain to her that it was not about perfection, but about all children having

given their ideas. As she had already thrown away the off-cuts I used clip-art and word-art to at least add the ideas back in. This was an important learning experience for Maheen about valuing all group member's efforts in the group process. Figure 3.5.13 shows the final poster.



Figure 3.5.13 The children's poster for the conference

The Inclusion and Exclusion 2008 Conference

I had not invited the children to attend the conference because it took place on a school day. However Maheen asked if she would be allowed to attend and I told her that she would need to discuss this with her parents and the head of her school first. Her father then obtained permission from the school for her to attend.

Maheen was very excited about going to the conference and prepared herself well – not only by looking at the slides beforehand to prepare what she

would say about them, but also by dressing smartly and behaving appropriately. She presented the slides that dealt with the children's group and added some of her own thoughts. She emphasised that fun had been very important for their group! Over lunch after the presentation she told me how proud she was of herself for having addressed a group of adults about things important to her, indicating that her involvement in the conference had been a good confidence boost for her.

Chapter summary

This chapter has presented how I engaged the children in the Kids' Club. Key aspects of their research process and the issues addressed are summarised here.

Not being able to include the disabled children in the group process was very disappointing, but at the same time this format gave their non-disabled siblings an opportunity to start reflecting on and expressing their views and feelings regarding family life with a disabled sibling. Whilst this limited the active involvement of the disabled children in the project, the key issue their siblings explored was their relationship with them. Through the research activities their understanding of their sibling's strengths and needs increased and it became easier for them to spend more time with him and communicate with him more effectively, so they had less frustrations. Making and organising parties for their disabled siblings further helped the children to practice this more positive interaction.

The discovery of the value of peer support was important too and seeing that the other children faced similar issues, made them realise that expressing negative feelings was both acceptable and helpful.

Through the process of working together as a group the children also learned some worthwhile general life skills, such as becoming aware of their own behaviour, gaining self confidence, expressing feelings and opinions, working

as a team and planning (evaluate information, come up with ideas, negotiate, evaluating outcome). This helped the children to become more aware of how they related to their disabled sibling, which they reported had a positive effect on their communication with them. It also helped them gain control over some of the activities, such as the organisation of the Eid Party, though the project was too short for them to gain more in control of the research process overall.

As the chapter shows it took a considerable amount of effort, creativity and persistence to achieve these positive, though limited, outcomes. The logistics involved, such as negotiating group meeting dates and times with the Imam and prompting children and parents to make sure they attended, often felt out of proportion, and would not be sustainable in the long run. This has implications for the considerations to be kept in mind when planning sibling support groups.

The other, very important, lesson to be learned from this chapter is that the active involvement of disabled children in research or support groups depends on the availability of a safe suitable venue and experienced facilitators, as much as on the commitment and conviction of the organisers that disabled children are able to make a positive and active contribution.

The next chapter describes how the different families and research groups and processes were brought together during the project.

Chapter 3.6

Making connections: bringing the families and group processes together



Sharing a meal at the closing party.

3.6: Making connections: bringing the families and group processes together

This chapter is the final chapter to describe findings from the study. It discusses why and how all participants met together during the project, as well as how the participants perceived the connection between the different group processes. The large meetings were important as making connections between the action research groups helped the family members to start reflecting on their communication with each other and the disabled child at home. However they were also very difficult to organise and indicate that time and infrastructure need to be available to make similar processes possible in family support projects.

There were three occasions on which the three action research groups were brought together. In addition representatives from each group attended a conference with me to co-facilitate a workshop. A local dissemination meeting is planned for late 2009.

Planning and rationale for the large meetings

In the research proposal I wrote that these meetings would be important for the participants to follow the progress of the research project as a whole and would particularly be an important opportunity for developing propositional knowledge (that is, knowing in conceptual terms that something is the case and expressed in statements and theories through language - see section on four forms of knowledge in chapter 2.1). I envisaged there would be around eight large meetings and that these would take place at the following stages:

- Initially for orientation workshops and sampling
- At the end of the exploratory phase, to share emerging themes from the family histories with the group as a whole, in order to discuss and verify them before embarking on action research cycles in the smaller groups
- At regular intervals during the research cycles in order to feedback to the other groups (every 6 to 8 weeks)
- At the end to evaluate participants' perceptions of the process and outcomes of the research, and to decide on methods of dissemination (in terms of what to disseminate to whom). The group might also use this meeting to decide whether and how to continue the learning process once the active research stage is over.
- Before finalisation of the thesis in order to present my interpretations and receive their feedback and approval of these.

In reality it soon became clear that bringing all families together for large meetings was difficult enough in itself, but that engaging all participants in focused activities and discussions in that setting was almost impossible. I therefore had to limit the number of large meetings, and change my expectations regarding the nature of activities that I could engage the participants in and the outcomes that might lead to. Feedback during thesis writing was obtained through separate meetings with the three groups.

Actual meetings held

This section describes the meetings I organised and what their significance for the overall research process was.

Introduction meeting

Once I had made contact with six families, I organised an introduction meeting so that the families could meet each other, with the hope that this would help them to make their decision to join the project. The meeting took place in September 2007 at the small local Mosque, where I was allocated a covered

outside area at the back of the building for the meeting. Three families attended, although one of them had to leave within a few minutes because their son Dawood, who has autism, was unable to cope with the new environment and strangers and ran back to the car. The parents of the other two families enjoyed meeting each other and I spent a short time giving the parents more information about the project and engaging them in discussion about their expectations from the project. The two disabled children who did stay were not able to engage in the activities I had planned for them and it was very difficult to divide my attention between the parents and the children. This is an extract from the notes I wrote after the meeting:

The venue had pros and cons; there was space to play, but there were many dangers. Imran kept going into a storage space behind a curtain and into the Wuzu (ritual washing) area to play with the water. It was also impossible to give any structure as there were no walls to give a natural boundary. Tariq and his brother were not interested in the drawing activity and Imran was unable to decide to join in. There was much noise and chaos!

Although this meeting was difficult and apparently unsuccessful, the three families that did attend all signed their consent forms soon after. In addition my reflections on the meeting helped me to decide how to move ahead. Again, I quote from my notes of the meeting:

Among the six disabled children I know so far only one has some potential for enjoying group work. I really think it will be counterproductive to 'will' the children with severe intellectual impairment or autism to be included in all children's activities. Apart from their frustration and distress, there are safety concerns too and the parents would be stressed and worried. I will need to think of ways a sibling group can do action research that will benefit their disabled sibling as well as themselves.

It was clear that it would not be possible to use any meetings for whole families together for in-depth feedback and reflection between the groups. Organising meetings for the men's and women's groups together was impossible because they could not leave their children, and as I was conducting the study alone in borrowed venues, there were no people who could act as facilitators or infrastructure available to have the adults and children meeting in separate rooms at the same time.

The Eid Party

The Kids' Club started in the October half-term school holidays (see chapter 3.5 for details). Organising an Eid Party for their families provided a good, culturally appropriate, focus for the club and gave the children an opportunity to reflect on their disabled siblings' strengths and needs, and to work together in planning and decision-making in order to make the party inclusive and fun for all.

As the men's and women's groups had not started their meetings by this time, the parents did not know each other yet, apart from two families who had met at the introduction meeting. The mothers and children of four of the five current participant families attended the party, but only one father came. One father was at work, whilst the remaining two (who had not attended the introduction meeting) decided to return home when the child they had sent ahead told them they did not see any other men inside (Mahboob had just taken his son Imran to the toilet when the child looked into the room). This was disappointing, but because we were in a room upstairs, I did not know about their decision until it was too late to try and convince them that this party was for them too. It did cause me to put much effort into inviting the men for their first group meeting, which indeed was attended by all fathers.

I set up the room with the help of Jamil and Inam who had arrived first. We put up the welcome banner the children had made (figure 3.6.1), a low table with paper and pens, and some group games to be played later. I then started to



Figure 3.6.1: Welcome banner for the Eid party

phone and send text messages to the other families, who eventually arrived, but we only had around one hour with everyone present.

The children enjoyed playing the games and winning little prizes, but still it was difficult to keep them together and prevent them from trying to play football with a beach ball in between their parents, peers, snacks, etc. Tariq was very hyperactive, causing quite a lot of noise, whilst Imran had difficulty dealing with all the strangers and the lack of structure. He hit some of the younger children, one of whom cried, which upset Imran's parents as well as Imran himself. The fact that Imran and his family had arrived on time, meant that they had spent a long time waiting and Imran had run out of steam by this stage. This experience did confirm that I had made the right decision to run the Kid's Club for non-disabled siblings only.

We managed a short time with the children in a circle to play pass-the-parcel and for the members of the Kids' Club to present the Eid cards they had made for their disabled sibling. I also presented each child with a gift at this time.

The mothers enjoyed meeting each other and I told them that their own meetings would be starting soon. The party gave the parents an opportunity to see what their children had done at the Kid's Club and how I interacted with them.

The Closing Party

Another large meeting was held at the end of the action research phase. At this time the group members within each group knew each other well and had a good understanding of the purpose of the project.

The women agreed in their last group meeting who would bring which dish, so that we could eat a meal together. As the children had stopped meeting a few months before, I asked them on home visits to give their ideas for activities, and they indicated they would like to do the same types of activities they had done in the Eid Party.

Five of the six families were represented at the party. Based on the outcomes of the previous meetings I carefully planned activities that would provide opportunities for exchanging experiences and ideas without requiring anyone to sit down and listen quietly for any length of time. This process was important for the participants as it helped them to connect their own experiences more directly with their family members' experiences in their respective groups. The process was also important for me as it provided evaluation data that helped me to gain an insight into how the families and individuals within them had contributed to and benefited from the project.

Evaluation through art

A few weeks before the party I had asked all participants to express some of the things they had done or learned during the project in a picture or poem.

For the children this was done in the shape of a competition, to be judged by all who attended the party. All pictures were displayed on the walls, with a feedback sheet underneath. Every participant was given three stickers, to put in the designated square on the feedback sheet for the three pictures they thought were best (excluding their own). In addition they could write any encouraging comments on as many feedback sheets as they liked.

Unfortunately the children of one family had forgotten to make their pictures,

despite the fact that I had explained the activity face-to-face during a home visit and had given them written instructions and a pack of paper and art materials for this purpose. They quickly sat down and made a picture there and then. The other difficulty was that the two older children who had been provoking each other so much in the children's meetings wrote some negative comments. In addition one child suddenly seemed to have gained a lot of stickers on his feedback sheet and I could not be sure whether he had cheated.

However, this activity worked very well overall. The first advantage was that all children were able to participate and the disabled children were keen to show what they could do. Secondly with fifteen works of art displayed on the walls, the participants needed to walk around and mingle in order to look at each picture and write down their comments. This led to good interaction between adults and children, and women and men. It also encouraged parents to take their children's artwork seriously and to model to each other how to give constructive feedback. Figure 3.6.2 gives an impression of the judging process.



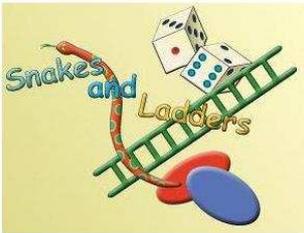
Figure 3.6.2: The art competition

All four mothers who attended the party had made pictures as well and we sat down together for fifteen minutes so they could explain to each other what they had made (see chapter 3.3 for details). This short but intensive time of

sharing was inspiring and further cemented the relationship they had built up over the course of the project.

In order to create the time and space for the women to share their artwork, I asked the men to help their children to complete the activity they were working on, which involved making a giant 'snakes and ladders' game. I had pre-prepared a grid measuring about one meter square and gave them number-stickers and cut-out snakes and ladders to position and fix on to the board. I explained the aim of the game was to raise awareness of disability issues and gave written instructions to refer to as well (see figure 3.6.3).

This activity worked well as there was enough to do for all children to participate and work together. The reasons for climbing up ladders or sliding down snakes remained rather vague, e.g. "you have made someone sad" and "you have been very kind: go up!". Playing the game once it was finished was very satisfying for the children (see figure 3.6.4).



Make your own Snakes and Ladders Game!

The aim of the game will be to make people aware of the needs of disabled children / people.

In order to climb **up** a ladder, you need to do something good / positive – write this in the square at the bottom of a ladder

In order to slide **down** a snake you need to do something bad / negative – write this in the square by the head of a snake.

You don't have much time, so make sure everyone helps – you can divide the tasks: thinking of 'good' and bad things, sticking on the snakes, ladders and numbers, decorating, writing a title, etc. etc....

Once the game is finished we'll play it together, if there is time!!



Figure 3.6.3: Instructions for making the 'snakes and ladders' game



Figure 3.6.4: Playing the 'snakes and ladders' game

None of the men had written a poem before the meeting, as I had requested them to do, so they did not sit together to share any creative work.

The final activity was to have a meal together, sharing the food that each family had brought. We all sat on the floor around a 'dastarkhan' (a large sheet with all the food set out on it) in good Pakistani style.

The Inclusion and Exclusion: 2008 Conference

An unexpected extra opportunity to involve all groups in a common activity, arose when I received a call for papers from the Race Equality Foundation for a conference which aimed to explore research on racism and ethnicity and the messages for policy and practice in key areas of public services. The organisers were particularly interested in papers that would be presented jointly by participants researchers. As this project matched the aims of the conference so well, I forwarded the call for papers to the research participants by email and got an initial response from two of the families. Gulzar proceeded

to write the proposal, which I submitted with minor changes and additions (see appendix N). Not only was the proposal accepted, but we also won the Brunel University Vice Chancellor's Travel Prize to support this venture, which was a great encouragement to the participants. The final feedback meetings of each group were used to generate ideas for messages to go into the presentation. In addition two participants made drawings especially for the presentation (Noor and Jamil, 12). Sarwar made the first draft of the PowerPoint presentation, which was sent to all families by email. A number of participants then added their ideas and comments. See appendix L for the PowerPoint presentation.

Four participants co-presented the conference workshop with me: two men (Gulzar and Sarwar), one woman (Maryam) and one child (Maheen, 13). Maryam opened the presentation by introducing the group and herself, and inviting the audience to reflect on the picture Noor had made (see picture on the cover of the thesis) and the commentary she had given (see slide 2 and 3 of the presentation in appendix L). This artistic and personal impression of the experiences of a Pakistani mother of a disabled child was deliberately chosen to set the scene for the remainder of presentation which reported on the project in a more analytical way. Maryam starting off the presentation was also a conscious choice, as it sent some important messages to the audience, which were that the most important people in this presentation were the participants rather than me, that the mother among the presenters was most entitled to present her fellow-mother's artwork, and that Pakistani women are not necessarily reluctant to speak out in public (as that is quite a common perception).

I then gave a very brief overview of the rationale of the study and the chosen research methodology, after which each co-presenter talked about their own action research groups and recommendations for service users, service providers and policy makers.

The audience gave much encouraging feedback and also came up with good critical questions about the problem of being seen as 'the awkward parent' if you assert your rights; about further details of what the Quran teaches about Islam; about how the plans for action would be followed up; and about how Pakistani families' experiences compare to families from other cultural backgrounds. The overall feedback was very positive, for example people stated they liked "the multiple perspectives – the warmth and the collaboration. The honesty" and "learning about what action research means". As an overall comment others said it was "really helpful, informative and powerful" and "fantastic work!". What people liked least was that there was not enough time for discussion and that "not much was mentioned about outcomes". Although the presentation had discussed outcomes at the family and group level, the latter was taken to heart by the participants, as it confirmed the importance of them following up their plans for action, which is still pending.

The co-presenters were happy with how the presentation went and greatly encouraged by the positive feedback received. Maheen (13) said "**I'm just so proud of myself**" for being able and brave enough to present her views to a group of adults.

Another motivating factor was that someone in the audience approached us afterwards and invited the participants to be part of a research project to study perspectives of disabled people from different cultural backgrounds. This would initially involve a one-off focus group session. Contact details were exchanged with Maryam, rather than me, which was another indication that the participants had displayed their competence well during the presentation. Maryam independently conducted two focus groups for this project in the weeks following the conference.

Plans for a local dissemination meeting

The participants were keen throughout the project that their ideas would be translated into messages for service providers in the local statutory and voluntary sectors and a dissemination event is planned for late 2009. A number of service providers have already inquired when and how the findings of the study would be made available to them, which indicates a potential for a good level of interest for this meeting. Preparing for and co-facilitating the conference presentation has been an excellent preparation for this event that is still to take place.

Reflections on the usefulness of the large meetings

In conclusion the energy and flexibility required of me to ensure large meetings were effective, were well worth the effort. The outcomes of the meetings noticeably increased as the project progressed. This appears to be mainly due to two things. Firstly the participants knew each other better and were more motivated to meet up and exchange ideas. Secondly I became better at designing the activities in a way that they became opportunities to exchange ideas that did not require intensive, focused discussions. Despite the fact that the groups themselves had difficulty continuing their research and learning processes without my facilitation, there was a considerable level of enthusiasm about making sure that their ideas were translated into messages for service providers at local and national levels, and a number of participants expressed their regret at the fact that no more meetings were planned. It appears that the relationships between participants and their commitment to the project continued to grow in the time between the Closing Party (formally the last meeting of the action research stage of the project) and the second feedback meetings six months later. This has implications for future projects, suggesting that continuous, or at least longer running, projects are likely to be more effective for Pakistani families, as the active participation – and with that the likelihood of implementing their plans - can be expected to increase once participants know each other better and gain confidence in understanding and contributing to the aims of a project.

Participants' views on how the group processes influenced each other

Large meetings were not the only way in which the participants of the three action research group communicated, or in which their research processes influenced each other. Many participants talked about the way they saw that their own research process influenced the way they did or said things at home, but also that they noticed effects of their other family members' involvement in their research groups.

It is important to acknowledge that the positive relationship that was established between the participants and me may have made them more inclined to give only positive feedback. However, much of the feedback was given spontaneously and/or was very specific, going well beyond saying whether or not they thought certain aspects were good or bad, which they could have restricted themselves to if they wanted to avoid hurting my feelings. Whilst the positive feedback is therefore likely to be trustworthy, it is difficult to know why hardly any negative feedback was expressed.

Telling each other about their groups

All children and most adults confirmed on their evaluation form that they told their family members what they had done at their meetings. The mothers of the two families whose children attended the Kid's Club most consistently also stated that their children had started to spend more time with and to improve their behaviour towards their disabled sibling since attending the Kid's Club (see Nadia's quote in chapter 3.5, p270). Sadaf realised that she had "**learned that children need to meet others and that I should make time for that**", indicating an increased awareness of the needs of her non-disabled children.

Working on improving communication in the family

Many the adults also reported in their evaluation forms that they were consciously working on improving communication with their family members and / or that they noticed their spouse was doing so. For example Haider wrote that he tried "to use different methods to see if harmony can be reached" and that he tried to "listen more"; Gulzar wrote that he was "trying to influence all family to be more attentive towards disability"; Sadaf and Mahboob both said they had learned that "if family members talk to each other more, it has a positive effect" (Urdu); and Maryam felt that her husband had been "able to listen to my concerns and worries with a different perspective". These comments not only imply that individuals can implement new ideas in their own family lives themselves, but also that the fact that their family members were engaged in a similar group process made it easier for them to respond.

The researcher linking group processes

A very obvious indication that the women saw the value of me working with the separate groups came to light when they directly asked me to address issues around communication and conflict resolution in the men's group. Whilst it was not appropriate to engage in this type of direct mediation, the fact that I was aware of the women's perspective on this problem, caused me to probe further when one of the men mentioned the problem in the context of one of the activities I offered them. This led to the men opening up about this problem and giving each other suggestions about how they could work towards resolving it. This way of addressing the issue was effective as it was not threatening, and as it did not require me to take on the role of an advisor, which would have gone beyond the scope of the project.

The focus on 'disabled families'

Yet another indication that participants were thinking beyond their own groups and individual learning processes were comments that emphasised the

importance of looking at whole families. For example Noor summed up the purpose of the project as follows: **"to bring together families of Pakistani background to share and understand each other"**. Nadia emphasised the importance of looking at whole families even more: **"this project was about disabled families"**.

The importance of valuing each individual

A final observation focuses on an almost opposite aspect of the research process. Maryam spoke about the fact that I had

made everyone feel that they were the most important person. Remember your first interview? That was best; the first time in three years that someone touched those 'untouchable' topics. They (service providers) asked about the child, but you are interested in what happened apart from the child (meeting 7).

This is an important observation, as it indicates that participants were convinced that not only was I interested in their stories, but that I consequently valued their contribution to the research process. I invested in these individual relationships by making sure I kept in touch particularly with those who had missed group meetings. This seemed to be an important motivator for sticking with the project until the end: none of the families dropped out of the project once the action research phase had started.

Visualising the connections

To sum up and illustrate these ideas about the way the different aspects of the research process affected each other and led to a positive outcome, please refer to Maryam's drawing (figure 3.6.5), which she made for the evaluation process. A few excerpts from her explanation about the picture follow:

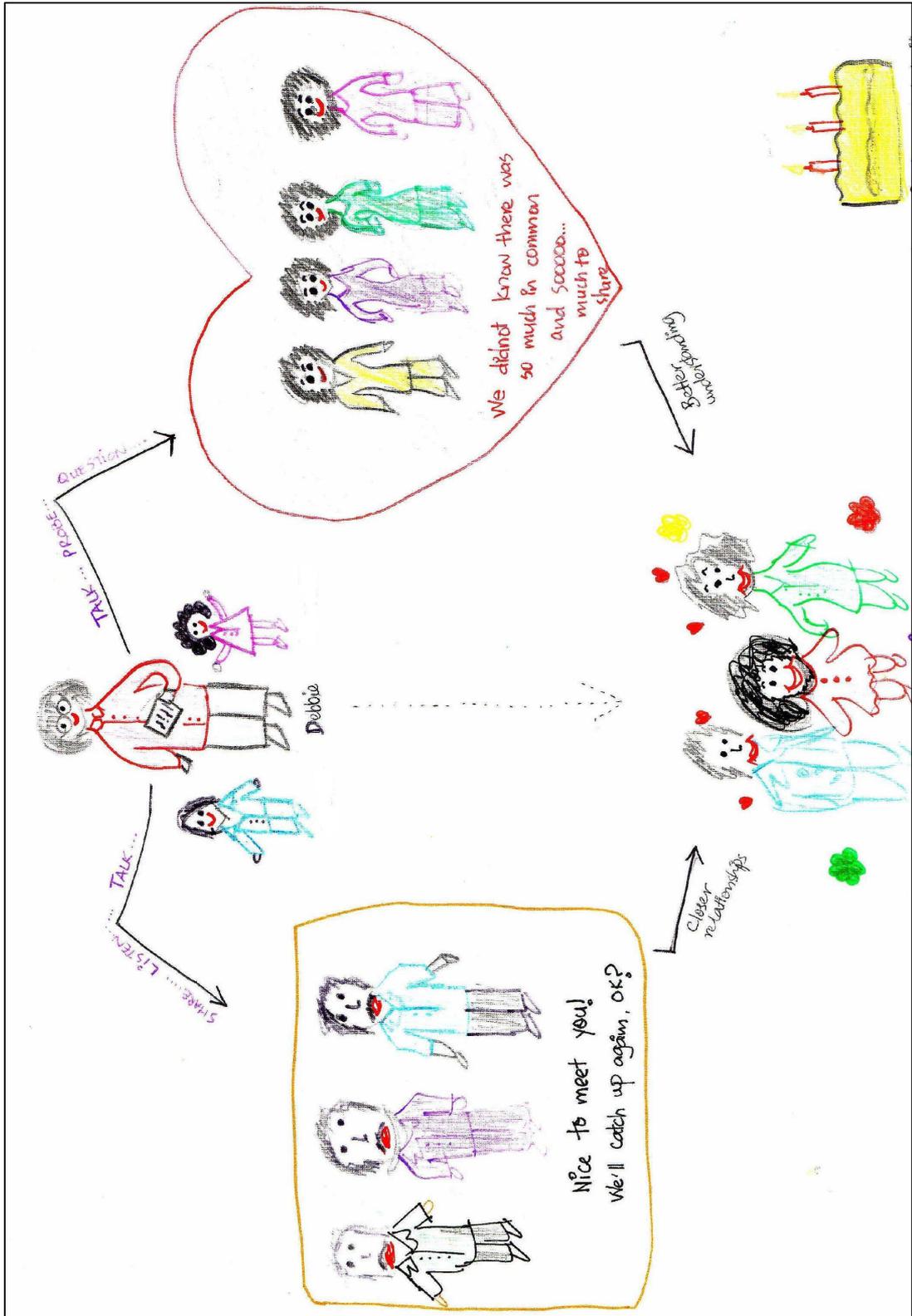


Figure 3.6.5: Maryam's perception of the research process

the pivot point for all of us was you - you were the one who talked to us, listened to us, who probed us, made us share things... we discovered we had so much to share and so much in common. It has made us bond with each other in a unique and special way, which is very unique to us as families with disabled children.

About the arrows she said that "they indicate your indirect and direct influence on the family". About the men's group she said:

you talked to the men, you made them think and talk about things. That is a very difficult thing to do actually, for men. They responded well... This has led to a happier and more closely-knit family.

Chapter summary

This chapter has shown that the energy and practical problems involved in organising the home visits, the three action research groups, and large meetings, were well worth the effort.

Connections between the different groups and family members were made in different ways. Firstly, as all family members were focusing on related issues, and started considering how their life with their disabled child / sibling could be improved, small positive changes within the home could start occurring.

Secondly, connections between the groups were at times also made by me as the researcher, when outcomes of one group influenced the way I responded to participants' input in other groups. Knowing this was helpful for participants when they tried to implement ideas gained during group meetings at home.

Thirdly, participants expressed a clear perception that this project was about whole families. Seeing their co-participants with their whole families in the joint

meetings gave them a clearer impression of the issues they faced. Seeing each other's families in a positive and inclusive atmosphere also helped to affirm the positive approach they were seeking to take to bringing up their disabled child.

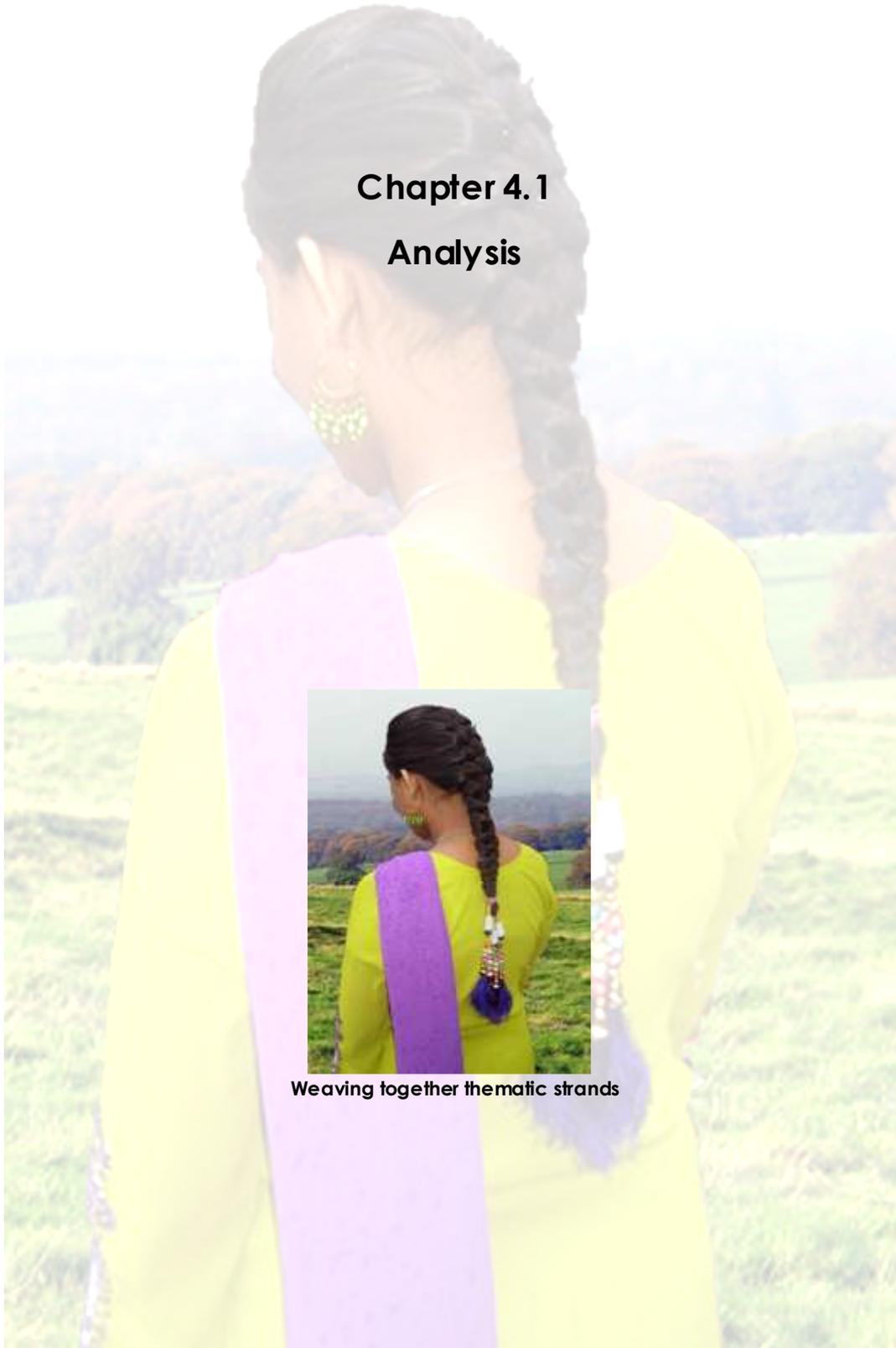
A final aspect of making connections was the importance of each individual participant, which the participants indicated was a significant motivator for participation in their groups and the joint meetings and sticking with the project until the end.

This chapter concludes Part 3 of the thesis, which has presented the findings of the study along with some initial reflections on their meaning and implications. The next and final part of the thesis provides further analysis and discussion about key issues and themes arising from the findings, leading to implications and recommendations for policy, practice and further research into the support needs of Pakistani and/or Muslim families with disabled children.

**PART 4: REFLECTING ON LEARNING AND IMPLICATIONS
FOR FUTURE RESEARCH, POLICY AND PRACTICE**

Chapter 4.1

Analysis



Weaving together thematic strands

4.1: Analysis: emerging threads and patterns

This is the first of the two chapters that make up the final part of this thesis, which analyses and discusses the meanings and implications of this research study both for the participants involved and for further research, policy and practice.

In this chapter the findings from the various processes described in Part 3 will be brought together so that emerging threads and patterns can be recognised and analysed.

In the first part of this chapter the original research questions will be revisited in light of how the project evolved, and then answered. In the second part cross-cutting themes, emanating from the answers and the processes which led to them, will be discussed. The third part considers to what extent the study met the quality criteria for participatory action research and emancipatory disability research, which were described in chapter 2.1. The final part presents the conclusions from the study.

Revisiting the research questions

The research questions were defined in chapter 2.2, with the proviso that they might need to be fine-tuned in view of the flexible, emergent nature of participatory action research.

The main research question remains the same:

How can Pakistani families with disabled children be facilitated to identify their support needs and explore how they could be met better within the family, in their communities and through the service system?

In order to analyse the findings described in the preceding six chapters effectively, the sequence of and relative emphasis on the subsidiary research questions have been adjusted:

1. *What are the perceptions of and attitudes towards disability, in the Pakistani community and the extended family?*
2. *What are the perceptions of and attitudes towards disability in the participant families ?*
3. *How are roles and responsibilities divided in the family?*
4. *What other issues that impact on the families' support needs were brought up by the participants?*
5. *What implications do the answers to the first four questions have for occupational justice and occupational balance experienced by the parents, siblings, and the disabled children themselves?*
6. *How can awareness of the above help the participants to evaluate their support needs and systems in order to identify areas that require change?*
7. *How can families / participants be facilitated to plan and implement change in these areas?*
8. *What has been the impact of the topics the participants discussed, reflected and acted on, on their well-being and occupational balance?*
9. *What has been the impact of engaging in the research process on the participants' well-being and occupational balance?*

Questions 4 and 9 add dimensions that were not explicit in the original phrasing of the research questions. However, there is no substantial overall change in the intention and focus of the study.

Answering the research questions

This section seeks to answer each of these questions by pulling together and summarising what the findings from the different research processes described

in Part 3 have shown. It therefore forms the starting point for the analysis which will be presented in later sections. The title of each sub-section reflects the subsidiary research question being answered in it, indicated in brackets as SRQ1, SRQ2, etcetera.

Perceptions and attitudes in the community and the extended family (SRQ 1)

The participant families described most of the initial reactions to their child's impairments they encountered as negative. They were blamed for the child's impairment, warned that their child would be a burden, or told to hide the deformities from visitors. As the child grew up people made fun of the child or used derogatory terms. If pity or sympathy was expressed, it was not usually followed by an offer of support. Superstition led people to think that the child's impairment might have a negative effect on other children's health. The negative perceptions of disability were often expressed in religious terms, for example that God must be punishing the parents for some sin committed in the past.

Although some of the participants thought that only a minority of Pakistani people held such negative views, in fact all participants talked of many examples of negative attitudes encountered, and of very few of positive attitudes. This led to isolation, as the families did not feel their child was welcome at community functions or at the Mosque, especially if the child had intellectual impairments or behavioural problems. This isolation also limited their chances of meeting other Pakistani families with disabled children.

The negative perceptions and attitudes existed in the extended families as much as in the community. In some cases (two of the six participant families) these attitudes did not change for the better at all, so that their contact with or support from them was minimal. In the other cases the attitudes improved as they got to know and started to accept the disabled child over the years, leading to more contact and variable levels of support.

Perceptions and attitudes in the participant families (SRQ2)

The participants acknowledged that their initial response to the news that their child had impairments was influenced by the pervasive negative views in their community. Some also said they had never given any thought to disability before the birth of their disabled child. Their initial reactions were of shock, grief, pain and denial. Where the diagnosis was unclear or late, this was difficult too as it created uncertainty about the prognosis and made it difficult to explain to others.

Faith

However in all families the parents' views started to change as they got to know and love their child. This was true for all parents, apart from one of the participants' ex-husband, who was not part of the project. Interestingly the positive perceptions and attitudes they developed – like the negative ones in the community – were also mainly expressed in religious terms. The parents now saw their child as a blessing rather than a curse. The idea that God was testing them was now viewed in a positive light, as this gave an opportunity for their faith and character to grow. God's will was seen to be in balance with their own responsibility to do whatever they could to improve their child's life. Faith therefore had a very positive influence on the families' ability to accept their disabled child. Most parents in fact emphasised that their disabled child was extra precious to them due to their constant worry and intensive care for them. At the same time, many participants also said that they believed that God could heal the child and that they prayed that He would do that.

Causes of impairments

Most participants believed that there were medical as well as spiritual reasons for their child's impairments, but in varying proportions. Even if they believed the causes were medical, there was a belief that those causes were still subject to God's will and that He expected them to respond to it in a positive way so they could grow spiritually, or in other words become 'a better person'. Only

the parents of one child believed the reason was not medical, but due to the use of black magic by a relative. Consanguinity was also mentioned by several participants, but only one family had been told that this was a likely cause of their child's impairments.

Siblings' perceptions

The non-disabled children were aware that their sibling was somehow 'different'. In the families of the two children with autism they were able to explain that they lived in their own, virtual world and had difficulty communicating. However, the brothers and sisters of children with only intellectual impairment had more difficulty explaining what was different, and pointed out that they had more things in common than were different. The children did not know why their sibling had impairments, but did want to understand them and their needs better.

Roles and responsibilities in the family (SRQ3)

In five of the families the mothers provided most of the practical personal care for the disabled child, whilst in the sixth family the father shared this aspect of care more or less equally. The other fathers also took on active roles to varying degrees. As all participating fathers were employed or studying full-time, both parents carried a significant burden of care, and indicated that there was little time for leisure and relaxation.

In most of the families the non-disabled children supported their parents by helping, minding and/or playing with their disabled sibling. In two families this included personal care tasks such as feeding or changing wet incontinence pads. Playing with their sibling was important as it made them feel included and reduced the apparent boredom which often led to behavioural problems. The children willingly supported their parents in caring for the disabled child, but acknowledged that this led to limitations in their leisure activities.

The families made use of some respite care during the day, but not overnight, even if the child had poor sleeping patterns which led to exhaustion of their parents. This was because they worried about the child's wellbeing or even because they feared the services might take their child from them once they consented to overnight care.

The extra care and attention given to the disabled child meant there was little time available for leisure. The parents also worried about them constantly, even during sleep. In addition, not feeling welcome at weddings and other functions restricted them in participating in this important Pakistani pastime.

All mothers indicated that they needed something completely different to do outside the home environment, such as work or study, to keep in touch with the outside world, to be distracted from their constant worry and care, and to work towards personal goals. Not all mothers managed this, and for one it was necessary to work full-time in a menial job for financial reasons, which added to her pressures, rather than relieving them.

None of the mothers indicated that they had difficulty fulfilling their role as main carers, and those who were married were generally satisfied with the amount of *practical* support their husbands gave. However most mothers talked about a lack of *emotional* support from and limited meaningful communication with their husbands. This made them feel alone with their problems, but in view of cultural expectations they found this difficult to address. The men were aware of these problems and able to talk about them to each other in a group session. Some reported in their evaluation forms they were trying to improve communication at home.

Additional issues affecting the families' support needs (SRQ4)

There were three important issues the participants brought up, namely professional support, financial issues and future care.

The availability and quality of professional support

All families valued their child's special school highly, as it facilitated the child's development, as it provided daily respite for the mother, and as most therapy input was conveniently organised through school. Some families felt actively supported by the school with regards behavioural management and knowing how to help their child learn at home, but in other families there was very little communication with school. Two of the disabled children were out of school for an extended period of time due to delays or problems in being allocated a place, causing much stress and frustration through fighting the system.

The families were not as positive about health and social care provision. Particularly difficulties gaining timely access, and unhelpful attitudes of professionals were common problems. At the same time they felt that the treatment provided was generally of good quality. In addition families that had immigrated from Pakistan in recent years were aware that provisions for disabled children are much poorer there, so they were not inclined to complain.

Accessing and negotiating with the various services was made very difficult where parents did not know how the system worked and/or where they had very limited English.

Financial issues

The first problem in this respect is related to the poor access to services, as most families had not been told by social workers or other professionals what benefits they were entitled to and had often found out by chance. In addition they talked of the cost involved in taking the child for numerous medical and other appointments; even though healthcare is free, travelling there and taking time off work can be costly. Finally some fathers had chosen to adjust their working hours in order to be able to support their disabled child and their wife, which limited their take-home pay and their prospects for promotion.

Future care

Whilst the families managed the current care needs for their disabled child, they worried about the future. Parents did not want to assume that their other children would look after their disabled sibling after their own death, even though in some of the families they did express their commitment to do so. With their current worries about using overnight respite care, parents found it difficult to accept that their child might need residential care in adulthood.

Implications for occupational justice and occupational balance (SRQ5)

Occupational science provides a helpful perspective on the families' situations and I will sum this up using Wilcock's (2006) terms of doing, being, becoming and belonging (see chapter 1.3).

Belonging

The theme of belonging was the most fundamentally important, both within the family and in the community. The mothers spoke of not having the opportunity to belong, to be valued for who they were, because they had to meet their family's expectation of running the house and caring for the children, so they were always 'doing' for others.

The disabled child, and consequently the family as a whole, was not accepted - or allowed to belong - in the community, leading to isolation and limited participation in community events. This made the families aware of how important it was for the child to be fully accepted and loved - to be allowed to belong - within the family.

Finally the non-disabled children also had a strong sense of belonging in their families, which made them loyal and willing to support their parents in the care for their disabled sibling, even if it restricted their own choices of activities.

Doing

Both mothers and fathers had an excess of things they had to do in order to sustain and look after the family, including the disabled child. They had very little time for leisure activities or other activities of their choice, or even to attend prayers at the Mosque. Similarly the non-disabled children had limited options for leisure and club activities, partly because they were occupied in caring for their sibling, and partly because their parents had no time or possibility to take them there. Where all these family members had too many things they had to do, many of the disabled children did not have enough to do and often appeared bored, because either their family did not know how best to entertain them, or no suitable toys were available, or the child's behaviour problems made it difficult to take them out to public places.

Being

The most pertinent aspect of the participants' sense of being was the importance of their faith, which provided a strong sense of identity, and a conceptual framework that helped them to accept and value their disabled child. Especially the women talked of the strength they drew from their faith to deal with difficulties at home, as well as to respond to negative attitudes in the community. Being asked to reflect on their personal experience of bringing up a disabled child was helpful as it affirmed this sense of being and identity.

Becoming

Both parents and non-disabled siblings indicated that having a disabled family member had had a positive impact on their personal development, making them more patient and understanding of people who are 'different', and causing them to re-evaluate priorities in life. However, some of the mothers felt limited in pursuing study or work occupations, which they expected would help them develop themselves. In addition parents felt that for their children with intellectual impairments and/or communication difficulties it was difficult to

develop a sense of becoming, even in terms of setting themselves short-term goals.

Occupational injustice

The challenges faced in belonging, doing, being and becoming constitute a situation of considerable occupational injustice, particularly its aspect of occupational imbalance. The families' main concern was to make sure their disabled child was well-cared for, involving all other family members in practical care constantly. The limited emotional and practical support from the extended family made it harder to carry this responsibility. In addition difficulties in accessing benefits and respite care limited their ability to engage in other meaningful occupations. Another external factor was the exclusionary attitudes encountered in the Pakistani community, which limited participation in culturally and religiously valued community events. Within the family the cultural expectation from the mother was that she should be content with sacrificing everything for her children, so she tended to take on a disproportionate share of the child's care. As the mothers felt they had no choice in this, they felt undervalued, which undermined their sense of belonging. All these reasons for feeling overburdened with caring responsibilities illustrate how occupational injustices tend to have external causes, in the form of "socially structured, socially formed conditions that give rise to stressful occupational experiences" (Townsend and Wilcock, 2004, p251).

How the awareness of the above helped the participants to evaluate their support needs and systems in order to identify areas that require change (SRQ6)

The interviews in the exploratory phase had given each individual participant the opportunity to reflect on the issues they faced by having a disabled child in the family. Once the participants had joined their respective groups the flipcharts summarising the issues they had raised made them realise they had much in common. More details and anecdotes were shared to increase their

understanding of each issue. Because of the nature of action research, they needed to prioritise one issue, which they could explore further and take action about. Each group came to their decisions in different ways.

The women's group: mutual support

The first two meetings made the women realise the value of sharing their joys and problems with others facing the same situation. Finding recognition for the uniqueness of their situation, they experienced membership of the group as a home-coming, giving a strong sense of belonging. This led to the decision to explore how they themselves could organise a support group to continue beyond the project, and to include other Pakistani mothers of disabled children.

The men's group: disability and Islam

The men noted the contrast between the community's mainly negative perceptions and their own mainly positive perceptions. They decided to consult with Islamic scholars and Imams to establish which perceptions were in line with what the Islamic scriptures really teach, with the intention to raise awareness of this in the community.

The children's group: understanding his virtual world

Because the children had been rather reticent about negative aspects of having a disabled sibling during the exploratory phase, the first holiday club (three meetings) focused on their siblings' strengths and likes, and on organising a party that would include them fully. Therefore they did not look at the flipchart with common issues until the fifth meeting, after I had engaged them in activities in which they could express some of their negative feelings and views in the fourth meeting. They chose two issues – understanding their disabled sibling better, and knowing how to deal with other people/children who did not know how to react to their disabled sibling. The children were able

to prioritise between these issues, reasoning that they would first need to increase their own understanding, before they could educate others about disability issues.

How the participants were facilitated to plan and implement change (SRQ7)

There are two aspects to this question. The first relates to the participants' own ability to engage in the action research process, and the second relates to the researcher's ability to facilitate that process. Both these aspects manifested themselves differently in each of the three groups. For all three groups my professional and personal background were important, as they assured the participants that I could be trusted to understand their situation, to support them in the process and to respect their cultural and religious views and practices. This led to a high degree of openness in the groups.

The women's group: learning to open up

For the women meeting and talking to each other was a very important aspect of the project. Therefore meetings were very informal and they felt free to talk about a range of topics whether related to the research focus or not. I observed that this safe and open atmosphere was very important and allowed time for this social process to happen. I also brought the women back to the topic through offering the creative activities to spark discussion or asking questions to steer the discussion back towards the focus.

Opening up in the group - and experiencing how supportive that was - motivated the women to open the group up to other women after the project. Poor attendance around this time made it difficult to move ahead, as the participants wanted to check with the absent members whether they agreed to making and distributing invitations. In view of the short time left for the project they went ahead with their plan. Distributing the leaflets at two events and in local Islamic bookshops gave them the confidence that they were able to approach people and explain to them what they intended to do. Despite the fact that their leaflets led to a very minimal response, the women remained

adamant that they would set up the group, and reviewed their approach. As time had run out for the project they did not see concrete results of their actions, but the most proactive participant was able to maintain the efforts afterwards. As a facilitator I emphasised their successes, to instil confidence in their ability to take decisions and act on their own behalf.

The men's group: profiling themselves as fathers of disabled children

For this group my understanding of the subtleties of Pakistani culture was particularly important. The choice of venue was made keeping in mind the fact that they were male and I was female, which required a public and respectable place to meet. This neutral place helped the men to regard me as a professional person, whose gender was not of interest to the research process.

The men were very willing, yet apprehensive about approaching Islamic scholars and Imams to enquire of them what the Islamic scriptures teach about disability. They repeatedly requested me to join them on their visits because they believed I would get more or better information from them. I repeatedly encouraged them that they were not only able to do this on their own, but also had a full right to do it. Having to profile themselves as 'Muslim fathers of disabled children' in this way was a new experience, which motivated them to be more proactive in challenging people's attitudes towards disability in informal settings. The response they received from the Islamic scholars and imams was disappointing and it took time and persistence to get enough information. The men's expectation that the Islamic scriptures inspire positive perceptions of and attitudes towards disability was met. In planning their action they reasoned that Imams would be instrumental in helping them to spread that message in their community. Again, they ran out of time to implement their plans.

The children's group: learning to make decisions

Interestingly most of the learning through reflection and action in the children's group took place *before* they chose their topic, as poor attendance meant that only three children (from the same family) had another three full sessions after choosing their topic. Despite my constant efforts to elicit the children's decisions and ideas, they required a lot of structure within which to take smaller decisions. For example, having triggered their reflections on their disabled sibling's positive points through worksheets in meeting one, and having suggested they could organise the Eid party, they were then able to take decisions on the details of refreshments and games that were suitable for their siblings. Negotiating decisions remained difficult through to the end; even in the final feedback meeting, when they made a poster for the conference presentation, they had difficulty deciding what to write or draw on it. Nevertheless, there was evidence of increased understanding of their disabled sibling and how to best interact with them, and subsequently their families reported positive changes in the way the children included and played with their disabled siblings; in other words the children took small, but very important actions at home, based on their reflections in the meetings.

Running out of time

In all three groups there was a clear sense of regret that time had run out for the project, just when they had got used to the idea that they needed to, and were able to, take their own decisions and actions. Motivation to follow up on their ideas, which had developed during the project, remained high, but implementation proved difficult without me facilitating the process. However relationships between the participants have been established and their perception of the passage of time appears to be slower than mine, so follow-up actions may yet happen. Observing this in the final feedback meetings, which took place 6 months after the end of the project, made it evident that any support or action research groups need to run for much longer than the

five months I had available, because the pace of developing the confidence to take action can not be hurried.

The impact of the project on participants' well-being and occupational balance (SRQ8 and SRQ9)

Much has been said about the participants' feedback on and evaluation of the project in the chapters about their group processes, and it is evident from that that the process of coming together for a common purpose, was as important as the topics and issues discussed in that process. This was true for all three groups.

The impact of engaging in the process per se (SRQ9)

Perhaps the simplest yet most fundamental finding of this project is that opening up to people 'like yourself', in order to listen and be heard, and to give each other mutual support, provides significant encouragement. This of course is nothing new, yet it stood out in comparison with the more specific, sophisticated objectives I had set before the study. The fact that none of the families had any in-depth contact with other Pakistani and/or Muslim families with disabled children was surprising in an area with a large Pakistani community and given the fact that five of the children attended special schools with ethnically mixed student populations and 'Ethnic Minority Achievement Coordinators' in place. Perhaps the schools and other service providers are also distracted by their more specific, sophisticated objectives, and thus forget about the obvious, simple strategy of bringing families together, which would make it so much easier to achieve those other objectives: a mother who does not feel understood – both in terms of language and in terms of her personal experience of mothering a disabled child – will have great difficulty taking on board any advice on how to raise her child.

The opportunity to share experiences in an accepting, respectful atmosphere led to much openness in each group, which in turn gradually prepared them

for deeper reflection on shared issues and subsequently for planning and taking action to address those issues. In addition, in each family participants were able to implement small changes in their behaviour and relationships, or in their perception of the dynamics of relationships in the family, as described in the chapters about the three research groups (3.3, 3.4 and 3.5.).

The impact of what they discussed and reflected on (SRQ8)

Both the realisation that they already had important experiential knowledge, and the sharing of knowledge about a range of topics helped participants to feel less overwhelmed and confused. For example, understanding their disabled sibling's feelings better motivated children to include them more, leading to less frustrations; finding out that their own religious scriptures supported positive perceptions of disability affirmed their own faith journeys and gave hope that negative community attitudes could be influenced; and finding out what services and benefits should be available led to more assertiveness in dealing with service providers.

Well-being or occupational balance?

In practical terms the roles and responsibilities of the different family members have not changed much, suggesting that perhaps the extent of occupational imbalance has remained the same. However the changes in the perception of their relationships and roles have made it less stressful to carry these responsibilities. For example becoming more aware of their siblings' moods and how they can influence them made it much more satisfying to spend more time with them; discovering that the disabled child is able to express their views made parents more optimistic about their developmental potential; and realising that their husbands did care and wish to reduce communication problems helped some of the women to understand them more and feel less stressed. Major changes in occupational balance need more time to be implemented as they would involve a change in cultural and family expectations regarding their relationships and the division of roles within the

home. However, coping with the existing situation better noticeably contributed to all family members' well-being.

Support needs identified through the process (Main Research Question)

Having answered the subsidiary research questions, the main research question needs to be reviewed. In a way the term "support needs" was chosen in order to be able to keep the scope of the research questions broad and flexible, so that the participants would have the freedom to choose their research focus. But what does this mean? It is unlikely that the participants could have answered that question in a one-off interview, even if the term would have been rephrased to "what things (conditions, resources, services, etcetera) help or hinder you to be able to raise your disabled child in the best way possible?" However through their engagement in the research process participants discovered a number of support needs as a by-product to that process: this is perhaps one of the most important strengths of a participatory and action-oriented research process.

For example the men wanted to know what the Quran said about disability so they could challenge negative attitudes in their families and community: by doing so they found out it would be very helpful to get moral support from their Imam, which was something they had not really considered doing before.

Similarly, the women were brought together in a group and talked about their experiences: by doing so they discovered that having a safe, familiar place for catharsis was what they needed most – without 'knowing' it. Several women showed they valued the new contacts they made by sustaining them beyond the project period, mainly through telephone conversations.

Finally, for the Kids' Club 'having fun' was high on the agenda: although they could have done that in other settings, doing it with children who also had a disabled sibling and therefore understood how they felt afforded an opportunity to express their concerns and frustrations. Thus working on

“understanding their sibling better” (their research focus) and discovering the value of peer support (their group process) together reduced their tensions and made it easier for them to support their disabled sibling at home. Apart from these broad, yet fundamental, “support needs” more specific needs were also identified in the process. They will be listed as the research question demands, that is, those needs within the home, in the community and through the service system:

Support needs within the home

Mothers need their husbands to express their moral support more; they discovered through the project that their husbands did appreciate their hard work and commitment, but more open and positive communication would make it easier to sustain that. This also needs to include clearer agreement about practical support and division of responsibilities. Mothers also expressed the need to pursue their personal interests and to be allowed time to do that.

Mirroring this, fathers need to be recognised for what they do do for their families, as well as for their love for their disabled child and commitment to their well-being. Improving communication with their wife and other family members is also a clear need the men were aware of, but is difficult to achieve as it requires breaking through cultural expectations as well as personal ones.

The non-disabled children need to be seen as children with their own needs to have friends and pursue their hobbies. Their willingness to support their parents in looking after their disabled sibling must not be taken for granted, but recognised and fostered.

The disabled children need to be understood more by their parents as well as their siblings. Although everyone rallies around to make sure the child's basic needs are met, the understanding of their communication, developmental, play and emotional needs was often lacking.

Support needs in the community

The fundamental issues faced within the Pakistani community are the widespread negative perceptions of disability, and negative attitudes towards disabled children and their families.

The first need is for the Pakistani community to become aware that their perceptions are neither based on Islamic theology, nor acceptable in view of human and citizenships rights. The men emphasised that the Mosque would be the best place to start challenging negative attitudes. In order for this to happen the religious leadership needs to become more supportive of families who face social problems in response to their child's impairments. For the disabled child themselves their inclusion into the community is fundamental to their sense of identity and belonging.

There is also a strong need, felt by mothers, fathers as well as children, to have peer support from other Pakistani families with disabled children. Particularly the parents strongly valued the nature and depth of support that was possible because they shared the same cultural background, religion and language, as this made it easier to express problems and issues closest to their hearts. For the children this background match was not as important, and opportunities to express their concerns and frustrations with other siblings of disabled children of other backgrounds would be valuable too.

Both the support from the Mosque and peer support would make it easier to respond to negative reactions to or about the disabled child within the Pakistani community.

Support needs to be met through the service system

Drawing support from services provided by the government, private or charity organisations is complex in the face of cultural, religious and language differences. Accessing services is difficult, particularly with poor English, or

limited knowledge of the system. More written and verbal information about available services and benefits needs to be provided to families in a language they can understand well.

However even with good English and local knowledge families indicated limitations in service provision. Special schools, which are highly valued by the families already, do need to focus much more on guiding families in supporting the child's development and behaviour at home. In addition special schools are very well placed to capitalise on their ability to bring families together for mutual support; both separate groups for families from the same backgrounds and general, heterogeneous groups have good potential for supporting families in raising their disabled child.

A key need in service provision is for the child and their parent to be seen and supported as persons. Contacts with professionals were often alienating; although technically useful – e.g. the right exercise, equipment or advice was provided – the lack of meaningful contact and relationship made it hard to take any of the provisions on board. This need for a personal approach to professional support is by no means unique to Pakistani families. It is a fundamental need for any family, but meeting this need becomes more complex and demanding in a cross-cultural setting. When families feel more valued and supported at the personal level, it becomes much easier to understand and accept any advice offered, making it more likely that it will be followed through, leading to a better outcome for the child, their family and the service provider.

Cross-cutting themes: the answers beyond the answers

Having given an overview of how the research questions have indeed been answered by the study this section identifies the answers that go beyond these answers by describing cross-cutting themes related to both process and content in depth.

What about the findings is specific to Pakistani families, and what is universal?

Many of the issues faced by Pakistani families with disabled children are not necessarily unique due to their ethnic background. Some aspects are universal, whilst others, which are more strongly affected by religious and/or cultural influences are unique to this population. That is to say, the combination of Pakistani culture, Islam, socio-economic status and educational background, is unique, whilst most of the individual components are shared with other ethnic groups. Furthermore, of many issues it is debatable to what extent they are universal and to what extent they are specific, and it may be more appropriate to speak of a continuum ranging from minimal to extensive impact of their Pakistani background on issues. Whilst this was not a comparative study, the following issues can be recognised as having a specific significance for Pakistani families.

Family relationships

In the participant families the extent to which traditional family structures and relationships were adhered to varied considerably. Five of the families were nuclear families, whilst in the sixth only the paternal grandmother lived with them. Also five of the marriages had been arranged, and three of the couples were first cousins. Relationships with the extended family were important and intensive for most families, although in two cases their response to the disabled child had caused estrangement on one or both sides of the family.

Within the nuclear families there was a strong sense of commitment to each other and providing ones share of care for the disabled child appeared to come naturally. Whilst this strong loyalty contributed to the families' ability to care for the disabled child well, it also made the children reluctant to share any disadvantages of or negative feelings about their caring roles.

The mothers of the families indicated that the level of communication with their husbands was unsatisfactory, and that this was both common and deemed

acceptable within their culture. The women's as well as the men's group processes made it clear that both spouses tended to be concerned about this, but that cultural expectations made it more difficult to start addressing this issue directly. However some positive changes were seen within the families' homes, as a result of the women's group discussing it and subsequently my choice to let a conversation about it develop in the men's group. This indicates that culture does not need to stop people from starting to reflect on and deal with problems they had considered unchangeable beforehand, and that this issue must not be left unaddressed by service providers.

The fathers of the families

Pakistani and/or Muslim fathers are often assumed to be a 'hard to reach' group (Khan, 2006, p4), though this may have more to do with those trying to reach them, who may worry about breaching social etiquettes due to their limited knowledge about their cultural and religious background, rather than the fathers' reluctance (Waugh, 2007). Having spent many years in Pakistan and the UK getting to know Pakistani families, I was well aware of some traditional values and customs that may hinder fathers in taking on an active parenting role. Examples of this are the strong cultural pressure to be the sole breadwinner, long and unsociable working hours, the matriarchal structure for raising children in which the mother and paternal grandmother tend to control how the children are brought up, and the pressure to be the disciplinarian that seems at odds with the latter (see Waugh, 2007, p11). Combined with the communication issues mentioned in the previous paragraph, and with the pressures arising from trying to integrate into a western society without losing some core traditional values and customs (see Waugh, 2007, p11), Pakistani men face an uphill task in being a good husband and father.

For Pakistani fathers who strive to do this, widely held stereotypes, fed by much bad press about them and very little positive reporting, can be extremely obstructive (Khan, 2006). This was one of the reasons why I chose to work with the three separate action research groups, as it gave the men an opportunity

to reflect on their role in raising their disabled child and supporting their family in light of the challenges associated with having a disabled child, and to explore how they could improve on their situation at home or in the community.

Whilst I am aware that the men in this study had consented to their families participating in the project, and were therefore possibly not entirely representative of all Pakistani fathers, it was also clear that they did indeed struggle with many of the issues just described. Their openness to talk about their experiences, views and feelings about their disabled child and social responses shown to them, was immediate (from the first individual interviews) and enduring (throughout the action research groups and further individual conversations). Some of that openness was probably due to my background of knowing the Pakistani culture, religion and language well, and at the same time not being a member of the Pakistani community, so that I was no threat to cultural norms around women working in a leading role with men, and no risk for increasing the social pressures of accountability to, or gossip within, the Pakistani community (see Waugh, 2007; Campbell and McLean, 2003). However much of that openness appeared to be due to the fact that they came together with other fathers facing similar issues and realised that they could learn a tremendous amount from, and be encouraged and inspired by each other. Giving expression to their views, deciding what they could do as a group, and then taking action accordingly was a liberating experience. For example identifying themselves to the imams as 'fathers of disabled children' and seeking their support in defending their rights, appeared to make them more aware of their pride of their child and commitment to their wellbeing, which in turn led to increased interaction with the child. The strength of a participatory and action oriented approach is that it enables the participants to become aware of what they already knew, had and felt, and to build on that to improve their situation. That process was encouraging to the participating men, even though their outcomes were not as big as they had hoped to achieve.

This positive outcome of working with Pakistani fathers in this study is congruent with the small number of existing support projects for Muslim and/or Pakistani fathers run or supported by the Fatherhood Institute (see Khan, 2006), the YMCA (see Waugh, 2007) and the Race Equality Foundation (see Abu Newsletter, online). However these are general projects, although the latter has given some attention to 'additional needs' in the family.

Community attitudes towards disability

In chapter 1.2 I wrote about the social attitudes towards disability faced by families of any ethnic background, quoting Dobson (2001), who describes how they felt excluded by, and had to contend with insensitive stares and comments from people outside the nuclear family: general society, sometimes extended family members, and even healthcare professionals. What is different for Pakistani families is that in their community the negative attitudes, judgments and exclusions tend to be expressed in religious terms, posing a challenge to the families that look for answers or support from that same religion. Western attitudes no longer tend to be expressed in religious terms, although this was still common only a few decades ago and are still reflected in comments like 'what did you do to deserve this?'. With a longer history of the disability rights movement and growing awareness of the social model of disability negative attitudes are not as widespread, or perhaps not as freely expressed, in general British society as they still are in the Pakistani community.

The men's group met with a lack of interest in disability issues among their Imams and scholars, yet they believed that the negative attitudes in the community will most effectively be challenged through religious teaching at the Mosques.

The role of Islamic teaching and faith

All participating parents talked about the way their perceptions of and attitudes towards disability had changed since they had a disabled child

themselves. The women emphasised that it was their concern for their child that caused them to pray more and that the strength they drew from that helped them believe that God was not punishing them or their disabled child, but rather blessing them. Some participants also talked of going back to the Islamic scriptures to find answers.

Within the families faith played an important role in their ability to accept the child the way they were, and to bear and/or respond to negative attitudes within the Pakistani community. Hearing other group members talk about their similar faith journeys affirmed participants in their own experiences, leading to the women working towards setting up a group where other Pakistani mothers could get that same encouragement, and the men making plans to involve the Imams in addressing the misconceptions that persist in the community in their sermons.

Consequence of being part of a minority population

As described in chapter 1.2, the Pakistani community in the UK faces a number of great challenges, including high levels of poverty and unemployment, poor housing, lower levels of education, a high proportion of people with poor English proficiency, and prejudice based on both racism and Islamophobia. When there is a disabled child in the family additional challenges arise, such as gaining access to services and benefits to help meet the high cost of raising a disabled child. Especially where English proficiency is low and/or families are new to the country, the organisation of statutory services can be very difficult to understand.

The participant families were affected by this array of marginalising factors to varying extents, and had struggled considerably to obtain the services and benefits that they were entitled to.

Community engagement

This study suggests that the support needs of Pakistani families with disabled children could to a certain extent be met by changes in the attitudes in their own community. The 'solution' is not difficult to understand, but the more difficult to implement. Cultural perceptions of and attitudes to disability have developed over many generations and a change in factual understanding – that Islamic teachings are affirming of disabled people and challenging the community to include and support them – will not automatically change attitudes.

Even engaging families directly affected by disability proved difficult in this study, so raising the interest of the community at large can be expected to be even harder. As the men found out, religious leaders were reluctant to spend time finding out about disability in the Quran and talking to them as fathers of disabled children. Therefore convincing them to preach sermons about the issue or otherwise support the families will require a considerable amount of time, effort and persuasion.

Both the men's and women's group noted that the local Pakistani community showed little initiative in improving the lives and circumstances of their members. They felt this is partly cultural, which is congruent with my own experience of trying to mobilise communities or individuals in Pakistan, as well as with the fact that there are indeed hardly any local initiatives taken by and for Pakistani people. Inspiring people to take action may therefore be quite a challenge.

The approach taken to engaging the community is also important. In this study, I required whole families to take part. Whilst this had many benefits, especially in terms of outcomes within the families, it also restricted a number of mothers, who would have liked to take part, but whose husbands were not willing to participate. To start changing attitudes will take time and commitment from a small group of people, but beyond that activities should not be demanding

much time and effort. Building on existing structures, such as using Friday sermons or announcements (as suggested by the men's group), or getting invited to existing committee meetings, is likely to be more successful.

Using services – why it is difficult and what needs to change

As indicated in the answer to the main research question above, using available services is difficult for these families.

Unfortunately, it is not only statutory, or other general services that are difficult to access, but even a local project specifically aiming to provide support to families with disabled children in the Asian community was not seen to be effective. The participants gave a number of reasons for this, which need to be considered. Firstly, they had found it difficult to fit into the multicultural support groups, as South Asian cultures, religions and languages are very different. Secondly they felt that the nature of activity was not effective: weekly mothers' meetings remained very superficial and although sometimes relevant information was provided the deeper reflection on or sharing of difficulties was not encouraged. In addition trips with the disabled children were not suitable for children with challenging behaviour, causing much stress to mothers. The impression the women had was that the staff was more interested in networking and high profile events, rather than supporting families with their complex problems. They felt this type of charitable project needs to be run either by mothers of disabled children themselves or by committed compassionate professionals.

Occupational science

Aspects of occupational justice and balance in the families have already been discussed above, where the research questions were answered. These insights were gained through reading the data with an occupational science perspective in mind, as well as through the circles-activity in the women's group in which I invited them to think about their lives from an explicit

occupational science point of view. Both these approaches can be used by occupational therapists to deepen their understanding of challenges faced by individuals and families from backgrounds different to their own.

Models of disability

Although in first instance the participants' concepts of disability appeared to be mainly in line with traditional and medical models of disability, it soon became clear that each family had experienced many social and societal barriers to participating in community activities and accessing services and benefits. The multiple barriers were often more difficult to deal with than the child's functional limitations associated with their impairments.

The families' experiences of living with a disabled child therefore can not be adequately described in terms of one single model. The implications of this finding will be deliberated on further in chapter 4.2.

Did this study meet the quality criteria for action research?

In chapter 2.1 I proposed that I would use the criteria by Anderson and Herr (2005) and Reason and Bradbury (2006) to evaluate the quality of the action research in this study. This section shows to what extent the criteria were met.

The generation of new knowledge

Much new knowledge was generated by and in collaboration with the participants, as summarized in the preceding sections of this chapter. Each group chose a focus for their own research activity and planned and implemented actions in order to gain information and insight about it. In terms of 'factual' knowledge, the men generated most, but in terms of increasing insight into perceptions, attitudes and relationships, all groups contributed and were conscious of this. Although similar knowledge and insights may have been available in different contexts, the unique combination of characteristics

and circumstances of this group of participants, and the whole-family approach to the research led to a deep insight into their support needs, with clear implications for action, particularly at service provision and community level.

The achievement of action-oriented outcomes

The three research groups progressed through iterative cycles of action and reflection, each in their own way. This journey of discovery through action caused participants to change their perspective on their own situation and how it might be influenced.

For example the men initiated contact with their imams and scholars to gain information, but then realised they may be able to provide support in raising awareness of disability issues in the Pakistani community as well. They persisted with this, despite a disappointing response by the imams and scholars, making them aware that their continued efforts will need to be intensive. The men's wish to spread their new knowledge was also evidenced by the fact that they have started to do this in their day-to-day contacts. At the end of the project they were considering how they might form a broader platform to include more fathers / men, produce a 'fact-sheet' about Islamic teachings on disability, work with imams to include these teaching in their Friday sermons and/or use local media (print, radio or local TV).

The women decided to try and set up a larger support group, and designed and started distributing a leaflet. They have found it difficult to sustain their joint efforts on this. However Maryam, who was asked to conduct focus groups for another researcher whom she met at the conference presentation, was encouraged by the positive response from the women she invited for the focus groups and renewed her resolve to set up a support group.

Due to poor attendance at the children's group it was difficult to work towards a concrete outcome. However several families reported an improvement in

the way their children supported, communicated and played with their disabled sibling when they returned from their group meetings, indicating that the children were able to put their increased understanding and perceptions about disability into practice.

For larger and more sustainable action-oriented outcomes to occur, a longer project period would be required. Occasional contact since the end of the project indicates that participants are continuing to reflect on what we did during the project and are keen to see a follow-up, although they feel unable to organise this independently. A planned dissemination meeting for local service providers, community leaders and other interested parties in which I have invited them to play an active role, may help in achieving this.

The education of both researcher and participants

The researcher gained an enormous variety of insights about the support needs of Pakistani families with disabled children, and about the best way to engage them in participatory action research. Due to the complexities of the families' lives, the logistics of organising research activities, and the challenge of facilitating the groups to take control over their own research processes, I learned through reflecting on every step of the process, and using those reflections to inform each next decision.

At the same time much of my education as the researcher took place in tandem with the education of the participants. In summary, key aspects of the latter were as follows:

- Becoming more aware of and expressing their own beliefs, attitudes, feelings
- Thinking through communication issues within the family and learning how to deal with them and address them
- Realising that their positive attitudes towards disability were much closer to Islamic teachings than the negative attitudes encountered in the wider Pakistani community

- Discovering the value of mutual support, particularly with people who share the same background
- Increased understanding of the idea of 'research' and that this can be of practical value for them
- Learning or strengthening a wide range of skills, including listening, debating, reflecting on and analysing information, taking decisions, negotiating with each other and others, taking initiative, verbalising ideas, designing leaflets (selecting information and presenting it in a way the intended audience will respond to), drawing, story telling and writing, etc. I noted that some of these skills were surprisingly underdeveloped, or undiscovered, at the start of the project. This may have to do with their marginalised status and not feeling they are expected or encouraged to exercise these skills.

Results that are relevant to the local setting

As is evident from the 'action-oriented outcomes' described above everything the participants and I talked about and undertook action about, was focused on how they and other Pakistani families with disabled children could be supported, and the local community educated about disability issues. In the final meetings both the men's and the women's group became quite inspired about wanting to make sure that what they learned would not be lost.

A sound and appropriate research methodology

Although not all proposed methods were easy to implement, they were in principle appropriate in this context. For example I would not attempt to approach people through the local mosque *only* again, but it was not an inappropriate strategy in itself.

Secondly, for this group of families it was definitely important to work in separate groups of men, women and children. It helped participants to delve

into the issues faced, including the recurring theme of communication issues within the family, quite deeply. This could not have happened in mixed groups.

Action research groups worked well in principle, as each group was able to engage in the research process, set themselves tasks, reflect on and review outcomes, etc. However, a longer period of time would be needed to pursue many of their good ideas.

An emergent, flexible design

The proposed research methods indicated that I would have to be flexible in conducting this study. Although my basic approach to the study was clearly set out, that approach allowed participants much freedom to choose both the focus and methods of their own research activities.

The first need for flexibility was when I had to review the ways and routes through which to contact families, when the invitation through the Mosques did not lead to any contacts. Later, once the groups were formed, the frequency and venue for meetings was negotiated and the participants were free to choose the research focus and to decide on appropriate actions. This was a new way of working for the participants and I needed to be alert and reflective at all times to avoid taking over, or guiding decisions.

The development of plural ways of knowing

The four ways of knowing as described by Heron and Reason (1997), were all important in this study.

Experiential knowing played a large part, particularly in the exploratory phase, when I specifically asked each participant to remember, reflect on and verbalise their experiences in relation to having a disabled child in the family. Within group interactions many anecdotes were shared to illustrate viewpoints or principles as well. Becoming aware that their own experiences provide a

level of knowledge that is essential for understanding their support needs and looking for ways to improve their situation, was an important factor in being motivated to be part of this study.

Presentational knowing was elicited particularly through creative activities. Strong examples of this are the women's drawings of metaphors of their (relationship with their) disabled child, and the children's drawings of Mr. Men characters to symbolise themselves and their disabled siblings. In the men's group I used this concept in designing their inventory activity, in which they looked at their skills and views with the help of a drawing of a man. My invitation to the men to write a poem also attempted to elicit this type of knowing. This type of expression of knowledge helped to bring out views that are not so easy to express eloquently in words. For example during for the evaluation activity Noor drew a picture in which she showed how her reality and the reality of the 'world out there' were fundamentally different and how she was only able to have a window into this other world, without being able to be a part of it.

Propositional knowing was developed when group members went beyond sharing experiences through stories and artwork, and started talking about factors influencing these experiences (such as cultural norms and expectations, reactions from outsiders, their worldview, etcetera) in order to understand their situation better and think about ways to improve it. Examples of this are Sadaf's story about misconceptions people express about the reality of raising a disabled child (see chapter 3.2) and the discussion around occupational injustice following the 'circles activity' in the women's group (chapter 3.3).

Practical knowing, described as the consummation of the previous three forms of knowing through acting on them, was also seen. For example the women experienced that a group of women like themselves could provide important support – this motivated them to invite others into their group, and feel confident about how to design and distribute a leaflet: this is a clear decisive

action, based on the things they had come to know up to that point. At the end of the project, the plans the groups made for using their newly acquired knowledge, show that they did develop a level of practical knowing, although they would have needed some ongoing support and more time to put this into practice.

Did this participatory action research project meet the criteria of emancipatory disability research?

In chapter 2.1 I suggested that, if carried out well and with a group of disabled people or families, participatory action research should meet the standards of emancipatory disability research suggested by Barnes (2002) and Barton (2005). Although most of these characteristics have already been addressed in this chapter so far, a number need to be addressed explicitly to demonstrate that this was the case of this study.

The control should lie with the participants

Handing over the control over the study to the participants was one of my central aims throughout the study. What became evident though was that for this marginalised group of people taking on that control is not a quick and easy process. The participants understood their need to take control and independent decisions, but clearly expressed their apprehension in doing so. Continuously stepping back when participants looked to me to take decisions helped them to start making decisions and taking actions on their own. However they did not get the time to take over the overall control over the project and the implementation of its findings, due to the short duration of the project.

Empowerment

The previous section around control, indicates one aspect of how I sought to facilitate the empowerment of the participants. Another example of

empowerment is the way the men started to profile themselves as fathers of disabled children when they approached their Imams, which led to them taking the initiative to engage relatives and community members in discussion about attitudes to disability. An example from the women's group is the feeling of "a sort of power" Maryam described from the discovery that they could come up with the idea for setting up a support group, design leaflets and step out in order to invite women. The children showed their excitement over organising the Eid party, and taking their own decisions in this, as this was the first time they had had any control over such events. In addition Maheen felt very proud of being able to stand up in front of an audience to talk about her involvement in the project when she co-presented the workshop at the conference. In all these instances it was the combination of the discovery that their experiential knowledge was valued with the taking of action, that led to participants feeling empowered.

Adherence to the social model of disability

The whole rationale for and design of the study was based on the social model of disability. The reflections and actions of each group revolved around addressing social aspects and barriers to the disabled children's and their families' participation in society. However I have taken a broader view of who is disabled (the 'disabled family') as well as of the social model of disability, which needs to become more explicit about its holistic nature, so that traditional and medical aspects of disability can be seen as an integral part of the social experience of disability, and so that the influence of other social characteristics such as ethnicity and religion are given due attention. See chapter 4.2 for an in-depth discussion of this.

So was this Emancipatory Disability Research?

While the ethos and approach in this study were fully congruent with emancipatory disability research, the different criteria were met to varying extents. It was not possible to achieve the crucial criterion of disabled people -

or in this case perhaps more feasibly their family members - having full control over all phases and aspects of the research process. It therefore did not meet all criteria of emancipatory disability research fully. However it did have a range of emancipatory effects, as described in the section titled 'empowerment' above. It also needs to be remembered that for a group that faces multiple types of marginalisation a project initiated by an outsider researcher who strives to hand over the control over the process as much as possible, may form a necessary first step towards being able to initiate and fully control future research or development projects.

Strengths and limitations

There are a number of strengths and limitations of using participatory action research with a group of Pakistani families with disabled children.

Strengths of the research process

The advantage of working closely and intensively with the families, groups and individuals was that it helped to build up a deep level of trust between participants and me. My knowledge of the Pakistani culture, religion and language meant that trust was established quickly, but over time this increased further. My initial approach was to listen with genuine interest and acknowledge challenges. This level of trust created safety, which enabled the participants to explore and express their feelings and views in great depth, which was helpful for the research process, but most importantly for themselves too.

Working with whole families meant that the mothers, fathers and children were all reflecting on issues related to the disabled child at the same time. Even though they did not feed back everything from the groups to their family members, it was evident that changes in communication with and behaviour towards the disabled child were easier to implement in the knowledge that the others understood the reasons for them.

Creativity, games and participatory activities helped participants to discover, express and discuss their own feelings and views. They also facilitated the research process of prioritising issues, planning action, implementing action and evaluating the outcomes of each step and the project as a whole.

Another advantage of using participatory action research was that it provided a structure, which helped participants to understand and keep track of the research process, but at the same time encouraged them to take over the control and decision making from me. The flexibility of the research method was helpful in that the participants felt free to choose the issues to focus on and the actions to address them. It was also helpful when attendance at the groups was variable and plans needed to be changed at times, which leads to the following section about limitations of the study.

Limitations

The strengths of a whole-family approach came at a cost in terms of recruitment. Despite an enormous amount of effort only six families eventually chose to participate in the project. The high demand on all family members, in terms of time and effort, over a relatively long period (nine months plus some follow up meetings) played a role in this, as indicated by a number of the other twelve families that contacted me but did not decide to participate.

The small size of each of the groups was conducive when all were present, but the variable attendance meant that in a number of meetings there were too few (two or three) participants there to continue the research process confidently.

This was made more problematic by the fact that there was only a short time available for the action research groups (only five months due to problems with recruitment), so the groups ran out of time to implement and follow through ideas and discover their own ability to do so. An associated issue was that participants, especially men and children, were not used to expressing ideas

and feelings about something so personal. Whilst learning to do so and discovering the value of it was a very positive experience for the participants, it did mean that particularly for the children's group a disproportionate amount of time was spent on this process and very little time was left for planning and taking action.

In all three groups it was evident that many participants were not used to being expected to take decisions and actions. Facilitating the process of them taking over the control was one of the most difficult aspects for me as the researcher. As this is a central aim of participatory action research, this can not be considered a limitation of the research process per se, but it did limit how much the groups could achieve in the short time available.

Finally there were some disadvantages of conducting this study independently rather than through an existing service or project. The main advantage was that the participants had the freedom to say and do things the way they saw fit – e.g. expressing dissatisfaction about services - without the risk of offending anybody. However there were several disadvantages, at various stages of the project. The first was that recruitment was very difficult and would have been greatly helped if potential participants would have already known the service and/or the researcher. Once the project was in progress, being part of a service or project could have eased issues such as booking venues and having people available to help with facilitating group meetings. Finally, without a structure to link into, it is difficult for participants to sustain their action and ideas beyond the project. Using existing services, e.g. school and pre-school projects might work better, as initiatives can be followed up without much cost in terms of resources.

Conclusions of the study

Having presented answers to the research questions and identified cross-cutting themes, and having considered to what extent the study met the quality criteria of action research and emancipatory disability research, the remainder of this chapter presents key conclusions arising from the findings, which summarise what insights into the support needs of Pakistani families with disabled children, and into the use of participatory action research with this group, this study has yielded.

Gaining access to the community

Recruiting research participants from a population facing complex marginalisation issues can be difficult and requires multiple strategies. To be successful in this community networks and gatekeepers, as well as statutory and voluntary agencies need to be approached and pursued consistently. In addition it is important to ensure that these contacts understand the importance of the study so that they will be able to motivate prospective participants to contact the researcher.

Where the researcher is from a different ethnic, cultural and/or educational background than the community, they need to be able to convince community contacts and potential participants that they have a good level of understanding and respect for these differences, in order to gain trust. This is as important as showing expertise in the issues being researched.

When community access is difficult and the demands on potential participants' time and efforts are high, inclusion criteria must be flexible. In this case the age-range and nature of impairment were less important than expected and the initial narrow criteria may have stopped families coming forward when invitations were extended through the local Mosques.

Community attitudes towards disability

The participants encountered mainly negative attitudes towards disability in the Pakistani community and received very limited support from their extended family members, friends and neighbours. This is congruent with findings of previous research studies.

These negative attitudes appear to be based on religious concepts, although there is no evident basis for this in Islamic scripture, as the men's group found. Therefore the best way to start changing attitudes in this community may be through teaching at the Mosque, not only because the attitudes are based on erroneous religious beliefs, but also because it is where Muslims congregate. In addition other community centres and community radio and television have the potential to convey this message to families within their homes.

The role of faith in explaining causes of impairments and accepting the child

Most participants drew significant strength from their faith. For most their strong faith did not mean that they necessarily held traditional / religious views on the causes of impairments, or dismissed medical explanations of impairments. Many expressed both views simultaneously, to different degrees.

The study has provided much deeper insight into the process by which parents' faith was strengthened after the disabled child was born. As they (particularly mothers) were worried about the child, they started to pray more, and wanted to understand the religious significance of disability. Understanding this and giving opportunities to share and express this within individual or group-based support services can enable service providers to make parents feel more supported.

Currently the detail of Islamic theological explanations of disability is not very clear to the families or the Imams. Therefore Islamic scholars need to study this

subject further and disseminate their findings through the Imams to the Muslim community.

Attitudes within the nuclear family

The study has provided deeper insight into Pakistani families' attitudes towards their disabled child. Significantly better understanding of the process of changes in attitude from largely negative (as in the wider community) to largely positive, and the role of faith in this process, has been gained.

At the same time it was found that their extended families' attitudes do not necessarily change in the same way and that they may receive little emotional or practical support from them. This is in line with findings from earlier studies and emphasises the need for service providers not to assume that supportive services such as respite care are less desired or needed by Pakistani families.

Women's needs: mental health and well-being

The high incidence of anxiety and depression in Pakistani women with disabled children, as suggested in the literature, is reflected in the 18 families contacted. Many mothers feel isolated or trapped in their situation.

The study has provided more insight into the dynamics that lead to Pakistani mothers of disabled children being least likely to receive adequate support from their husbands. Cultural expectations that the mother willingly 'sacrifices all for the family', and poor communication between husband and wife are major factors, while the child's impairment per se is not necessarily a reason for being unsupportive in itself.

The study also showed that the participating men were aware of and willing to address these problems, but that they needed support to do so. This was mainly because the cultural expectations of marriage and family relationships they had been imbued with in their upbringing had not prepared them for a

supportive and equal partnership, and because causing a shift in expectations and behaviour was difficult to achieve within the cultural context they were part of. In this project one spontaneous, extended conversation about family relationship issues in a 'safe' group setting, prompted the men to reflect on and start changing their behaviour at home, indicating that interventions around parenting and relationships can be expected to be successful.

The research process also highlighted the value of mutual support for Pakistani mothers of disabled children. The women emphasised the importance of the meetings being meaningful and in-depth, as opposed to 'getting together for tea' as they had experienced before in different settings.

Pakistani dads of disabled children

Fathers' basic perceptions and attitudes towards their disabled child were already quite positive, but they were unsure how to provide their wives and families with emotional support in the context of cultural expectations regarding marital relationships and division of responsibilities within the family.

The men welcomed the new experience of coming together to exchange experiences and ideas around disability, and to work towards improving aspects of family life. They found this process helpful and supportive.

In terms of the research process, most men were not used to being expected to be assertive and take action, but showed they were willing and able to learn to do this in the context of the project. They also indicated that this experience helped them to be more pro-active in addressing unhelpful attitudes or views in social situations.

Sibling support

Children spent much time at home to support their parents in looking after their disabled sibling. They appeared to be taking on this role quite naturally and

voluntarily, which illustrates the relatively greater importance of inter-dependence in Pakistani culture.

Pakistani culture meant that the children mostly had a very strong sense of loyalty to the family and wanted to avoid giving negative impressions, hindering the expression of their feelings. However, as they became more reflective of what their relationship with their disabled sibling meant to them and gained more understanding of their impairments, they found it easier to know how to support them and felt affirmed in their commitment to them.

The children were able to engage with the research process despite a number of logistical challenges. They gained worthwhile general life skills, such as becoming aware of their own behaviour, gaining self confidence, expressing feelings and opinions, working as a team and planning (evaluate information, come up with ideas, negotiate, evaluate outcome).

The children found the peer support provided through the Kids' Club activities very helpful as it helped them realise it was legitimate to express negative aspects of family life with a disabled sibling and made them feel understood. It is not clear from this study whether separate services for Pakistani siblings would be needed, but existing general sibling projects need to be more proactive in reaching Pakistani children. In addition they would benefit from a more family-centred approach to service provision by their disabled siblings multi-agency team, as this would provide them with the acknowledgment of and support in their supporting role for their sibling.

Participatory action research with Pakistani families with disabled children

Participatory action research fits well with the Pakistani culture as it involves much conversation and sharing of stories. Also the cultural appreciation for poetic and allegorical language was helpful for expressing representational knowledge.

It was useful for all family members to be reflecting on the same issue at the same time in their respective groups, as it facilitated small but important changes in behaviour at home.

Whilst participants initially had difficulty with taking initiative, control or decisions, and with sustaining motivation to follow through their ideas, it was empowering when they did. It also increased their confidence and skills. The progression of each group process was slow due to the previous point, due to variable attendance, and due to the time needed to form trusting relationships with each other to enable collaborative action. This implies that research or support groups need to be sustained over a much longer time for them to be of maximum benefit to their members.

The participatory approach enabled participants to reflect on and express the many views and ideas they already had, and to explore new ideas with each other. This personal development was an important outcome of the project for many of the participants, even if it was hard to demonstrate this through tangible, observable outcomes.

Creative and non-verbal expression was particularly useful for those whose English was poor, or who were least accustomed to expressing their views verbally, as it made them aware of their often tacit views and feelings and of their ability to contribute to the group process.

Having a clear focus or theme for group activities and discussions was very important, as this led to in-depth communication.

Motivating the Pakistani community

It was difficult to engage the Pakistani community and to raise their interest in disability issues. Participants observed this too when they were considering what approaches might work for reaching and engaging the community.

The Pakistani community is strongly disadvantaged and these families illustrated that as families with disabled children they face even more challenges, which makes it hard to be hopeful and take initiative.

Even this motivated group of participants had difficulty sustaining their motivation without external encouragement. Therefore observable outcomes beyond the family setting were limited.

This implies that in order to improve the lives of Pakistani families with disabled children both general community development initiatives and specific disability related projects will be needed, preferably co-organised by community members and professional agencies.

Relevance of the social model – multiple perspectives

Participants had a clear awareness of social and societal barriers put in the way of disabled children and their families. They expressed this clearly, without having prior knowledge of the social model of disability and its terminology.

The nature of the child's impairment had an impact on their social experience of disability. Although all impairments carried stigma, negative responses were stronger to children with intellectual impairments and behaviour problems.

Medical and religious explanations for impairments were not seen to be contradictory to each other, or to the social experience of disability. Rather, faith was important in conceptualising and responding to the social experience of disability. This indicates that there is a need to acknowledge the influence of people's worldview on the way they make sense of their situation, within the theory and application of the social model of disability.

Poor access to services

The participants recognised that some issues around service provision were universal (e.g. long waiting times, needing to chase up appointments to speed

up the process, etc.), whilst others had to do with being an ethnic minority (cross-cultural communication), or having poor English language skills (being informed about services and communicating with service providers). However the main issue was the attitude of many service providers, which they described as distant and unhelpful, making them feel unacknowledged as parents. Some participants felt racism played a part in this, but found this difficult to substantiate.

Special school was highly appreciated, but in several families not enough advice was offered for the home situation, nor explanation about how to support home based learning.

It was difficult to trust respite care, because it is culturally not acceptable for staff of the opposite sex to care for (older) children, because of concerns that the child might be abused or neglected, and finally because of a worry about the child eating 'haram' (unclean for Muslims) food.

Occupational science perspective

This was a useful additional perspective for the women, as it helped them to evaluate their situation in a new way, which made them recognise that some of the taken-for-granted cultural practices were unjust.

Belonging was a very important aspect for this group, partly because of the cultural valuing of family and interdependence, and partly because they felt so excluded from the community.

In terms of 'being' and identity faith played a central role. Reflecting on and expressing this important element of their identity was very important for the women as it allowed them to explain their relationship with their disabled child more clearly too.

Occupational imbalance was an issue for all family members, but most strongly for the mothers, due to a cultural expectation to 'sacrifice all' for her family,

poor communication with and emotional support from her husband, limited or no use of respite care services, and/or very limited practical support from the extended family. This led to the families being quite isolated and having little participation in community events.

Participatory Action Research and its emancipatory goals

This study has brought attention to the way in which families are excluded and disempowered in light of disability, within an already disadvantaged community. Social responses and barriers encountered did not only affect the disabled child, but also the family as a whole. The term 'disabled families', used by some participants, appears apt.

This PAR study had emancipatory goals and aimed to leave the control over research topics and methods with the participants. The achievement of emancipatory goals depended greatly on my willingness to relinquish this control and facilitation of this starting to happen. It was also a process that could not be rushed and whilst it unfolded well, there was not enough time to reach a stage in which the participants took over the control fully.

The disabled children and their well-being were at the heart of the study and their parents and siblings reported that they had a clearer understanding of their impairment and needs, and that they had found better ways of communicating and interacting with them. In addition participants demonstrated more confidence and initiative in seeking support from disability services and religious leaders.

The inclusion of the disabled children in the research process was achieved to an extent. In the exploratory phase the disabled children expressed their views through communication methods they were able to use. Furthermore, joint meetings, such as the party organised by the Kids' Club, were expressly planned to be inclusive of the disabled children. However, a suitable infrastructure and sufficient human resources would have been necessary for organising an action research group for or with disabled children.

Family members' altered perceptions of and expectations from the disabled child appeared to have a positive impact on the way they interacted with them. This is evident from participants' responses in evaluation activities and constitutes a valuable practical outcome for the disabled child as well as the family.

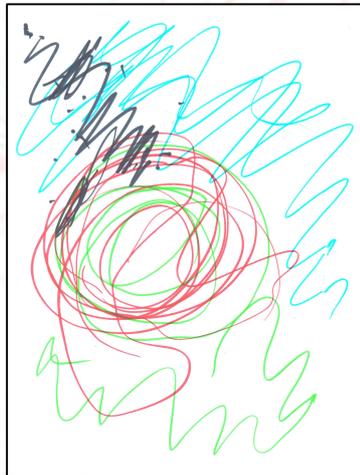
This study has shown that participatory action research can be used to good effect to work towards meeting the criteria of emancipatory disability research. Some criteria were easier to meet than others. For example the criteria of adherence to the social model of disability, use of flexible methods to meet the purpose of the study, and valuing of personal experiences for understanding barriers to participation were clearly met and underpinned the design of the study. Criteria that were more difficult to achieve fully - or demonstrate - included the extent of empowerment and the control over the research process lying with the participants. However a lot of progress was made in these aspects having moved from a particularly disempowered initial position.

This section has presented the broad range of conclusions that have been drawn from the study. One important reason for this broad range is that the research focused on both the content and the process the participants went through. Another reason is that the research process was made up of several distinct processes in different groups (men, women and children, whole families) and settings (the respective groups, all families together, each family at home). Finally the control each group had over the focus of their research efforts also brought a diversity of topics.

Chapter summary

This chapter has analysed the findings by answering the research questions and by drawing out cross-cutting themes. The chapter has shown that this study has provided deep insights into a range of issues around disability as well as the use of participatory research with Pakistani families. In addition to these new insights the chapter also indicates what the limitations and constraints were, which are as important in considering the implications of the study as are the successes. The final part of this chapter presented the conclusions from this analysis. The next, final, chapter discusses some key themes in further depth, and considers their implications beyond the project.

Chapter 4.2:
Discussion



Dawood's artwork

4.2: Discussion

This final chapter of the thesis discusses a number of key themes arising from the findings in further depth, indicating what implications they have beyond the local context and participants of the study.

The issues that will be discussed are religion and the social model of disability; mobilising the Pakistani religious leadership; marital and family relationships; and finally, three methodological issues.

After this discussion the following section points out the limitations of this study by outlining what I would do differently if I were to undertake it again.

The final section presents the recommendations that arise from the thesis.

Religion and the social model of disability

Based on the answers to the research questions that the findings have provided, it is evident that the social model of disability is highly relevant for making sense of the experiences of Pakistani disabled children and their families. At the same time the fundamental influence and importance of faith in interpreting disabled people's lived experience is not often made explicit in the social model.

Models of disability

Whilst this was a secular study with a broad objective of 'exploring support needs', the participatory action research approach gave participants the choice of topic for their own research. As the initial interviews had included questions on each participant's personal experience and feelings about having a disabled child in the family, both men's and women's groups felt free to decide that exploring the role of faith and religion was the most important both for themselves and the

community. This may make it appear that for the Pakistani community the traditional / religious model of disability is most dominant. However for most families it was very important to understand the medical causes of their child's impairments, in order to make sense of them and seek medical and therapeutic treatment for them. In addition, all participants were acutely aware that the most distressing aspects of life with a disabled child were the indifferent or negative attitudes of others, including members of the Pakistani community and service providers.

The participants were not presented with theoretical models of disability, and were thus not restricted in expressing their views. The fact that each of these key models of disability had a role to play in their experience, has valuable lessons to teach.

Firstly, it indicates that besides the more frequently debated medical and social models, more attention needs to be given to traditional / religious models of disability. Any model of disability is influenced by the context and worldviews of those who developed or named it; traditional models have roots that reach far back to a time when medical science was less developed and dominant; the medical model established itself in an era of rapid and highly advanced development of medical science; social models developed in the post-modern era as a reaction against the negative impact of modern (medical) developments on people's lives and communities. On the one hand it is important to make the influence of contexts, eras and worldviews explicit, whilst on the other hand it must not be assumed that with the arrival of new models old models become obsolete.

In addition, earlier models may well be influenced by newer ones without being discarded. For example in recent years a number of Christian theologians have re-examined the text and ethos of the Bible and developed new theologies of disability, with a variety of viewpoints. Some claim to be 'liberatory' by taking a social justice perspective and conceptualizing the incarnate suffering Christ as a 'disabled God' (Eiesland, 1994). Others profile themselves as 'radical' by emphasizing that all people are created in God's image and challenging

Christians to realize that disability is about rights and empowerment rather than charity and pity. They point out the need for the church to be 'of all and for all' (McCloughry and Morris, 2002; Fritson and Kabue, 2004). Yet another challenges the 'cult of normalcy' that has tended to exclude and denigrate disabled people inside and outside the church. This view suggests that disabled people confront able-bodied people with their own vulnerability and that both need to enter into a relationship of mutuality in which both give and receive in order to understand Christian spirituality more deeply (Reynolds, 2008). These authors all have personal experience of disability as either they or a close family member have impairments. They acknowledge that attitudes towards disability within the church have often been found wanting even if intentions were good, and that their new theologies of disability have been prompted and influenced by the social model and current human rights perspectives in society.

Perceiving the relative influence of the various models is even more complicated in a multi-cultural setting, and it is important for people of any worldview (whether religious or not) to be aware of their own assumptions and attitudes and how they are affected by their own and society's dominant worldview, as this makes it easier to recognize and value other people's differing worldviews. Watson (2006, p152) points out that

shared values and beliefs are so pervasive that we take our worldview for granted. A cultural orientation and appreciation of people's worldview helps us to understand behaviours and provides insights into what motivates them.

Similarly Atkin and Hussain (2003, p162) point out that normalcy, and therefore what is considered an 'impairment' - and subsequently an acceptable response to it - "is not a given universal, and impairment needs to be seen in its social and cultural context".

This process is not about 'going back' to a 'traditional' model that was more prevalent in the past, but rather about giving space for people to conceptualize a

model that is congruent with their worldview, and that is flexible enough to incorporate traditional, medical as well as social aspects.

This study has shown how important it can be for people of faith to go back to their scriptures and reflect on their perceptions, attitudes and practices. It has also shown how religion and culture affect each other: negative attitudes towards disability in the Pakistani 'Muslim culture' seem not to be based on the Qur'an, yet are expressed in religious terms.

Based on the literature review and the men's group's findings, there is little evidence of a new Muslim theology of disability so far. However, a small number of scholars have explored existing Islamic interpretations of disability (Ghaly, 2005, 2008; Bazna and Hatab, 2004) and implications for service provision (Ghaly, 2007; Bazna and Hatab, 2004). Furthermore there are some Muslim organizations of and for disabled Muslims in the UK, and one Mosque, Masjid Umar in Leicester, which promotes access and participation for disabled Muslims at Mosques (Sindhi, 2007), indicating the beginning of a shift in attitudes towards disability in parts of the Muslim community, increasing the chances of a positive response to initiating and supporting projects that seek to raise awareness of disability issues in the Pakistani community and Muslim leadership.

In conclusion the 'lived experience' of disabled people is made up not only of their impairment and barriers imposed by others, but also of their worldview, ethnicity and social circumstances (see Thomas, 2007; Shakespeare, 2006). Studying these important factors – especially religion, which has not been a major focus of research into disabled people's experiences, particularly in the disability studies literature - that influence the way individuals experience disability, can contribute to the continued development of social model thinking, so that it may become more nuanced and holistic (Pinder, 1996; Atkin and Hussain, 2003). This would give more room for disabled people of diverse backgrounds and the people they interact with to interpret and address the complex issues they face in more meaningful ways. This is important because the ideology of the social model of

disability has started to influence (the wording of) disability policy, suggesting that a deeper understanding of how religious and cultural issues impact on disability can inform both the policies and the service providers who are expected to implement the policies.

Implications for approaches to intervention and support

Given the multifarious aspects of living with impairments, no single approach to providing intervention or support will meet the needs of either disabled people themselves, the people immediately around them, or society as a whole. Medical and therapeutic intervention to minimize the extent of an impairment and maximize the level of the disabled person's functional ability are doubtlessly extremely valuable for enabling maximum participation in society. At the same time this participation is impossible without the ability and willingness of communities – including not only ethnic, religious and local communities, but also communities of service providers - to recognize the equal rights to inclusion in and the positive contribution of disabled people to society. This process of social change in turn needs to be supported by equitable public policies.

Within this multi-level approach to enabling disabled people to participate fully the influence of other social characteristics needs to be understood. These may include ethnicity, religion, gender, sexual orientation and socio-economic status, or indeed - as this study illustrates - several of these characteristics at once. This calls for a sound base of fair policies that ensure equal access to equal quality of services (see WHO, 2009), and a flexible, responsive person-centred and/or community-centred approach to intervention. The Canadian model of Family Centred Services, which “recognizes that each family is unique, that the family is the ‘constant’ in the child's life, and that they are the experts on the child's abilities and needs” (Law et al, 2003, p2) gives good scope for implementing these policies. As particularly the mothers in this study emphasized, this does not merely call for good professional knowledge and skills, but more importantly for positive personal attitude and effort put in by the individual professional to understand their clients' unique circumstances and response to living with impairments.

A comprehensive social model of disability and an appropriate response to it, like the one suggested (but thus far not widely implemented) by the College of Occupational Therapists (see chapters 1.3 and 1.4) will be helpful in coordinating action taken at different levels by different agencies. The principles taken from the Ottawa Charter for Health Promotion (1986) clearly emphasize the need for coordinated, multi-level responses, that is, to develop personal skills, create supportive environments, strengthen community action, reorient health services and build healthy public policy.

Current government policies relevant to disabled people and service delivery reflect the principles of the Ottawa Charter, e.g. the National Service Framework for disabled children states the need for social inclusion, integrated services and families' involvement in planning services (2004, p39). More recently the government report 'Aiming High for Disabled Children' (HM Treasury and Department for Education and Skills, 2007) was informed by a consultation exercise with families and professionals and committed to "take action in three priority areas to improve outcomes for disabled children: access and empowerment; responsive services and timely support; and improving quality and capacity". These policies are encouraging signs of the social model influencing the government's approach to providing services to disabled children.

However this study has illustrated that disabled children and their families have not yet felt the positive impact that these policies promise on their lives. Beyond the rhetoric, the implementation of the set goals not only requires a shift in working relationships between the different service providers, but also in the whole approach taken to supporting disabled children and their families: essentially a shift from medical model thinking to social model thinking, with the child's and family's rights and well-being becoming the central focus of service provision, and specific interventions becoming a means to an end, rather than verifiable actions to be entered on the departmental outcome measures. Apart from this shift in thinking, this will also take much time to achieve, which is illustrated by the fact that the

participant families did not report having experienced many supportive attitudes or initiatives in keeping with the new policies so far.

Issues around access to services for Pakistani and other ethnic minority families

Having discussed the need for the social model of disability to give more importance to worldview and ethnicity, and the implications of this for service provision in general, this section applies these principles to the service provision to Pakistani – and other ethnic minority - families with disabled children.

The section of chapter 4.1 about issues specific to Pakistani families (p 324) gives some indications about how the principles of the Ottawa Charter and current government policies might best be applied to the Pakistani community. Whilst all of these principles are important and challenging, the strengthening of community action may be most difficult to achieve, particularly for an issue that carries a strong stigma. Both the men's and the women's group experienced this in their attempts to engage community members or leaders in their actions. Whilst this confirms the need for strengthening community action, it also illustrates that consistent external professional and financial support will be needed to achieve this in local communities.

Despite the more favourable policy climate, statutory services still tend to expect black and minority ethnic communities to fit into standard services and to take the initiative to access services, rather than looking for ways to ensure services meet communities' specific needs and being proactive in drawing people into the service they need (Temple et al, 2008; Chahal and Iqbal Ullah, 2004). Practical guidelines for professionals working with individual families are available (e.g. Husain, 2005), though it is difficult to know to what extent they are used. However working towards strengthening community action with the Pakistani community may well be essential for enabling families to know how to access services on the one hand, and increasing the understanding and appreciation of the particular strengths and needs of the Pakistani community by service providers on the other

hand. As discussed in chapter 4.1 strengthening community action could be quite difficult and would need to involve facilitating families with disabled children themselves and Mosque leadership to be proactive in raising the community's awareness of disability issues and challenging negative attitudes. This could include making sure Mosques and other community venues are both welcoming and accessible to disabled people. Statutory services would need to work in partnership with community members to provide information and services at community level, ensuring these are both culturally relevant and supportive of the families as a whole.

Whilst it may not be practically possible for statutory services to take a leading role in the necessary community development activities, the policies' increased emphasis on integrated services does give scope for statutory services supporting and learning from voluntary and independent sector projects that work within and with minority communities. This can be developed at local levels, but existing reports and guidelines already give clear directions too, for example Mencap's "Reaching out" report (2006) and the Research and Practice briefing on "Improving services to meet the needs of minority ethnic children and families" (Barn, 2006). Based on the experience of the participant families, these types of guidelines and earlier research findings (e.g. Shah, 1996; Chamba, 1999; Bywaters at al, 2003; Hatton at al, 2004) have not had a noticeable impact on local services in their culturally diverse borough. Given that good information is available but not implemented systematically, both a change in commitment to providing equal, accessible services to all ethnic population groups at management level, and a change in attitude towards client and family-centred working with diverse clients at individual practitioner level are needed before positive change can occur.

This study has demonstrated that Pakistani families are both willing and able to be involved in evaluating current and influencing future services, and that participatory approaches can facilitate this process.

Mobilising the Pakistani religious leadership

Throughout the project it has been difficult to engage with the local Mosques in a collaborative and constructive way. Chapter 3.1 has presented a number of possible reasons for this. In addition the men's group experienced resistance to raising disability issues first-hand when they attempted to gain access to and information from Islamic scholars and Imams. Both participants and other community members have suggested that key problems may have been the particularly sensitive and stigmatised issue of disability, a general lack of initiative and motivation in the Pakistani community to get involved in community activities, and a lack of relationship and trust between the Mosque management and community members. The men's group emphasised that the latter was in part due to the unhelpful management structures and status issues within the management committees of the Mosques. In addition participant families had either not approached the Mosque for support as they did not expect it to be available, or had had a negative response.

It is difficult to know to what extent the local situation is reflected in other areas of the country. Sindhi (2007), a blind Muslim associated with Masjid Umar in Leicester, states that "within the Muslim community people with disabilities tend to remain isolated... (and) receive very little support from their religious communities". While the website states it wishes to hear from disabled people "about the barriers that you face as Muslims within the Muslim community and how we can work together", the participants of the men's group had no success in gaining a response from Masjid Umar despite repeated attempts. Nevertheless their initiative indicates that raising awareness of disability issues is problematic in Mosques in other areas too.

The publication of a "Management guide for Mosques and Islamic Centres" (Warrach, S and Feroze, K, 2007) indicates that issues around Mosque management are more broadly recognised as needing to be resolved too. Apart from internal management strategies, it includes a chapter on community development. The first author is quoted as saying that

The Mosque is uniquely positioned in British society to offer solutions to real problems in many areas where Muslims live. In areas where there is deprivation and under-achievement it is the Mosque which is the only credible and sizeable institution that can really engage the community, *if administered and projected coherently* (Begum, 2007, emphasis mine).

The East London Mosque is an example of how these principles can work in practice, as it is involved in projects in health promotion, improving school attendance, and domestic problems women face (Faith-based Regeneration Network, online a).

Whilst it may be less surprising that engaging with Mosque leadership can be difficult for a female non-Muslim researcher, the fact that the participants of the men's group met with a very poor response too is more problematic. Whilst the best way ahead would still be for Muslims to encourage Mosques to respond to community issues (as the men's group suggested in spite of their negative experience) they may need encouragement from outsiders to achieve this, as suggested in the previous section.

Having made a start with raising awareness of disability issues in the two local Mosques, and having highlighted the need for support from the Mosques and community for families with disabled children, there are a number of factors that may facilitate the development of such support.

Firstly, statutory services need to draw on already existing policies to become more proactive in collaborating with faith based and other community organisations to explore how religiously and culturally appropriate support systems may be set up.

Secondly, the local Mosques need to inspire their congregations to take the initiative to develop a more supportive community and projects, by networking with similar initiatives in other areas. For instance reports by the Joseph Rowntree Foundation (Singh, 2005) and the Council for Disabled Children (Simon, 2006) give

examples of good practice in community initiatives, including Muslim and/or Asian ones. For example Tassibee in Rotherham which started as a prayer meeting for Muslim women in 1993 has developed into a large developmental training organisation; one of their projects involved training community members to run self-help groups for women with mental health needs, leading to members gaining confidence and skills for employment and to improved awareness of mental health issues in the community. The project is supported by the local Community Mental Health Trust (Singh, 2005). The strength of this model is that the initiative and continued effort comes from within the community, whilst statutory services provide professional support and value the complementary role the project plays in overall service provision. However for a project like this to work a strong, visionary community lead is needed to be able to move on from an isolated group of women to a larger professional project that can attract funding to become sustainable.

Thirdly exploring funding opportunities within their own faith community as well as through the government (see the Faith-based Regeneration Network, online b) will help in considering what kind of projects may be possible.

However, considering the experience of this study, developing community based projects will need to start small and be built up gradually. In addition one or more individuals need to be identified, who can take the initiative, inspire other community members to be involved, and ensure that the Mosques remain supportive.

Marital and family relationships

Issues around relationships in Pakistani families have been described at various points in the thesis. The literature review showed that previous studies found that the incidence of mental health needs in Pakistani carers (mainly mothers) of disabled children was higher than in white British families, explained mainly by very poor support from their husbands and extended family members in their caring

role, as well as negative attitudes towards the disabled child and their mother (Fazil et al, 2002; Emerson et al, 2003; Bywaters et al, 2003; Hatton et al, 2004).

These findings were also reflected in this study, with 16 of the 18 mothers contacted reporting mental health needs to varying extents, and both the women's and men's groups acknowledging problems in providing emotional support and communication between spouses. It was evident that having a disabled child could be a contributing factor to stress and depression, but neither the women nor the men considered this to be a major cause of their relationship issues, with exception of the divorced mother, who indicated that her already poor marriage did not survive the very negative response of her ex-husband to his disabled son.

It is therefore important to see the problems faced by these families with disabled children in the wider context of Pakistani culture, whilst remaining conscious of the difficulties of interpreting cultural practices and of the danger of stereotyping the experiences of people of a different cultural background (see Burr, 2002; Huseyn and Cochrane, 2004). In addition cultural practices are liable to change over generations, particularly where parts of extended families migrate. Nevertheless the following section should be helpful.

Qadir et al (2005) who carried out a study into marital satisfaction among women in Pakistan describe the Pakistani context of marriage. They point out that marriage is "a process of unifying families, rather than just two individuals, and the emphasis is on fulfilling broad social obligations" (p196). Most marriages are arranged by the parents and as women "are constrained by traditions that enforce extreme submission to men" (p196) they have little option to refuse. In addition, there is a strong stigma associated with divorce, so their families would expect women to endure a poor marriage rather than get a divorce which would bring shame to the whole family. Once married the woman is the responsibility of her husband's family.

As girls are brought up to expect and accept this way of finding a marriage partner, and to respect parental authority as a religious duty (p196), it is difficult to

go against these traditions. However Shaw (2000, p163) points out that both in Pakistan and in the UK young people do sometimes refuse in order to marry a partner of their choice. In the UK this may be more common, especially when parents seek to arrange their marriage with a relative from Pakistan. However this remains a difficult issue, as parents seek to strengthen the ties with relatives 'back home' (Shaw and Charsley, 2006, p405) and the young people foresee problems in marrying a cousin who does not speak English or know the British culture, especially if there is a difference in level of education as well (Shaw, 2000, p189).

Bhopal's (1998) study of South Asian women in East London describes how the mother in law plays a very important role in a women's life, including in the upbringing of her children. Whilst this arrangement has advantages as well as disadvantages, chapter 4.1 has pointed out that it can be difficult for the husband to find a positive fathering role that fits in with the power relationship between his mother and his wife.

To return to Qadir et al's study (2005), they found that most women saw marriage as a social and familial obligation and that "women need to prepare themselves to adjust because the man seldom does, if ever" (p201). Nevertheless they expected a sense of mutual respect, some level of equality, and care from their husband and his family. The study also showed that "those women who were dissatisfied with their marriage (were) more at risk of common mental disorders" (p205).

It must be kept in mind that within the cultural context Pakistani families are as diverse as white British families. It is therefore very important for service providers not to make assumptions about family dynamics and relationship and to support families as they present themselves, rather than based on stereotyped expectations based on their ethnic background.

Furthermore, whilst it appears that the incidence of depression and anxiety is relatively very high among Pakistani mothers of disabled children, previous studies

do not give much detail about the nature of the marital relationships of these women and how they may be affected by their cultural background. A recent research review by One Plus One (a research and support organisation for couple and family relationships) found that any couple raising a disabled child "are at greater risk of divorce or separation and of experiencing poorer marital quality than parents raising non-disabled children" (Glenn, 2007, p26). This review did not examine the impact of culture or faith, and further research into the impact of raising a disabled child on Pakistani parents is needed. In the mean time Pakistani parents may find some guidance from general organisations such as One Plus One and Contact a Family (2008).

Three methodological issues

Finally, there were three issues that I was aware of throughout the project, and which remain 'unsolved'. They were unavoidable and hard to control, but as they influenced the research process it is important to acknowledge them.

A 'positive sample'

Whilst representativeness is not required or expected in a small participatory action research project, the sampling criteria appeared to lead to a rather 'positive sample'. For example, as all family members had to agree to participating, this meant that all fathers showed a certain level of acceptance towards their disabled child and commitment to the well-being of their families. A number of contacted mothers indicated that their family could not participate due to their husbands' unwillingness. In addition the families understood at the time they consented to participation that the research project would be time intensive and their active participation would be required.

It can therefore not be assumed that other groups of (Pakistani) families would be able to engage in the research process to the same extent and that similar approaches to providing support would prove successful.

However the culturally sensitive approach to exploring relationship issues could be applied by support projects, which are willing to go beyond 'drinking tea' as the women described it. The "Strengthening Families, Strengthening Communities" programme developed by the Race Equality Foundation (online), is an example of a parenting programme that could be adapted for families with disabled children.

Positive responses from the participants

Another issue that may have affected the outcomes of the project is the fact that I met a significant level of openness and positive responses from the participants. Whilst this was helpful, I was also aware that I might not be getting the whole story, that participants might be quite selective about what they did and did not disclose. During meetings the interactions were frequently positive and enthusiastic, yet attendance was erratic, bringing commitment to the process into doubt – yet reasons for not attending were mostly plausible so perhaps their lives were too full to include another commitment. The same considerations apply to the lack of implementation of ideas beyond the project. For a researcher the only option remains to take participants' responses at face value for the purpose of reporting findings, and to make their awareness of these issues evident.

The emancipatory effect: differentiating between 'me' and methodology

The third methodological issue is that it is difficult to prove what caused the emancipatory effect in this project. From the researcher's perspective, their reasons for choosing an emancipatory approach to research are likely to be related to their personal epistemology and ethical viewpoint. From the participants' perspective it may be difficult to distinguish between the research method and the personal traits of the researcher as well, and to differentiate the personal interaction from the tools of the research method. I therefore believe 'me' and the 'methodology' can not be entirely unravelled: a traditional researcher seeking to keep distance between themselves and the respondents, or to keep control over the process is likely to have difficulty in achieving emancipatory goals even when they apply suitable methods, whilst a researcher committed to using

research to improve their participants' situation is likely to achieve this even when more traditional methods are used.

Whilst my personal and professional experience have shaped my approach as a researcher and were very important in gaining the trust of the participants and facilitating them throughout the research process, the participants also recognised that the methods had an emancipatory effect in themselves, much of which stemmed from being facilitated to take action, e.g. the men profiling themselves as fathers of disabled children in order to request information and support from their Imams, the women designing leaflets and distributing them, and the children taking charge over organising the Eid party. In addition each group's control over the choice of topic for their action research, and the subsequent actions to be taken instilled confidence in their own ability to start dealing with the issues they faced in their lives.

Limitations: What would I do differently 'next time'?

Notwithstanding the wide range of new or enhanced insights gained from this study, with the benefit of hindsight there are a number of things I would have chosen to do differently.

Firstly I would embed the project within an existing service or project. Considering the central and positively viewed role of the special school this would be the best option, though family support projects could also work well. This would require a very different preparation and recruitment process, as the relevant team would need to be convinced of the need for and benefit of a research project like this. However the chances of sustainability of the process beyond the formal project time would be much higher.

Secondly, by not operating alone, the existing infrastructure and personnel can be used and built on, making it easier to bring whole families together in a safe and secure setting.

Thirdly I would involve different agencies in the planning and facilitation and support of the project, as this would promote team working and ensure a more integrated approach to supporting families.

Fourthly – and very importantly – I would involve the participants much more in the planning stages of the research, so that the ownership and control over the whole project would lie more strongly with them. For this a much longer project duration would be needed and this could only be done in the context of a PhD if the researcher already had a relationship with the participants before starting their studies.

Finally, participatory action research would still be the main approach of choice, as it provides a practical hands-on focus and offers opportunities for developing personal skills, both of which give the potential of participation in the project being an empowering experience. As the three different groups in this project have shown, participants may choose a wide range of practical methods (e.g. surveying local initiatives, interviewing community leaders, designing and sending invitation leaflets to a support group, exploring their own experience through games and story writing) to gain information and insight, or plan for action. Given more time and depending on the local situation the practical methods may vary, but the overall participatory approach remains highly relevant for community based research.

Recommendations

A number of recommendations can be made based on this study. Many of the recommendations are based on the participants' views and reflections on their research process, which they stated throughout the process, and particularly clearly whilst preparing for the collaborative conference presentation (see appendix I).

Models of disability

- The social model of disability needs to incorporate cultural and religious influences on the experience of disability more explicitly, and to acknowledge that (components of) the traditional and medical models of disability are not obsolete.

Improving access to and use of services

- Services need to be more proactive in supporting families from disadvantaged communities
- In cross-cultural care an open and caring attitude is fundamental, as this will lead to better listening and recognising cultural strengths to be built on in treatment and advice given. This is consistent with client / family-centred working and with current legislation such as the National Service Framework, Every Child Matters and the NHS Plan.
- As legislation to enable good service provision for all population groups is in place and many examples of good practice are freely available, critical research into the barriers and processes that hinder the delivery of good and equitable services needs to be undertaken.

Role of faith in explaining cause of impairments and accepting the child

- Service providers need to recognise and build on the strengths of families' faith and faith-inspired attitudes, and to recognise its role in the process of learning to accept and support the child.
- Islamic scholars and Imams need to educate themselves about Islamic teaching about disability, so that they can support families with disabled children and challenge negative attitudes

Mobilising the community

- Community development is needed, but funding and expertise are lacking within the (local) community, so external input will be needed initially – also

linkages need to be made with successful projects in other areas with large Pakistani communities

Supporting family relationships

- Existing services (e.g. special schools, support projects, therapy services) need to look for opportunities to bring mothers / parents together in culturally homogeneous groups and to facilitate deeper sharing. This can be facilitated through creative and participatory activities
- Further research into the culturally specific aspects of marital relationships of parents of disabled children is needed.
- Any family support project must involve fathers as their (lack of) support has a major influence on their wives' and disabled children's wellbeing
- Existing services need to give more attention and support to siblings, e.g. special school, social services and/or therapy services, both at home and in support groups.

Participatory Action Research

- Both statutory and community based services need to apply the ethos and practical methods of participatory (action) research, in order to improve the participation and support of families with disabled children of different ethnic backgrounds.

Participatory action research with Pakistani families with disabled children

- Disadvantaged communities need to be supported in gaining more control over their lives through participatory/emancipatory research projects.
- Future participatory action research projects in disadvantaged communities need to be much longer to allow time for trust building and for changes to take place at a pace the community can follow.

Occupational science perspective

- Occupational therapists need to understand cultural differences in family relationships and in perceptions of and attitudes towards disability, and to explore with each family how they experience them.
- In order to support the child effectively, the mother's and other family members' needs must be recognised and addressed.
- Community approaches need to complement individual treatment approaches, either by initiating or by linking in with already existing community projects.

Concluding remarks: The heart of the matter

Whilst this study has provided rich and detailed insight (knowledge of the information kind) into the support needs of Pakistani families with disabled children, the more fundamental insight (knowledge of the wisdom kind) has been around

how we go about generating knowledge that is both valid and vital to the well-being of individuals, communities, and for larger-scale social change. Action research challenges the claims of a positivistic view of knowledge which holds that in order to be credible, research must remain objective and value free (Brydon-Miller et al, 2003, p11).

The nature of the relationship has been about me as a researcher being on the participants' side, working together at a subject-subject level, in line with the principles of the critical social paradigm of research. The central importance of this was expressed eloquently by Maryam, who not only indicated how this was important in this project, but also what this might mean for effective service provision:

You made everyone feel as if they were the most important person in the project... Nobody had ever asked about ME before. Other professionals just

look at your child's problem, or even just part of the problem, never at the mother raising that child.

It is this ethos that allows for depth of communication and the acknowledgment of parents' central role in raising their disabled child, of their need for recognition and support in doing so, and of the value of their worldview for living positive lives with their disabled child. It is also this ethos that will enable service providers to implement current policies that emphasise the right to full inclusion for both ethnic minorities and disabled people, as the specific local requirements will become clearer through the level of communication and partnership that it facilitates.

Chapter summary

This final chapter has argued that the role of religion and faith in disabled people's lives needs to be more emphasised in the social model of disability and indicated implications for service delivery, particularly in cross-cultural settings. This was followed by a discussion of the issues around mobilising the Pakistani religious leadership to address poor community attitudes towards disability. In addition marital and family relationship issues and methodological issues were discussed. Finally the recommendations resulting from the thesis were presented, organised according to the major themes identified in the last two chapters, regarding the research approach as well as the content of the study.

An important and unexpected finding from his thesis was that faith and religion play a much more important role in the lives of Pakistani families with disabled children than previously recognised. This has important implications for service provision to Pakistani families as well as those from other ethnic and faith backgrounds.

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Appendices

- A. Poster presented at the COT Conference 2008**
- B. Interview guides for adults, non-disabled children and disabled children**
- C. Information sheets for participants**
- D. Individual consent / assent forms**
- E. Parental consent forms**
- F. Consent for the use of specific images**
- G. Initial posters and leaflets**
- H. Invitation letters distributed through schools and projects**
- I. PowerPoint slides of conference presentations**
- J. Overview of all visits and group meetings**
- K. Leaflet produced by women's group**
- L. PowerPoint presentation for Inclusion & Exclusion 2008 Conference**
- M. Evaluation forms**
- N. Conference proposal: first draft by Gulzar and final draft by me**
- O. Volunteer agreement**
- P. Story from "Views from our shoes"**

Appendix A

Poster presented at the COT Conference 2008

Crossing Borders: career progression for the w@ndering OT.

 1984 – 1989
The Netherlands
BSc OT

Old style 'training' with intensive teaching time focusing on medical sciences, OT skills and creative skills.
Medical / individual model of disability – therapist as expert helper.



 1991 – 1994
Pakistan
Voluntary Service Overseas:
Occupational Therapist
Community Based Rehabilitation
CPD provided by VSO focused on community development and practical skills. Learning to apply OT skills in a totally different context.
Starting to see individual within their community and need to address negative attitudes in society, but still focused on treating the individual.



 1999 – 2006
Pakistan
Teacher Educator for Inclusive Education, Development Consultant and Occupational Therapist (part-time for 2 years)
CPD difficult to come by and not OT-specific: curriculum planning (PBL), research methods, presenting at conferences. Focus in majority of assignments remained on disability and child development.
Major shift towards human rights perspective and social model of disability.
Professional identity crisis: "am I still an OT?". Writing chapter for "OT without Borders" made me reflect on how my background in OT shaped the way I worked in other (?) roles.



2009
Who knows what and where next?
I am looking forward to more / new CPD!
Whatever the job title will be, I now feel confident about making my identity as an OT explicit and using it to my advantage.



 1989 – 1991
England
Occupational Therapist
Acute physical rehabilitation
Continued Professional Development (CPD) focused on strengthening clinical skills, e.g. hand rehabilitation, CVA, Sensory Integration.
Medical / individual model of disability.

 1994 – 1999
Multi-cultural borough in England
Paediatric Occupational Therapist
Multi-disciplinary working and teaching others.
MA: Education and International Development.
CPD still focused on strengthening clinical skills, e.g. Bobath certification, SI, neuro-science, dyslexia. But also MA level module 'Teaching and Learning for OTs' and later project management and multi-disciplinary project development (before returning to Pakistan).
Still focused on individual child, but focusing on context of family and school more. Starting to see importance of inclusive education.

 2006 – present
England
PhD Health Studies
Full-time CPD?! PhD explores support needs of Pakistani families with disabled children in the UK, using an occupational justice framework through Participatory Action Research. This study integrates and draws on many previous professional and personal experiences.
Concepts around occupational justice support human rights perspective and the need to work from a social model of disability.
Reconciling my identity as an OT with roles fulfilled 'outside' traditional OT is liberating and enriching.

Appendix B
Interview guides for adults, non-disabled children
and disabled children

Interview guides for the exploratory phase.

Topics / questions are for guidance only and not all of them may be asked in each family, depending on the direction the participants take the interviews. The sequence may also vary, although I will always start with positive questions, rather than merely focusing on problems experienced. Additional questions may be added as the interview takes place.

Topics and questions are based on subsidiary research questions a. to f.

The name of the disabled child in the family will be inserted in place of “A”

Interview guide for parents / other adults:

What do you love most about A?

What have you learned from A and from being his/her parent?

In what way is your relationship with A different from your relationship with your other children?

What do you find most difficult about being A's parent?

Are there things you can not do because of A's impairment?

When did you find out about A's impairment?

Who told you and how?

How did you react at the time?

How did others in the family react?

How did people outside the family react?

Who provided support or treatment at that time?

Can you tell me about A's impairment?

What words do you use to describe his impairment in your own language(s)?

What words do others in the Pakistani community use to describe his impairment in your/their own language(s)? What do you think about these words?

Why do you think s/he has this impairment?

What have the doctors told you about the cause?

Which daily / regular activities that you carry out do you enjoy / are meaningful / important to you?

Do you get the opportunity to carry out these activities as often as you would like?

Why?

Are there daily / regular activities that you carry out which you do not enjoy / are not meaningful / fulfilling to you? What are they? Why do you think you need to do them?

What things do you do for or with A daily / often / sometimes? E.g.:

- activities of daily living
- school related
- play / activities
- talking / reading together
- outings
- other

Who gives you support in looking after A?

- within family (household / extended family)
- in the local community
- voluntary organizations
- statutory services

Within each of these, who and/or what do you find most helpful? Why?

Are there types of support offered to you, which you do not find helpful? Why?

What types of support have you had and found (un)helpful in the past?

Can we look at family photo albums together?

Focus on the place / role of A in the pictures

- elicit stories / memories
- is the child present at major events, such as weddings
- does A seem to enjoy the event / activity

Interview guide for non-disabled children

First I will ask the child to make a time-line of a typical school day and weekend day. This is an open instruction and the child will not be asked explicitly to consider their disabled sibling in the timeline.

We will then look at the timeline together and ensure these topics are discussed:

- regular activities and whether they are school, otherwise obligatory, or leisure
- which activities they like best / least and why
- what they like best / least about school

Invite the child to do a 'draw and write / tell' activity, based on the following open instruction:

"Please draw a picture about A and you. You can write a caption / story with your picture and / or tell me about the picture once you're finished".

Questions will lead on from the above activity and may include:

Do you play with A? How many times per week / day? What do you play?

What other things do you do together?

Do you help A with things? If so, how do you help him/her?

Do you help the person who mostly looks after A in other ways?

What do you like most about A and about being his/her sibling/cousin?

What have you learned from A?

What do like least about A and about being his/her sibling/cousin?

How do your friends react / relate to A? (includes trying to gauge whether children do not want to be their friend because of A, which may be too sensitive to ask directly)

Are there things you don't / can't do because of A's impairment?

Why do you think A has impairments?

Interview guide for disabled children

The format and nature of questions will depend on the nature and extent of A's impairment(s). Modes of expression and communication may include:

- verbal communication (talk)
- drawing / painting
- looking at photographs (family album and those taken for data collection) and talking about them and/or observing facial expression and other non-verbal communication
- using flashcards with symbols depicting people (actual portraits of family members), places, activities and objects, to be sorted into like / dislike, do often / rarely, who does what with/for me, etc.

If possible start with a "Draw and write / tell" activity, based on the following open instruction: "Please draw a picture about you and your family. You can write a story with your picture and / or tell me about the picture once you're finished".

The activity will be adapted according to the child's physical and intellectual abilities.

Questions will be asked concerning:

- Most and least favourite people / activities / toys
- School life
- Who they do and don't like to play with and who they actually play with (within family)
- Who is/are their best friend(s) and what they do together
- Who helps them and with which activities
- Activities they do most often; whether they like them; why they do them
- Activities they never / rarely do, but would like to do more often
- Awareness of / ideas about their impairment
- Awareness of / ideas about how this might lead to barriers / restrictions
- Awareness / experience of attitudes of people in family / community / school / general public

Appendix C
Information sheets for participants

Pakistani families with disabled children: exploring what kind of support is needed and how to get this support.

Information sheet for adult research participants

What is the research about?

A lot of families with disabled children in the UK find it difficult to find enough support from family, neighbours, voluntary services and formal services. This is even more difficult for families from ethnic minority backgrounds and earlier research suggests that Pakistani families are finding it hardest of all. The research aims to improve this situation by finding out what families themselves can do to get better support.

Who is the researcher?

My name is Debbie Kramer-Roy and I am a PhD student at Brunel University. I have lived in Pakistan for 9 years and have worked with disabled children and their families in different ways both in Pakistan and in England. I have 2 supervisors at the university. I do not work for any voluntary or formal services now.

How will the research be done?

This research will involve a number of families in exploring what exactly their support needs are, keeping in mind the specific issues faced by Pakistani families. All family members living at the same address as the disabled child will be involved. Initially I will work with each family to put together their 'story' relating to the disabled child through talking, family members taking photographs, children making drawings and looking at the things you regularly do together. After that, separate groups will be formed for men, women and children, to do their own 'action research', which means that I will guide participants in prioritising issues, planning action, taking action, thinking about the result of the action, planning more action, etcetera, by themselves. This approach means that you have a lot of control over what happens in the research, and that taking part will help you learn new ways of making sure enough support is available in future too. You may be able to use any knowledge, skills or hobbies that you already have in the research, depending on the action your group decides to take. Activities in the groups could include discussions, games, role-play, art work, writing and listening to stories, taking and discussing photographs, planning what to discuss with service providers, etc. The exact activities and whether they will be recorded in any way will depend on the group decisions.

How much time will it take?

From May to September 2007 I will visit each family approximately four times, to talk to all family members and carry out some other activities involving photographs and creative activities. From October 2007 to April 2008 participants will be working in groups and agree how often they should meet, ideally once every 2 to 3 weeks with possibly some (individual) action in between. There will also be some meetings for all the participants to share what you have found out with the other groups.

How will the research benefit me?

I expect that there are two ways in which you will benefit. The first is that it is likely that by the end of the research more support (within the family, from the community and/or from services) will be in place for the disabled child and family, through your own actions. The second is that taking part in action research will give you new skills and confidence that will help you in getting access to services and influencing their quality even after the research project is finished. However it is impossible to guarantee that the research will result in these benefits. The outcome will partly depend on the decisions that are made by individual participants and / or groups, and on the response from people that you may decide to involve in the action.

Are there any risks of participating in the research?

Because the research requires active participation and is about the family's life with the disabled child, it can be quite personal and intensive. It is possible that this process may be uncomfortable or cause misunderstandings at times. But, because you have a lot of control over what to discuss or how to take action, the intensity of the process depends more on the choice of the group (you) than on the researcher (me).

Agreeing to be part of the research project:

Participation in the project is completely voluntary and nobody will put pressure on you, either to become a participant, or to continue to be a participant. You have the right to withdraw at any time, without any negative consequences.

What will happen with my contributions?:

The things that you say and the other products that are made during the research (e.g. photographs or art work) will become part of any reports that will be written. This will be done anonymously, so that individual people can not be identified from these reports. The group may decide to share the outcomes in ways that do identify people, but only if all participants are happy with that. No photographs will be used in reports, unless people shown in them give explicit written permission for it.

Some of the things you say may be quoted word for word in reports. However this will only be done if doing so will not reveal your identity. Other things you say may be written about using different words.

Your contribution will not only benefit yourself, but also other Pakistani families with disabled children and all the different services that are seeking to provide support to them.

Safety and support:

If during the research I were to have concerns about the well-being and/or safety of your children or any other family member, it may be necessary for me to contact service providers or other professionals who can help your family. However I will only do so after discussing the issue with you, or – in the case of serious concerns over child safety - informing you.

If you have any further questions about the research please contact me:

Mobile phone number: 07960820560

Email address: debbie.kramer-roy@brunel.ac.uk

I look forward to working with your family on this project!

Debbie Kramer-Roy
PhD Student
Brunel University
School of Health Sciences and Social Care
Uxbridge
UB8 3PH
Tel: 01895 268678

This research project has been approved by the Research Ethics Committee of the School of Health Sciences and Social care of Brunel University.

If you have any concerns or complaints during the research project, you may contact:
Professor Peter Beresford, Research Supervisor.
Tel. 01895 268741, email peter.beresford@brunel.ac.uk

or Mr. David Anderson-Ford, Chair of the Research Ethics Committee.
Tel. 01895 268731, email david.anderson-ford@brunel.ac.uk.

Alternatively, you may use Brunel University's postal address mentioned above for both contacts.

Pakistani families with disabled children: exploring what kind of support is needed and how to get this support.
Information sheet for children who can not read yet.

NB: flashcards with symbols will be used to tell the child about the research, see end of this document.

My name is Debbie and I am a student.

I want to help you and your family to find out how to get better support.

I will come to your house and talk to you and all other people in the house.

We will write a story about you and the family together.

After that you will be in a group of children to do lots of fun activities.

You will think of things children can do to help each other, their parents and maybe others.

You don't have to do anything you don't like.

You can tell me in your own way what you do and don't like.

I will listen to you.

I will record what you say and photograph you and the things you make or do. Some activities may be video recorded.

Your ideas and things you make will be used to tell other people about the project, so that they can learn from it too.

I will first ask your parents for permission to show your name or photograph to others.

If I am worried about your well-being and/or safety I may have to contact people who can help your family. I will only do so after talking about it with you and your parents, or – in the case I am very worried about your safety - telling you and your parents that I have to do it.

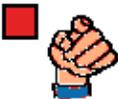
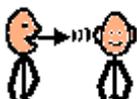
You can ask me any questions you like.

I look forward to working with your family on this project!

Debbie Kramer-Roy
PhD Student

Using flashcards:

Individual flash cards of each of the following Picture Communication Symbols (PCS) will be used to tell the child about the research project and to gain their consent. The size of the flash card will be approximately 8 x 8 cm and they will be laminated so that the child can handle them him/herself. After the verbal explanation/conversation supported by symbols, the child will sign the consent form if physically possible.

 Debbie	 Student	 Help / support	 Family	 Think
 You	 Your	 Visit	 Talk / explain	 How?
 Write	 Story	 After	 Group / children	 Tell / say
 Like / enjoy	 Special activity	 Don't	 Don't want	 Don't like
 People	 Idea	 Ask	 Parents	 Show
 Name	 Photograph	 Video record	 Understand	 Don't understand
 Listen	 Yes	 No	 Stop	 Question

Appendix D
Individual consent / assent forms

Pakistani families with disabled children: exploring what kind of support is needed and how to get this support.

CONSENT FORM

<i>The participant should complete the whole of this sheet him/herself</i>		
	<i>Please tick the appropriate box</i>	
	YES	NO
Have you read the Research Participant Information Sheet?	<input type="checkbox"/>	<input type="checkbox"/>
Have you been able to ask questions and talk about the project?	<input type="checkbox"/>	<input type="checkbox"/>
Have you been given clear answers to all your questions?	<input type="checkbox"/>	<input type="checkbox"/>
Who have you spoken to?		
Do you understand that your voice may be audio recorded, you and any things you make may be photographed, and some activities may be video recorded?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to your voice being audio recorded?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to being photographed?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to things you make or activities you do being photographed?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to activities you do being video recorded?	<input type="checkbox"/>	<input type="checkbox"/>

	YES		NO
--	-----	--	----

Do you understand that your name will not be mentioned and your photograph / video will not be shown in any report about the study, unless you and the group decide this should happen?	<input type="checkbox"/>		<input type="checkbox"/>
Do you understand that you are free to stop being part of the study:			
- at any time	<input type="checkbox"/>		<input type="checkbox"/>
- without having to give a reason for withdrawing?	<input type="checkbox"/>		<input type="checkbox"/>

Do you agree to take part in this study?	<input type="checkbox"/>		<input type="checkbox"/>
Signature:			
Name in capitals:			
Date:			
<u>Witness statement</u>			
I am satisfied that the above-named has given informed consent.			
Witnessed by (signature):			
Name in capitals:	Date:		

This research project has been approved by the Research Ethics Committee of the School of Health Sciences and Social care of Brunel University.

Pakistani families with disabled children: exploring what kind of support is needed and how to get this support.

ASSENT FORM

<i>The participant should complete the whole of this sheet him/herself</i>					
		<i>Please point at the appropriate box</i>			
		YES NO			
		 			
<i>Have you read the information?</i>					
					 
<i>Has Debbie explained things you did not understand?</i>					
					
<i>Do you understand Debbie will first ask you and your parents</i>					
					 
<i>for permission to show your name or photograph to others?</i>					











Do you understand you can stop working with Debbie at any time?









Would you like to work with Debbie in this project?






Signature of the child:





Signature of parent:

Name in capitals:

Name in capitals:

Date:

Date:

Witness statement

I am satisfied that the above-named has given informed consent.

Witnessed by:

Date:

Name in capitals:

This research project has been approved by the Research Ethics Committee of the School of Health Sciences and Social care of Brunel University.

Appendix E
Parental consent forms

Pakistani families with disabled children: exploring what kind of support is needed and how to get this support.

CONSENT FORM FOR PARENTS on behalf of their child

	<i>Please tick the appropriate box</i>	
	YES	NO
Do you allow your child to take part in this study?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to your child's voice being audio recorded?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to your child being photographed?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to things your child makes or activities your child does being photographed?	<input type="checkbox"/>	<input type="checkbox"/>
Do you agree to activities your child does being video recorded?	<input type="checkbox"/>	<input type="checkbox"/>

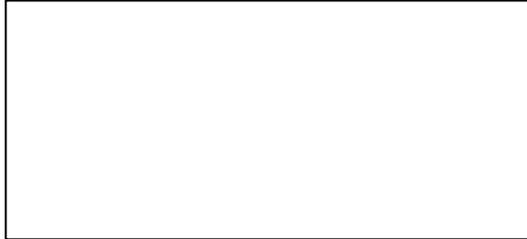
	Please tick the appropriate box	
	YES	NO
Do you understand that your child's name will not be mentioned and his/her photograph / video will not be shown in any report about the study, unless you and the group decide this should happen?	<input type="checkbox"/>	<input type="checkbox"/>
Signature of parent:		
Name in capitals:		
Date:		
<u>Witness statement</u>		
I am satisfied that the above-named has given informed consent.		
Witnessed by:		
Name in capitals:		
Date:		

This research project has been approved by the Research Ethics Committee of the School of Health Sciences and Social care of Brunel University.

Appendix F
Consent for the use of specific images

Pakistani families with disabled children: exploring what kind of support is needed and how to get this support.

Consent for using pictures for publications / presentations:



		Please tick the appropriate box	
		YES	NO
I consent to the above image being included in the following publication / presentation:		<input type="checkbox"/>	<input type="checkbox"/>
____(exact details will be inserted)_____			
I consent to the above image being used for any further publications / presentations that relate directly to this research		<input type="checkbox"/>	<input type="checkbox"/>

Signature:
Name in capitals:
Date:

Appendix G
Initial posters and leaflets

Pakistani families with disabled children:

*exploring what kind of support is needed
and how to get this support.*

You are cordially invited to come to an information meeting about a research project that is based on the above questions. It is aimed at families with children who have significant physical, intellectual, hearing or visual impairments.

This is a practical project in which ALL members of the family will carry out activities and learn new ways of working on this problem together.

The researcher is Debbie Kramer-Roy, a PhD student at Brunel University in Uxbridge. She has lived in Pakistan for many years where she has worked with disabled children and their families, communities and schools.

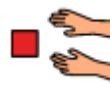
Debbie speaks Urdu fluently, so you do not need to be able to speak English to take part in the project.

Date: Sunday 17 June 2007

Time: 3:00 p.m.

If you are not sure whether this meeting is for you, please feel free to phone Debbie on 079 60820560

If you are not sure whether this meeting is for you, please feel free to phone Debbie on 079 60820560



I want to help you and your family to find out how to get better help.

This research project has been approved by the Research Ethics Committee of the School of Health Sciences and Social Care of Brunel University, Uxbridge UB8 3PH.

صعزود پاكستانى بچوں كے خاندان:
 ان كو يڪن سيارے كى مزدور تھے اور كياں سے وه به سيارا حاصل كر سكتے
 هیں .

كيا آك كى باره سوال كى كركے كا كوئى صعزور تھے به ؟
 كيا آك كو اهيے خاندان كے بچے سيارا اپنے ميں كوئى مشكل هیں آرهى به ؟
 كيا آك ان مسائل كى وضويات سو چنا چايتے هیں اور ان كو منظر عام به لانا چايتے
 هیں ؟ تاكه ان كا حل تلاش كيا جاسكے .
 هم آك كو فونى آره كر كيتے هیں كه آك سيارا كى Research Project كى information
 meeting ميں آهينى هوكه اوهر توكے كمتے سوالات به مشكل هے . به Project ان
 افراد كے بچے به ميں كے بچے ذهين يا جسمانى طوره به صعزور هیں يا بهتر
 مننه اور ديكهنے كى معلاصبت به ضرور هیں .
 به ايكيا محلى به كرام هے ميں ميں خاندان كے تمام افراد مل كر ان مشكلات كا
 حل تلاش كر سكتے هیں .

تحقيقى كرنے والى Debbie Kramer به كوه لائبريدجى Unibaidge University كى PhD كى
 طالبه هے . وه كا فنى كرم به پاكستان ره كلى هیں . جياں به انهنوں نے صعزور بچوں اور
 ان كے كهر والوں كے ساكه سوكهوں اور كيهو ميں ميں كا فنى كام كيا هے .
 Debbie آره دوران كے ساكه بول سكتى هے اس بچے آك كو اس Project ميں حصه بهينے
 كے بچے انگلش بولنے كى ضرورت هيا هے .
 بهرا به باني دورے كوئوں كو هم اس meeting ميں آهنے كى دعوت هوں .

تاريخ
وقت
جگه

اگر آك كو سمجه هيا آرهى كه به به كرام ميں بهى هے تو بهرا به باني اس ميون بهتر به واليم
 كرم 079 66820560
 ميں آك كى اور آك كے خاندان كى صعزور كرم كى كه آك به سيارا كيهے تلاش كر سكتے هیں .
 Research Ethics Comittiy of Bathell, Research Project
 ميں پاس بهو چكا هے .

Appendix H
Invitation letters distributed through school s and projects

23 July 2007

Dear Parents,

An exciting project for Pakistani families with disabled children is about to start!

The main aim of this research project is that it will help participating families to find better support for the disabled child and the family members who look after him or her.

My name is Debbie Kramer-Roy and I am a PhD student at Brunel University in Uxbridge. I have lived in Pakistan for many years where I worked with disabled children and their families, schools and communities. I speak Urdu fluently.

The first part of the project will involve some interesting home based activities for all members of the family. I will visit each family a few times and spend time with each family member. During the second part of the project there will also be group meetings for men, women and children separately, which will be interesting as well as useful.

If you would like to hear more about the project, please contact me to find out more on 079 6082 0560. I can come and visit you to talk about the project if you wish; you will still be free to decide whether or not to participate even if I visit!

You may have heard about the project already through the Mosques in and I enclose the leaflet that was distributed there for your information – it has the information in Urdu at the back.

I look forward to hearing from you!

Debbie Kramer-Roy
PhD Student
Mary Seacole Building
Brunel University
Uxbridge UB8 3PH

Appendix I
PowerPoint slides of conference presentations

Improving the lives of Pakistani families with disabled children in the UK

PhD Students Conference
Brunel University July 2006
(poster)

Why my interest in this group?

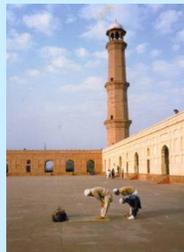
- Work experience with Pakistani families in Pakistan and England
 - As occupational therapist in UK
 - As occupational therapist, teacher educator, awareness raiser / activist, community development worker in Pakistan
- Gradual move from medical model to social model of disability
- This research will weave together various personal and professional experiences into a tapestry



Family life

Immigration can lead to problems¹

- **Mother:**
 - At home, provides all child care
 - Poor English
 - Isolation
- **Father:**
 - Unemployed or low-skill / low-income job
 - Feels misunderstood and unwelcome in English society
 - Loss of role in family and mosque
- **Generation gap:**
 - Parents strengthen own culture
 - Children are torn between own and host culture



Problems faced in relation to the disabled child²

- Significantly poorer than counterparts from majority population (income, employment, housing, benefits)
- Poor access to services
 - language barrier,
 - discrimination, negative attitudes
 - Stereotyped assumptions by service providers, rather than listening to carers
 - Mismatch between felt needs and available services
 - Not involved in planning or running services
- Poor attitude towards disability in own community
- Mothers bear the brunt:
 - Blamed for producing 'defective' child
 - Take on most of the caring role
 - Poor emotional or practical support from husband and other relatives
 - High rates of anxiety and depression



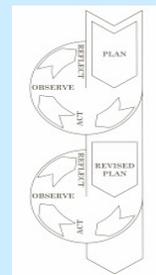
Research Methods

- Critical Social Research⁴ paradigm:
 - motivation is to contribute to improved conditions and quality of life of the participants / the population they represent
- Principles of Emancipatory Disability Research⁵
 - Research agenda and process controlled by participants
 - Researcher is accountable to the disabled community
 - Research adheres to social model of disability
 - No illusion of 'objectivity'; researcher profiles personal stance clearly to the participants
 - Mainly qualitative methods / strategies
 - Individual and collective experience of disabled people are fundamental in understanding social injustice and inequality
 - Must have meaningful, practical outcome for disabled people



Proposed sequence of events

- Exploratory stage:
 - literature review
 - getting to know existing services
- Proposal writing:
 - research participants to be involved in this process
- Active research stage:
 - Life / family histories using creative methods
 - Regular meetings / activities with group(s)
 - Action research cycle: reflection, planning action⁶
- Analysis and thesis writing:
 - Meticulous field-notes and on-going analysis will be essential due to amount and richness of data



By the sweat of your hand you shall eat your bread. You shall eat the bread of adversity, and you shall eat the bread of hunger. You shall eat the bread of sorrow, and you shall eat the bread of grief. You shall eat the bread of tears, and you shall eat the bread of bitterness. You shall eat the bread of death, and you shall eat the bread of life.

Occupational Therapy

- Important to challenge OTs to think and act outside the box
- New concepts and principles debated in occupational science:
 - Engagement in the research process is a purposeful occupation in itself
 - Outcomes in the area of occupational justice³: enabling people to participate to the greatest extent possible in occupations they choose or need to be engaged in, leading to increased control over their own life and improved occupational balance and enhanced participation in society
- Occupational therapy skills transfer well to facilitating the research process
 - Enabling participants to take control over the research process and activities
 - Analytical and creative thinking
 - Facilitating group processes



Participants and focus

- Participants will be 6 to 8 families of first generation Pakistani Muslim immigrants:
 - Children with disabilities and/or
 - Mothers and/or
 - Fathers and/or
 - Other family members
- Possible focus issues:
 - Concepts of disability in light of religion, cultures and personality
 - Position / status in communities
 - Relationship with service providers
 - Accessing services and benefits
 - Caring roles and support relationships within the family
 - Developing better coping strategies
 - Self-advocacy and awareness raising
 - Influencing agencies to improve cultural appropriateness of services



Your comments and ideas

There are still many questions to be answered before I can proceed:

- Should I focus on the family as a whole or one or more members?
- How do I enable a disempowered group of participants to take control of the research process?
- Will the objectives for the participants and for me be the same? How do I phrase the research questions?
- To what extent do I emphasize occupational therapy / science concepts both in rationale / underpinnings and in terms of outcomes?

References

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5. Barnes, C (2002). 'Emancipatory disability research': project or process? *Journal of Research in Special Educational Needs* 2(1) pp??
6. Kammis, S, McTaggart, R and Retallick, J (2004). *The Action Research Planner, 2nd Edition (Revised)*. Karachi: Aga Khan University Institute for Educational Development.
7. Line drawings from Werner, D (1987). *Disabled Village Children*. Palo Alto: Healthrights.

Support needs of Pakistani families with disabled children in the UK.

Inclusion and Exclusion Conference 2007

Debbie Kramer-Roy
PhD Student – Brunel University

What do we know already?

- What are the key issues faced by people from Pakistani origin in this society?
- Which additional issues / problems might arise when a disabled child is born in the family?



Key issues for Pakistani families (1)

- Poverty: 60% are low-income families (68% after housing cost), compared to 20% overall¹
- High unemployment rate (twice the rate compared to white population for men; three times for women)²
- Less likely to have professional qualification or higher education (especially men)²
- More likely to work unsocial hours due to shift work, restaurant and retail jobs – impact on father's role in children's upbringing³

Key issues for Pakistani families (2)

- Higher incidence of ill health
- Problems with English proficiency among first generation, especially women
- Rise in "Islamophobia" after 9/11 and 7/7, leading to more alienation⁴
- Men feel misunderstood and misrepresented and struggle to redefine their role in the family (being the 'provider' and need for 'authority')⁴
- Lack of faith/culture appropriate provision of social and leisure activities⁴

Add a disabled child to the equation (1)

- Higher prevalence of disabilities (3 x for severe learning disability; 6x for hearing loss; 4 x for sight loss; 10x genetic causes according to one study)⁵
- Cost of raising disabled child 3.5 x as high as a non-disabled child – benefits do not cover the difference⁶
- Less likely to get benefits, more likely to get lower rate⁶
- Poor access to health and social care (not for want of trying!)⁷

Add a disabled child to the equation (2)

- Negative attitudes towards disability in all sections of society, but possibly more overt in Pakistani community⁸:
 - God's will / testing / punishment - not based on Quran, but common belief
 - Mother often blamed for child's disability
 - Less likely to receive emotional or practical support from husband, extended family or community
 - Support from religious community is rare
- High incidence of depression and anxiety among primary carers (70%, versus 47% in general population)⁹



Impact of research?

- What could be reasons for the research findings not impacting significantly on service delivery and support becoming more appropriate and more available?
- What needs to change in the approach to research and service development?

Complex web of marginalization

- Families have a number of characteristics that make society see them as the ultimate "other":
 - Ethnicity: colour, culture, language, also former colony
 - Religion: the 'dreaded' (highly misrepresented!) Islam
 - Disability
 - And for most main carers: gender
- Traditional research does not challenge or address the resulting oppression effectively
- A critical emancipatory approach to research is needed

Critical Emancipatory Research¹⁰

- Researchers take account of historical, social and political influences on human thought and action
- Observes that social structures have historically served to oppress certain groups in society, particularly the working class, women and ethnic groups
- Research has emancipatory goals and seeks to bring empowerment to oppressed groups
- Purposes are:
 - to expose inequalities and injustices;
 - to give voice to excluded and marginalised groups;
 - to help explain generalised oppression in order to enable positive social change

Principles of Emancipatory Disability Research¹¹

- Research agenda and process controlled by participants
- Researcher is accountable to the disabled community
- Research adheres to social model of disability
- No illusion of 'objectivity'; researcher profiles personal stance clearly to the participants
- Mainly qualitative methods / strategies
- Individual and collective experience of disabled people are fundamental in understanding social injustice and inequality
- Must have meaningful, practical outcome for disabled people

But how?

- Emancipatory Disability Research does not suggest or prescribe certain methods, but adopts and adapts qualitative and quantitative methods depending on focus and purpose of the research
- Emancipatory potential depends more on the researcher's attitude and relationship with the participants (co-researchers) than on the exact method
- Still, a structured research process is needed

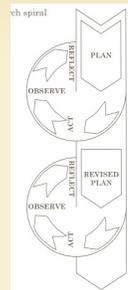
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- Participatory Action Research belongs to a family of approaches under the umbrella of "Action Research"
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- an emancipatory practice aimed at helping an oppressed group to identify and act on social policies and practices that keep unequal power relations in place
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The Action Research Cycle¹⁵



- the engagement in the cyclical action research process of reconnaissance / observation, analysis, planning, action and reflection facilitates participants in being able to act on what they know, i.e. "practical knowing"

Impact of Level of Participation¹⁶

Mode of participation	Involvement of local people	Relationship of research and action to local people
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What will I do?

- Find small number of families willing to participate (!); sampling probably through Mosques
- Construct family (hi)story around the disabled child with each family – use variety of methods
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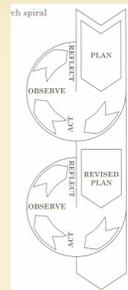
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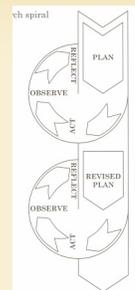
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خوش آمدید

Gaining Access to Pakistani Families with Disabled Children

Debbie Kramer-Roy



خوش آمدید

Title of the study:
Exploring support needs of Pakistani families with disabled children in the UK using an occupational justice framework: a participatory action research study.

Current stage:
Attempting to identify participant families



خوش آمدید

Entering the community

- “Sampling is a complex social process of gaining access to the community itself” (Sixsmith et al, 2003, p579)
- “Community entry forms a large part of, and is an essential step in, the process of community participation” (Tareen and Abu Omar, 1997, p97)
- “Recruitment of (participants) can ‘make or break’ social research projects, yet this has received little research attention” (McLean and Campbell, 2003, p41)
- “Before we can engage with anyone in cycles of action and reflection we need to have the ability to establish relations with an appropriate grouping of people, which means we must either have some access to the community or we need to develop legitimacy and the capacity to convene that goes along with it” (Reason, 2007)

خوش آمدید

Who enters when and where?

- Based in Pakistan, married to Pakistani husband – ‘quasi insider’ as well as outsider??
- Practical and theoretical knowledge of culture, religion, language, etc.
- Chose to live in largely Asian neighbourhood to become part of the scene before ‘entering’ as a researcher



خوش آمدید

What I planned to do:

- **Importance of men’s involvement:**
 - Often perceived to be ‘a problem’
 - Gatekeeper to family domain
- **Decided to advertise information meeting through Mosques:**
 - Announcement after Friday prayers
 - 700 flyers
 - Posters also in Islamic bookshops and community centres



خوش آمدید

What happened?

- During negotiations with gatekeepers in the Mosques, response was mainly positive.
- But one person suggested I might be working under cover for the Home Office and I had to convince the committee at one of the Mosques that I could be trusted!
- Building trust and relationships was slow, but sure and required much cultural sensitivity!



What happened?



خوش آمدید

- Nobody came to the meeting!
- Why?! Many reasons suggested by community contacts and literature:
 - Stigma and shame about disability?
 - Difficult to take initiative to attend or phone?
 - Lack of trust between gatekeepers and potential participants? (Emmel et al, 2007)
 - Don't want to be seen 'acting white'? (Campbell and McLean, 2003)
 - Bad time? – Sunday afternoon
 - Wrong venue? – conservative Mosque
 - Participation expected to be extra burden?
 - Doubt the usefulness of research?
 - Poster not attractive enough?
 - Didn't see the poster or flyer?

What am I learning?



خوش آمدید

- Reassuringly: I am not alone!

"The initial period of fieldwork can be frustrating and give rise to self-doubt. The (researcher) may lie awake at night worrying about some mistake, some faux pas, made during the day. There may be times of embarrassment, feeling foolish.... On the other hand, the initial period of fieldwork can also be an exhilarating time, a period of rapid new learning, when the senses are heightened by exposure to new stimuli, and a time of testing one's social, intellectual, emotional, and physical capabilities" (Patton, 2002, p313)

What am I learning? (2)

خوش آمدید

- About Pakistani community in the UK:
 - Importance of Pakistani identity (as opposed to British identity)
 - Selective participation, as it may confuse the public and private spheres
 - Keeping things in the family: culture of shame and gossip
 - Recruitment through organisations of limited value
 - Access to women hard to achieve and normally through men
 - Key importance of personal recommendation / snowballing



McLean and Campbell (2003), Campbell and McLean (2003)

What am I learning? (3)

خوش آمدید

- About disadvantaged communities in general:
 - Gatekeepers can help or hinder (or both)
 - Advertising does not tend to work well
 - Need variety of sampling techniques (Sixsmith et al, 2003)
 - Although access to communities is generally considered 'open', ethnic and 'class' difference between community and researcher can make it 'closed'. (Hornsby-Smith, 1993)
 - Importance of 'impression management' (Silverman, 2005; Kaufman, 1994)



What next?

خوش آمدید

- Pursuing existing contacts to encourage them to lead me to families
- Asking Special Schools to send letters home with Pakistani pupils
- Carers' Centre newsletter
- Give talk about work in Pakistan to enable community to get to know me (but need 'host': Mosque? Voluntary sector project?)
- Snowballing, BUT need one or two families to start with!



خوش آمدید؟

- The 'welcome' has not been as forthcoming as I might have wished!
- Importance of conceptualizing recruitment as a socio-culturally contextualized process unique for each community
- The recruitment process provides valuable data, both in its own right and in preparing the researcher for interacting well with the participants at later stages.

McLean and Campbell, 2003

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Participatory Action Research by/with Pakistani families with disabled children



Debbie Kramer-Roy
'ResearchingChildren' Conference
Innsbruck 10 – 12 December 2007

Overview of the presentation

- Background of the study
- About Participatory Action Research
- Progress so far
- Children's involvement
- Looking ahead / questions

Why this study?

- Both previous research studies and my own professional experience indicate that Pakistani families with disabled children in the UK face many challenges and have many unmet needs
- Despite this being an identified problem for well over a decade, services have not improved significantly

For full details see Kramer-Roy (2007)

Objectives of the study

1. To identify the support needs of Pakistani families with disabled children and to explore how these needs can be met more effectively
2. To explore how engaging the research participants in undertaking participatory action research in groups of men, women and children can facilitate their active role in achieving objective 1

Why me?

- 9 years of working in Pakistan (so far) and 4 years with Pakistani families in the UK:
 - Understanding of culture, language, religion
 - Both insider and outsider
 - Used participatory and rights-based approaches in variety of roles - OT, CBR, project planning and evaluation, teacher education (IE), research.



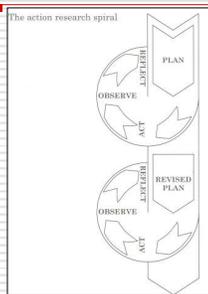
At a children's session

Why Participatory Action Research (PAR)?

- An emancipatory practice aimed at helping an oppressed group to identify and act on social policies and practices that keep unequal power relations in place (Herr and Anderson, 2005, p8)
- Lived experience and knowledge of people are directly valued and central to the process. Aims are to produce knowledge and action that are directly useful to the participants and to empower them through the process of constructing and using their own knowledge (Reason, 1994, p6)
- Bundling of practical and academic knowledge in order to improve the situation

How does (P)AR work?

- A spiral of cycles, each of which consists of planning, action, observation of the impact of the action, and evaluation of that action and its impact
- A dynamic process in which these four aspects are not seen as static steps, but rather as moments in the action research spiral.



(Kemmis et al., 2004, p3-4).

The PAR process in this study (1)

- **Reconnaissance phase:**
 - Based in each family's home
 - All members of the family individually and together
 - Activities
 - Interviews (all family members, if possible)
 - Timelines
 - Draw and Tell
 - Photography (disposable cameras)
 - Illustrated family story for each family

The PAR process in this study (2)

- **The action research cycles**
 - In three groups: men, women, children
 1. Group members get to know each other and start to understand how they will do research together - forming 'communicative space'
 2. Groups reflect on the themes / issues that emerged from the reconnaissance phase
 3. They prioritize and choose issues to resolve (based on importance, urgency and/or 'do-ability')
 4. Cycles of Planning, Acting, Observing and Reflecting commence

The PAR process in this study (3)

- **Dissemination**
 - Participants - adults and children - will be encouraged to actively participate in dissemination at local level.
 - Exactly what will be disseminated, as well as how, depends on group decisions!
 - Important part of the emancipatory process and ensuring that findings can have a real impact on support services / systems

Progress so far

- Initial difficulty in finding families
- Reconnaissance phase almost over
- Group meetings have started
 - One each for men's and women's groups
 - Four for the children's group
 - Two for all families together
- Initial meetings are part of reconnaissance as introductory activities generate additional data



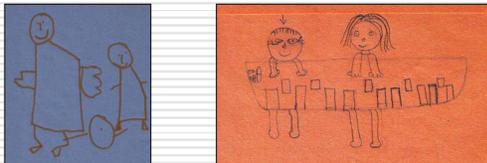
Photography activity

So what did the children do?

- **Daily Timelines:**
 - All siblings did this
 - Found this difficult and left major gaps
 - Mostly did not mention disabled child at all
 - But it formed a good and tangible starting point for interview and made it easier to ask about caring tasks and relationships

Daily Timeline	Name

Draw and Tell



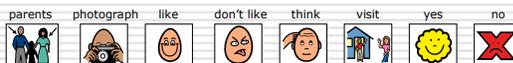
- "Please draw a picture of you and your brother / sister"
- Mostly 'portrait' style
- Some show favourite activity (see above)
- Overwhelmingly positive images

Interviews with non-disabled siblings

- Based on timelines and drawings
- Exploring relationship with disabled child, concepts of disability, time use, caring roles, impact on friendships
- It was evident that the majority of children were not used to talking about their perceptions, ideas and feelings related to having a disabled sibling

Interviews with disabled siblings

- Not all children are able to speak and/or draw
 - Questions became more 'closed'
 - More difficult to avoid leading questions
 - Using less verbal ways of communication like play and symbol cards
 - Use of observation more important



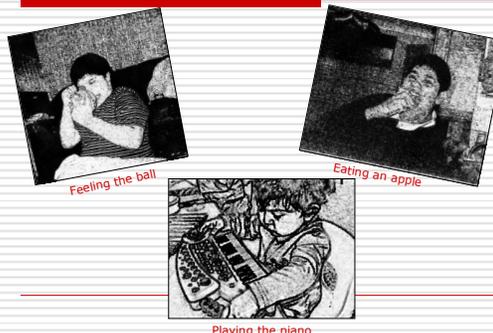
Working with symbols



Photography

- Purpose was to get a visual impression of family life with the disabled child through all family members taking pictures and writing down why and where they were taken.
- Challenges:
 - Cameras did not work well.....
 - Very limited range of activities, mainly in home
 - Difficult to get an appointment with the whole family to view and talk about the pictures
- BUT viewing sessions were enjoyed by all and the pictures led to lots of stories enhancing my insight into family life and relationships

Some of the photographs



Children's group - successes

- During holidays (3 days so far) and one Saturday per month (1 so far)
- Children getting to know each other and starting to share their stories, ideas and feelings – gradually!
- Also starting to gain confidence in planning and deciding things together
- Starting to realize that they can conduct research

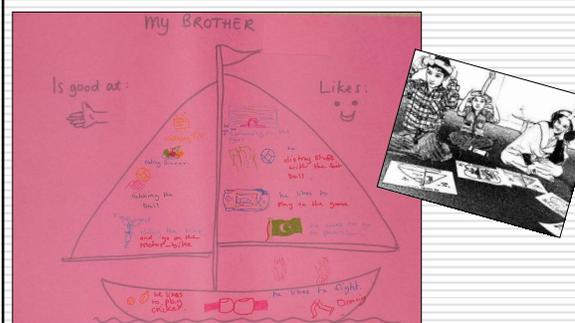
Children's group challenges

- Making sure children attend meetings takes huge efforts
- Some children shy and reluctant
- Age range 5-12: challenge of designing activities suitable for all
- Balancing fun and 'serious' activity
- Arriving late – less time; entertaining early arrivals
- Venue – upstairs in large Mosque / school complex
- Concentration / noise!

Siblings only?!

- I had to give up my ideal of making the children's group inclusive:
 - Some disabled children were severely disabled or very young, or very hyperactive:
 - Issues of safety, distressing context and practicalities
- There are advantages
 - Siblings need opportunity to spend time away from disabled child
 - Issues discussed more openly
 - Focus will be on making things better for the family, starting from the disabled child.

Some examples of activities: Worksheet about what their disabled brother likes / is good at



Planning for the family Eid Party

- Children thought of activities their disabled siblings could join in with and enjoy
- Also suitable / favourite foods, keeping in mind restrictions (religious / allergies)
- They made Eid cards for their disabled siblings based on likes identified in previous activity;
- They made a large welcome banner for the party



Mr Men and Little Miss

Have a look at the examples of Mr Men and Little Miss characters.

Can you make a character to represent yourself?

And one to represent your brother with special needs?

And anyone else in the family?



Examples of the children's Mr Men



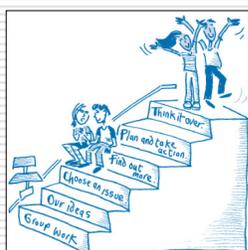
Feelings cube

Gibbs et al (2002, p72)

- 3 positive and 3 negative feelings: non-threatening game to allow sad or negative stories to be shared
- *"I felt embarrassed when my brother started screaming in the supermarket"*
- *"I felt angry when my dad blamed me for the mess my brother had made"*



Becoming researchers



Source: Gibbs et al (2002, p13)

- Children discussed what research is and whether children can be researchers ('no' became 'yes!')
- Using Child-to-Child Trust resources to explain – participatory, investigation-based health education: very congruent with PAR
- Stage: approaching the third step - 'choose an issue'
- Hope to have time to work on more than one issue!

Questions in my mind:

- How to facilitate decision-making without being directive? Gradual process?
- How to ensure feedback by children to the other groups? (2 meetings for all participants together were not successful!)
- How to encourage attendance / parents bringing children?
-

Acknowledgements:

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 - The children and their families who are participants in this study for being a great source of inspiration and learning for me.
 - My supervisors, Prof. Peter Beresford and Prof. Judith Harwin for their faith in me and their very valuable support and advice.

Thank you!

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Exploring support needs of Pakistani families with disabled children in the UK using an occupational justice framework: a Participatory Action Research study

Debbie Kramer-Roy
4th March 2008 ARSG




Why this study?

- Both previous research studies and my own professional experience indicate that Pakistani families with disabled children in the UK face many challenges and have many unmet needs
- Despite this being an identified problem for well over a decade, services have not improved significantly

For full details see Kramer-Roy (2007)




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At a children's session at the Mosque




Why Participatory Action Research (PAR)?

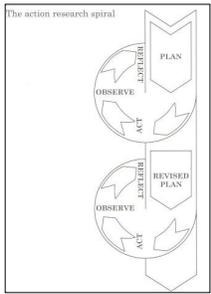
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The PAR process in this study (1)

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 - Draw and Tell
 - Photography (disposable cameras)
 - Illustrated family story / album for each family

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The PAR process in this study (2)

- The action research cycles
 - In three groups: men, women, children
 1. Group members get to know each other and start to understand how they will do research together - forming 'communicative space'
 2. Groups reflect on the themes / issues that emerged from the reconnaissance phase
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- Dissemination
 - Participants – adults and children - will be encouraged to actively participate in dissemination at local level.
 - Exactly what will be disseminated, as well as how, depends on group decisions
 - Important part of the emancipatory process and ensuring that findings can have a real impact on support services / systems

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Progress so far

- Initial difficulty in finding families
- Reconnaissance phase stretched as final family signed up in January, though groups started earlier
- Group meetings
 - men's group going well
 - ladies' group – mixed success
 - children's group – some successes, but poorly attended
 - all families together – poorly attended



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Finding families

- Importance of men's involvement led me to invite through the Mosques – this did not work despite (apparent) cooperation of 'gate keepers'
- Then approached special schools, carers projects, etc., who passed on invitations, but still very low response rate. Phone calls increased response rate slightly.
- Some 'snowballing', but most families did not know others, even in child's school: isolation
- Project too daunting or time consuming?
 - Probably, but once involved the participants enjoy it and see the benefit

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Men's group

- Meet once every 3 weeks (due to shift work) at a local Mosque
- Well attended
- Men feel at ease and share more personal views and feelings than expected
- Chosen focus: "what do the Quran and Hadith teach about disability?"
- Approaching Islamic Scholars and a Mosque that works on disability issues

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HEAD: thinking skills: what are you good at?

EARS: who or what do you listen to?

SHOULDERS: what responsibilities weigh heavily?

TRUNK: how do you maintain balance in your life?: home / work / relaxation / leisure

HANDS: in what ways do you help family members?

BAG: what things / resources do you have or can you use?

FEET: what is your foundation?: e.g. values, worldview, etc.

what **'WHAT'** do you wear? (roles)

EYES: what is your vision?

MOUTH: language and communication skills

HEAR: social skills and network / who is important to you?

HANDS: what practical skills are you good at?

LEGS: what steps could you undertake to change life for the better?

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Ladies' group

- Meets every 2 weeks in one of their homes
- Started off very well – positive feedback about opportunity to share, it being 'uplifting' – 'catharsis' and very open
- Last two meeting poorly attended – genuine reasons, but...
- More person-focused than men – difficult to move the process on, so no focus chosen yet

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Children's group - successes

- During holidays and one Saturday per month
- Children getting to know each other and starting to share their stories, ideas and feelings – gradually!
- Also starting to gain confidence in planning and deciding things together
- Starting to realize that they can conduct research

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Becoming researchers

Source: Gibbs et al (2002, p13)

- Children discussed what research is and whether children can be researchers ('no' became 'yes'!)
- Using Child-to-Child Trust resources to explain – participatory, investigation-based health education: very congruent with PAR
- Chosen focus: "to understand my disabled sibling better so I can help him/her feel happier"

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Some examples of activities:

Worksheet about what their disabled sibling likes / is good at

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Feelings cube

Gibbs et al (2002, p72)

- 3 positive and 3 negative feelings: non-threatening game to allow sad or negative stories to be shared
- "I felt embarrassed when my brother started screaming in the supermarket"
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Children's group challenges

- Making sure children attend meetings takes huge efforts – attendance gradually getting less
- Some children shy and reluctant
- Age range 6-13: challenge of designing activities suitable for all
- Balancing fun and 'serious' activity
- Arriving late – less time; entertaining early arrivals
- Venue – upstairs in large Mosque / school complex – large empty room
- Concentration / noise!

Issues on my mind:

- Recruitment challenges
 - How DO you make contact with such isolated disadvantaged families?
 - Were selection criteria too idealistic? Several other mothers wanted to participate, but husbands did not.
 - Is it a problem that all fathers have positive perceptions of disability and good relationships with their disabled child? (not 'representative'?)
 - What to do with data of initial interviews with families that joined later?
- How to shift the locus of control from me to the participants?
 - In terms of the research focus : should my 'need' to answer MY research question be allowed to interfere with participants' needs and priorities?
 - In terms of the process: their perception that I should decide, approach people, because they are new to it or think they don't have the skills.
 - In terms of "getting them to attend"
 - Anxiety over lack of time makes me want to 'rush' them (though I try not to!)
- How to ensure feedback between groups?
 - 2 meetings for all participants together were not successful!
- How to tackle analysis and thesis writing?
 - Plenty of data, but worry that the AR process was too short
 - How to conceptualize analysis in AR (focus on process)



References

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Occupational justice in the lives of Pakistani families with disabled children in the UK: a PAR Study

Debbie Kramer-Roy
Brunel University
COTEC Congress 2008



Why? - OTs as social researchers

- OTs need to take on the challenge to work not only with people with impairments of various kinds, but *"also with those suffering from the disorders of our time, such as occupational deprivation, occupational alienation, occupational imbalance and occupational injustice ... (in order) to enable occupation for personal wellbeing, for community development, to prevent illnesses and towards social justice ..."*.

Wilcock (1999, p10)



Why? - Personal / Professional Experience

- 9 years in Pakistan working in OT, community based rehabilitation, health promotion, teacher education
- Using community based, person-centred and/or participatory approaches to enable disabled children and their families, schools and communities to improve their quality of life and position in society



Why? – Pakistani community in the UK

- Higher levels of poverty and unemployment
- Poorer housing
- Prejudice based on both racism and Islamophobia and
- A lack of faith and culture appropriate provision of social and leisure activities.

(National Statistics Website, 2002; Equal Opportunities Commission, 2004; Khan, 2006)



Why? - Pakistani families with disabled children

- A higher prevalence of childhood disability in the Pakistani community
- High cost of raising one or more disabled children
- Less likely to receive benefits at appropriate rates
- More difficulty in accessing health and social care
- Specific issues in the Pakistani community:
 - blaming the mother for the child's disability
 - a belief in disability as God's punishment
 - lower levels of support received in the extended family and the community
 - therefore high levels of distress to disabled children and their primary carers (mostly mothers)

(Beresford, 1995; Bywaters et al, 2003; Chamba, 1999; Fazil et al, 2002; Hatton et al, 2004)



Critical / new paradigm research

- Little progress has been made in either defining the specific support needs of this group more precisely, or in meeting these needs
- Complex web of marginalisation calls for critical and participatory approach to engage families actively in identifying and starting to address their support needs

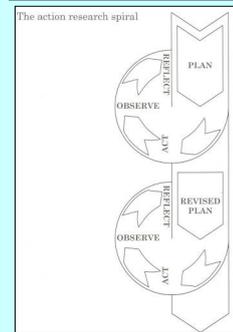
(Kramer-Roy, 2007)



How? Participatory Action Research

- An emancipatory practice aimed at helping an oppressed group to identify and act on social policies and practices that keep unequal power relations in place (Herr and Anderson, 2005, p9)
- The lived experience and knowledge of the participants are directly valued and central to the process. PAR aims to produce knowledge and action that are directly useful to the participants and to empower them through the process of constructing and using their own knowledge (Reason, 1994, p6)
- The bundling of practical and academic knowledge in order to improve the situation

The process of (P)AR



- A spiral of cycles
 - planning
 - action
 - observation of the impact of the action
 - Reflection on that action and its impact.
- A dynamic process (Kemmis et al, 2004, p3-4)
- Exploratory phase to identify issues first

The study (1)

- 7 families participated
- Exploratory phase at each family's home
- Separate PAR groups of men, women and children carried out their own action research cycles

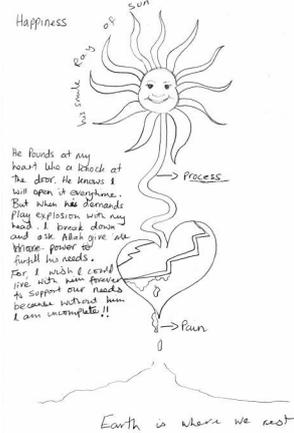


The study (2)

- Recruitment was slow and difficult: short time available for AR groups
- Participants had never been invited to reflect on their situation before
- The groups' action focused on gaining deeper understanding of needs, and tentative steps were taken towards meeting these needs (see Herr and Anderson, 2005, p55)

Ladies – trigger activity

- "Draw or write a poem/story, expressing an allegory about your (relationship with your) disabled child"



Ladies - action: invite other Pakistani mothers to informal support group

Are you a PAKISTANI mother?

Do you have a SPECIAL NEEDS child?

Do you need HELP or FRIENDSHIP? Would you like to meet with other mums like you?

Let miracles find you. Make a difference in some one's life.

کیا آپ ایک پاکستانی خاتون ہیں؟

کیا آپ کا کوئی بچہ/بچی خصوصی نوبت کا مستحق ہے؟

کیا آپ کو مدد یا کسی ہمدرد کی ضرورت ہے؟

آئیے آپ کی منتظر ہے!

آج ہی نمبر ملائیں

Men – trigger activity

HEAD: thinking skills: what are you good at?

EARS: who or what do you listen to?

SHOULDERS: what responsibilities weigh heavily?

TRUNK: how do you maintain balance in your life?: home / work / relaxation / leisure

HANDS: in what ways do you help family members?

BAG: what things / resources do you have or can you use?

FEET: what is your foundation?: e.g. values, worldview, etc.

WHAT 'HATS' do you wear? (roles)

EYES: what is your vision?

MOUTH: language and communication skills

HEARS: social skills and network / who is important to you?

HANDS: what practical skills are you good at?

LEGS: what steps could you undertake to change life for the better?

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Men - action

- Noted that negative attitudes in the community are expressed in religious terms – disability as a punishment for sin
- Consulted Islamic scholars to find out what the Quran and Hadith teach about disability
- Difficult to gain information, but process very important
- Now planning how to use this information to challenge attitudes

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Children – trigger activity

- Initially children were superficial and 'too' positive
- Feelings cube had 3 positive and 3 negative feelings. After rolling the dice the child told a story about when they felt that way

(Gibbs et al, 2002, p72)

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Children - action

- Clear focus about their research focus: "to understand our disabled sibling better so we could make him/her happier"
- Wrote stories and poems

Kite Kite

*I'm part of project on flight
I'm supposed to attain a great height.
But unfortunately I got stuck in a tree
So it looks like I am here for the night*

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Concepts of occupation

- Doing, being, becoming and belonging equals survival and health

$$d + b^3 = s h$$

- In these families "belonging" was a vitally important aspect

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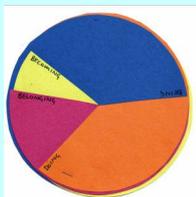
Belonging (1)

- Interdependence more important than independence
 - Marriage contract between families – good daughter-in-law responsible for good relationships in the family but also affects family's position in the community
 - Gossip and shame are a threat
- Community sees child disability as a punishment for (mother's) sin
 - All families talked about how this issue caused much grief in child's early years
 - But all now view child as blessing to the family and reason for enhanced personal development and faith

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Belonging (2) – one of the mothers

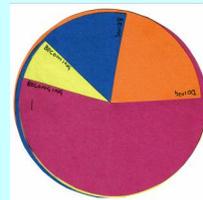
- This mother showed how little she felt she was allowed to 'belong', or think about 'becoming' – she felt she was always 'doing' and that that was expected of her.
- Sense of 'being' was very important to her and had been influenced by her strengthened faith and resilience through raising her disabled child.



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Belonging (3)... and her child

- Contrast between the child's belongingness within the immediate family and the lack of acceptance in the extended family and community, including the Mosque
 - an ongoing source of frustration and grief,
 - has significantly reduced the social contacts and support the family has
- For him to be allowed to 'belong' was paramount for his well-being
- He had little idea about what he might 'become' in the near or distant future.



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Belonging (4)

- Non-disabled children
 - very loyal to the family and willingly share in care for disabled sibling
 - Initially unwilling to express negative views / aspects
- Mothers experienced feeling of 'homecoming' in their research group
 - No need to 'defend' themselves
 - 'Uplifting' to find recognition
- Lack of belongingness in community leads to occupational injustice as it restricts whole family's choice of occupations for present and future

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Congruence of PAR and OT (1)

- PAR is "*consistent with the values of occupational therapy and occupational justice*" (Trentham and Cockburn, 2005, p440) and a particularly suitable choice of research approach.
- PAR is an occupational form that gives the participants an opportunity "*to develop the skills and knowledge necessary to take greater control over their own lives; in so doing, they promote their own health as well as the health of other community members*" (Trentham and Cockburn, 2005, p446)

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Congruence of PAR and OT (2)

- Working as a team of co-researchers is very congruent with the principles of client-centred practice:
 - respect for the person's skills and insights,
 - taking responsibility for one's own choices,
 - enabling participation, flexibility, and
 - keeping in view the links between person, environment and occupation(Letts, 2003, p83-4)

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Congruence of PAR and OT (3)

- 'Action' and 'collaboration' are central, whether you work with individuals or groups.
- The successful outcomes of both processes depend much on the therapist or lead researcher's openness to learn from their partners, rather than viewing oneself as the 'expert'.
- OTs' values and skills – such as- group facilitation and use of creative activity – are both very helpful in conducting PAR and are further strengthened in the process of doing it as well.

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Thank you!

o I would like to thank the following people:

- The families who are participants in this study for being a great source of inspiration and learning for me.
- My supervisors Prof. Peter Beresford and Prof. Judith Harwin for their faith in me and very valuable support and advice.

Thank you for listening!



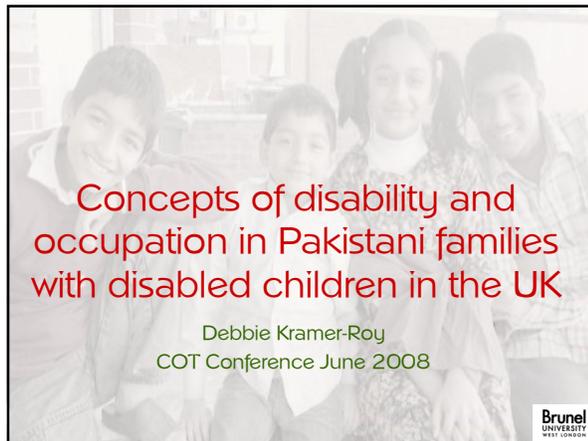
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Concepts of disability and occupation in Pakistani families with disabled children in the UK

Debbie Kramer-Roy
COT Conference June 2008

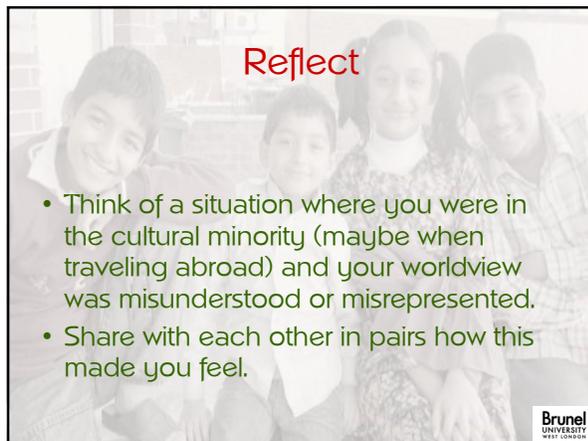
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Cultural Competence

- Need to be aware of your own culture and its impact on your worldview, beliefs and attitudes
- Keep in view universal aspects: common humanity BEFORE focusing on differences
- Keep in mind power and vulnerability in situations

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Reflect

- Think of a situation where you were in the cultural minority (maybe when traveling abroad) and your worldview was misunderstood or misrepresented.
- Share with each other in pairs how this made you feel.

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Pakistani community in the UK

- What do you know about this community?
- From the literature:
 - Higher levels of poverty and unemployment
 - Poorer housing
 - Prejudice based on both racism and Islamophobia
 - A lack of faith and culture appropriate provision of social and leisure activities.

(National Statistics Website, 2002; Equal Opportunities Commission, 2004; Khan, 2006)

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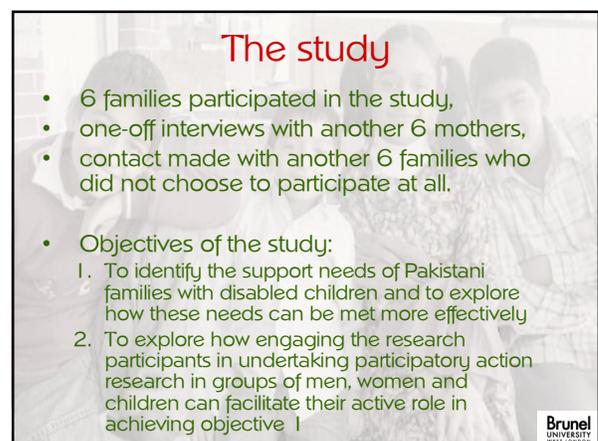


Pakistani families with disabled children

- A higher prevalence of childhood disability in the Pakistani community
- High cost of raising one or more disabled children
- Less likely to receive benefits at appropriate rates
- More difficulty in accessing health and social care
- Specific issues in the Pakistani community:
 - blaming the mother for the child's disability
 - a belief in disability as God's punishment
 - lower levels of support received in the extended family and the community
 - therefore high levels of distress to disabled children and their primary carers (mostly mothers)

(Beresford, 1995; Bujwars et al, 2003; Chamba, 1999; Fazil et al, 2002; Hatton et al, 2004)

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The study

- 6 families participated in the study,
- one-off interviews with another 6 mothers,
- contact made with another 6 families who did not choose to participate at all.
- Objectives of the study:
 1. To identify the support needs of Pakistani families with disabled children and to explore how these needs can be met more effectively
 2. To explore how engaging the research participants in undertaking participatory action research in groups of men, women and children can facilitate their active role in achieving objective 1

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Research Method

- In Participatory Action Research the **lived experience and knowledge** of the participants are directly valued and central to the process.
- It aims to produce knowledge and action that are **directly useful** to the participants and
- to **empower** them through the process of constructing and using their own knowledge

(Reason, 1994, p6)



Cultural fit of participatory research

- Affords time for being together and sharing stories
- Venue and format of meetings:
 - Women met at one family's home: giving and receiving hospitality is important
 - Men met at local Mosque: public and neutral territory
 - Children: fun and games, non-threatening, discovering shared problems



Concepts of disability

- The negative concepts and attitudes described in the literature do indeed exist in the Pakistani community
- Once a disabled child was born into the family, the parents (and often other close relatives) started to change
- Now all mothers and most fathers express almost opposite concepts and attitudes, but still rooted in their Islamic worldview



Process of personal growth

- Mothers talked about initial feelings of distress and blame for bearing a disabled child being put on them, usually by people in extended family or community
- Love for and worry about the child builds a commitment that is stronger than prejudices
- Eventually (usually after several years) they considered their child as a blessing - not a punishment - their faith in God was strengthened through tendency to pray more.
- "Testing" is construed positively, as God only tests those He wants to enter into heaven.



What the Quran says

- The men's group enquired from Imams and scholars what the Quran says, in order to address negative attitudes:
 - Not a punishment - 'morally neutral'
 - Everybody is created according to God's will
 - Physical or mental 'perfection' not important in the Quran: "the noblest of you in the sight of God is the one who is most deeply conscious of Him" (Quran 49:13)
 - Muslims are exhorted to show mercy and look after those who are 'weak' in society.



What the participants said at the end of the project

- Any parent can have a disabled child, it is not a punishment from God (mother)
- Disability is not our fault, it is God's will (mother)
- It's due to genetics and nothing else (mother)
- He is a gift from God (sister)
- He has made me more aware of God; "he touches your heart with more depth and softness and innocence" (father)
- You should be proud of all your children, regardless of disability (mother)
- He is a special child who needs to be treated with special care (father)



Concepts of occupation

- Mostly not discussed in occupational science language, apart from one session with a small number of mothers
- Influenced by concepts of disability as well as general cultural background
- I used Wilcock's (2006) "formula" to organize data

$$d + b^3 = s h$$

- In these families "belonging" was a vitally important aspect

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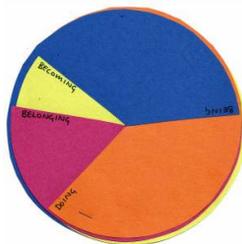
Belonging (1)

- Interdependence more important than independence
 - Marriage contract between families – good daughter-in-law responsible for good relationships in the family but also affects family's position in the community
 - Gossip and shame are a threat
- Community's view that child disability is a punishment for (mother's) sin
 - Caused much grief in child's early years
 - Continues to restrict participation in social activities

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Belonging (2) – one of the mothers

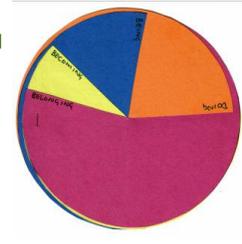
- This mother showed how little she felt she was allowed to 'belong', or think about 'becoming' – she felt she was always 'doing' and that that was expected of her.
- Sense of 'being' was very important to her and had been influenced by her strengthened faith and resilience through raising her disabled child.



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Belonging (3) ... and her child

- Contrast between the child's belongingness within the immediate family and the lack of acceptance in the extended family and community, including the Mosque
 - an ongoing source of frustration and grief,
 - has significantly reduced the social contacts and support the family has
- For him to be allowed to 'belong' was paramount for his well-being
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Belonging (4)

- Non-disabled children
 - very loyal to the family and willingly share in care for disabled sibling in most families
 - Initially unwilling to express negative views / aspects
- Mothers experienced feeling of 'homecoming' in their research group
 - No need to 'defend' themselves
 - 'Uplifting' to find recognition
- Lack of belongingness in community leads to occupational injustice as it restricts the whole family's choice of occupations for present and future, e.g. attending Mosque, weddings, etc. is restricted

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Being

- Main theme here is the way parents talk about their personal growth and stronger – more positive - faith, which now has a greater impact on their identity and helps them respond to negative attitudes better.
- The changed perception of the child being a blessing rather than a punishment, helps parents to accept the child the way they are, i.e. to allow the child to "be".

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Doing

- In most families the mother takes on most of the practical care of the child.
- Leads to lack of occupational balance and all mothers spoke of the need (not always fulfilled!) to have part-time work or study to distract, maintain contact with the outside world or develop themselves.
- Fathers also spoke of lack of time for themselves, combining full-time work with care for the child / family
- Siblings were involved in practical care and their options for developing their own interests were limited.

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Becoming

- Personal growth already described above
- Dominating themes when participants talked about the future, related to
 - not knowing what to expect from their child's abilities in adulthood
 - worrying about who would care for them after their own death
 - a desire to look for ways to support other Pakistani and/or Muslim parents in the same position
- Most mothers had no time or permission to think about, or work towards, personal future goals

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Occupation and culture

- Current definitions of occupation demonstrate a valuing that is particularly reflective of Western experience and worldviews and the concept of occupation must be re-defined in each new cultural context (Iwama, 2005)
- For this group of Pakistani families with disabled children living in a Western context the aspects of 'belonging' and 'being' were relatively very important and strongly influenced by their cultural and religious background
- BUT mothers pointed out that many issues they face are universal.

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Implications for Occupational Therapy

- What do you think?
- Allow more time and attention for relationship and accepting hospitality
- Be aware that 'independence' may not be as high a priority as in 'white British' families
- Don't feel shy to ask people to explain their concepts of disability and their reasons for doing relevant occupations in certain ways – it shows respect, not inappropriate curiosity
- Expect that differences may have a positive impact, rather than necessarily being problematic (to the therapist!)

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Conclusion

- Specific knowledge about ethnic minority groups can be useful, but is not the most important – memorizing 'facts' can have a stereotyping effect
- Look for commonalities first, then ask about differences openly and sensitively
- Expect differences to have positive aspects as well as possible negative ones
- And eat the samosas even if it is against department policies!

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Thank you!

I would like to thank the following people:

- The families who are participants in this study for being a great source of inspiration and learning for me.
- My supervisors Prof. Peter Beresford and Prof. Judith Harwin for their faith in me and very valuable support and advice.

Thank you for participating!

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Concepts of and attitudes towards disability in the Pakistani Community in the UK

Debbie Kramer-Roy
Disability Studies Conference
Lancaster University
2nd September 2008



Pakistani community in the UK

- From the literature:
 - Higher levels of poverty (3x)
 - Higher levels of unemployment (2x for men, 3x for women)
 - Poorer housing
 - Higher incidence of self-reported ill-health (2x) and disability across the lifespan (1.5x)
 - Limited English proficiency depending on age, generation, length of settlement and 'residential density effect'
 - Prejudice based on both racism and Islamophobia
 - A lack of faith- and culture appropriate provision of social and leisure activities.

(National Statistics Website, 2002 and 2004, Equal Opportunities Commission, 2004; Khan, 2005; Modood, 1997)



Pakistani families with disabled children (from the literature)

- A higher prevalence of childhood disability in the Pakistani community
- High cost of raising one or more disabled children
- Less likely to receive benefits at appropriate rates
- More difficulty in accessing health and social care
- Specific issues in the Pakistani community:
 - blaming the mother for the child's disability
 - a belief in disability as God's punishment
 - this leads to lower levels of support received in the extended family and the community
 - therefore high levels of distress to disabled children and their primary carers (mostly mothers)

(Beresford, 1995; Bywaters et al, 2003; Chamba, 1999; Fazil et al, 2002; Hatton et al, 2004)



The study

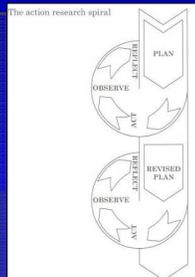
- Objectives of the study:
 - To identify the support needs of Pakistani families with disabled children and to explore how these needs can be met more effectively
 - To explore how engaging the research participants in undertaking participatory action research in groups of men, women and children can facilitate their active role in achieving objective 1.
- 6 families (all members) participated in the full study
- one-off interviews with another 6 mothers
- contact made with another 6 families who did not choose to participate



Research Method

- In Participatory Action Research the **lived experience and knowledge** of the participants are directly valued and central to the process.
- It aims to produce knowledge and action that are **directly useful** to the participants and to **empower** them through the process of constructing and using their own knowledge

(Reason, 1994, p6)



The use of PAR in this study

- Exploratory phase based in each family's home – individual interviews, drawings, photography
- Separate groups for women, men and children, in which they carried out their own action research cycles
- Few meetings / parties for all families together



Cultural fit of participatory research

- Affords time for being together and sharing stories
- Venue and format of meetings:
 - Women met at one family's home: giving and receiving hospitality is important
 - Men met at local Mosque: public and neutral territory put them at ease
 - Children: fun and games, non-threatening, discovering shared problems



Concepts of disability

- The negative concepts and attitudes described in the literature do indeed exist in the Pakistani community
- Once a disabled child was born into the family, the parents (and often other close relatives) started to change their views
- Now all mothers and most fathers express almost opposite concepts and attitudes, but still rooted in their Islamic worldview

Men's group

- Noted that negative attitudes in the community are expressed in religious terms – e.g. disability as a punishment for sin, negative sense of 'testing'
- Consulted Islamic scholars to find out what the Quran and Hadith teach about disability
- Difficult to gain information, but process of approaching their scholars and Imams was very important, as in doing this they had to profile themselves as fathers of disabled children and to claim their right to get an answer from their scriptures

Men's group: What they found out

The Qur'an does not contain many specific references to disability, but much can be inferred

- **God's will:** "Nothing on earth or in heaven is hidden from God: it is He who shapes you all in the womb as He pleases" (3:5-6)
- **Removing stigma:** "No blame will be attached to the blind, the lame the sick. Whether you eat in your own houses, or those of your fathers, Or any of your friends' houses, you will not be blamed ... whether you eat in company or separately" (24:61)



Quran translation used:
The Quran. A new translation
by M. A. S. Abdel Haleem
Oxford University Press, 2004

- **Meeting the needs of the disadvantaged:** "Be good to your parents, to relatives, to orphans, to the needy, to neighbours near and far, to travelers in need and to your slaves. God does not like arrogant and boastful people, who are miserly and order other people to do the same, hiding the bounty God has given them." (4:36-37)
- **Testing – disability as a 'calamity':** "We shall certainly test you with fear and hunger, and loss of property, lives or crops. But [Prophet], give good news to those who are steadfast, those who say, when afflicted with a calamity, 'We belong to God and to Him we shall return'. These will be given blessings and mercy from their Lord, and it is they who are rightly guided." (2:155-157)

This gives the sense that God tests the patience of those with disabilities and tests others to have mercy and care for them (unmarked source obtained from one of the local Imams).

سُوْرَةُ الْحُجْرَاتِ
بِسْمِ اللَّهِ الرَّحْمَنِ الرَّحِيمِ
يَا أَيُّهَا النَّاسُ إِنَّا خَلَقْنَاكُمْ مِنْ ذَكَرٍ وَأُنْثَىٰ وَجَعَلْنَاكُمْ شُعُوبًا وَقَبَائِلَ لِتَعَارَفُوا
إِنَّ أَكْرَمَكُمْ عِنْدَ اللَّهِ أَتْقَاهُمْ إِنَّ اللَّهَ عَلِيمٌ خَبِيرٌ

(Arabic text taken from <http://muttaqun.com/quran/>)

"....In God's eyes, the most honoured of you are the ones most mindful of Him: God is all knowing, all aware (of people's true worth and the thoughts they harbour)"

The Qur'an, Sura 49 (Al Hujraat) verse 13

Men's group: Planning for action

- The men concluded there is no moral judgment on disabled people in the Qur'an and that Muslims are exhorted to support them and include them – negative attitudes in the community may be based on cultural, rather than religious beliefs.
- They wish to share this information with other Pakistani families with disabled children as well as the wider community
- At the end of the project they were/are working on a factsheet, and planning to call a community meeting (implementation pending...)

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Women's group

- A sense of 'homecoming' in the group
 - No need to 'defend' themselves
 - 'Uplifting' to find recognition - sharing painful experiences provided catharsis



Women's group: the importance of faith



- Shared and reflected on experience of faith and how this led to their change in perception of the reasons (cause and purpose) for disability from a Muslim perspective.
- Talked about their personal growth and stronger, more positive faith, which now has a greater impact on their identity and helps them respond to negative attitudes better.
- The changed perception of the child being a blessing rather than a punishment, helps them to accept the child the way they are.
- Yet, there is also their hope and prayer for healing of their child's impairment

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Women's group: how support could be improved

- Service providers do not ask about their views / faith, feelings, ability to cope, but only see (the aspect of) their child's impairment that they are expected to treat / address – they find this very alienating
- Mutual support very beneficial: meeting other mothers from the same religious and cultural background plays a different role than general groups / services
- The women intend to continue / expand this group locally

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"What would you like people in the Pakistani community to understand about your disabled child?"

- Any parent can have a disabled child, it is not a punishment from God (mother)
- Disability is not our fault, it is God's will (mother)
- It's due to genetics and nothing else (mother)
- He is a gift from God (sister)
- He has made me more aware of God; "he touches your heart with more depth and softness and innocence" (father)
- You should be proud of all your children, regardless of disability (mother)
- He is a special child who needs to be treated with special care (father)

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Models of disability

- Besides the more frequently debated medical and social models, more attention needs to be given to **traditional / religious models of disability**.
- "Shared values and beliefs are so pervasive that we take our worldview for granted. A cultural orientation and appreciation of people's worldview helps us to understand behaviours and provides insights into what motivates them." (Watson, 2006, p152)

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Old or new models?



- Any model of disability is influenced by the context and worldviews of those who developed or named it – important to make this explicit
- Not about 'going back' to a 'traditional' model that was more prevalent in the past, but rather giving space for people to conceptualize a model that is congruent with their worldview

Scriptures and practices

- Religion and culture affect each other: negative attitudes towards disability in the Pakistani 'Muslim culture' seem not to be based on the Qur'an, yet are expressed in religious terms (*how about Western 'Christian culture' and the Bible?*)
- Important for people of faith to go back to their scriptures and reflect on their practices
- Important for people of any worldview to be aware of their own assumptions and attitudes and how they are affected by their own and society's dominant worldview, as it makes it easier to recognize and value other people's differing worldviews

Implications for Research



- The 'lived experience' of disabled people is made up not only of their impairment and barriers imposed by others, but also of their worldview, ethnicity, social circumstances
(Thomas, 2007; Shakespeare, 2006)
- Studying disability in this broader light may contribute to the emergence of a more 'holistic model' of disability (Pinder, 1996)

Why this emphasis on faith?: Implications for researchers and service providers

- This was a secular study with broad objective of 'exploring support needs'
- PAR approach gave participants the choice of topic for their own research
- Initial interviews had included questions on each participant's personal experience and feelings about having a disabled child in the family – no one had shown interest in *them* or their views before!
- Given the choice, both men's and women's groups decided exploring the role of faith was the most important both for themselves and the community
- Researchers and service providers would do well to keep this in mind when working with communities whose cultures value 'being' over 'doing' and 'interdependence' over 'independence'!

Thank you!

- I would like to thank the following people:
 - The families who participated in this study for being a great source of inspiration and learning for me.
 - My supervisors Prof. Peter Beresford and Prof. Judith Harwin for their faith in me and very valuable support and advice.

Thank you for listening!

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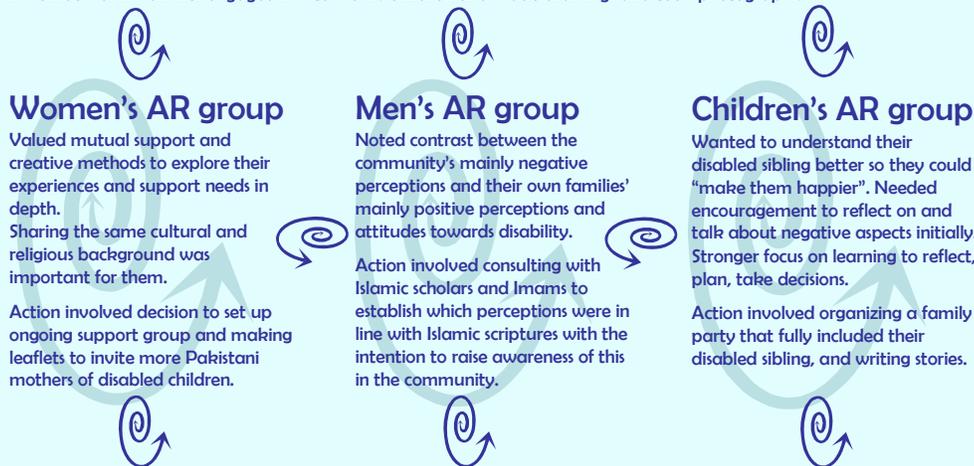
Reflecting on Religion and Relationships: Pakistani families with disabled children explore their support needs through Participatory Action Research

- Observe:** Pakistani families with disabled children are among the most disadvantaged in the UK and their support needs remain largely unmet
- Reflect:** There is a need to involve these families in action oriented research to understand their needs better and how they could be met more effectively
- Plan:** PhD research proposal within critical/emancipatory research paradigm
- Act:** Engaging six families in PAR:

PAR is an emancipatory practice aimed at helping an oppressed group to identify and act on social policies and practices that keep unequal power relations in place. The lived experience and knowledge of people, often oppressed groups, are directly valued and central to the process (Reason, 1994). The engagement in the cyclical action research process of reconnaissance / observation, analysis, planning, action and reflection facilitates participants in being able to act on what they know (Kemmis et al. 2004).

Exploratory phase: reconnaissance

All members of six families engaged in interviews. Children also made drawings and took photographs.



Making connections at family parties and within each home

- Reflect:** Thesis writing with feedback loops to participant groups
 - Data consists of transcripts from interviews and meetings, participants' drawings, photographs, etc. and researcher's reflections. Data concerned both the research process itself and the knowledge and insight gained through the process.
 - Data analysis was ongoing as necessary in an emergent research design. Participants were part of this process during the project and during thesis writing. Conference presentations (10, including 1 with participants) were a useful tool for reflection and analysis.
- Plan:** Recommendations for further research, policy & practice:
 - The social model of disability needs to incorporate cultural/religious influences on the experience of disability more explicitly
 - Service providers need to recognise and build on the strengths of families' faith and faith-inspired attitudes
 - Muslim leaders need to challenge negative attitudes towards disability in the Pakistani community
 - More research into the culturally specific aspects of marital relationships of parents of disabled children is needed.
 - Services need to be more proactive in supporting families from disadvantaged communities – a personal, caring relationship with mother / parents is of key importance
 - Community approaches (including support groups) need to complement individual treatment approaches in cross-cultural care
 - Occupational therapists need to understand cultural differences in family relationships and in perceptions of and attitudes towards disability, and to explore with each family how these impact on occupational balance and belongingness.

Debbie Kramer-Roy, PhD Student, Brunel University debbie.kramerroy@brunel.ac.uk



Reference: Reason, P., 1994. Three Approaches to Participative Inquiry. In: N.K. DENZIN and Y.S. LINCOLN, eds. Handbook of Qualitative Research: Thousand Oaks, California: Sage Publications, pp. 324-339
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Appendix J
Overview of all visits and group meetings

Overview of home visits and group meetings

September '07	October	November	December	January	February	March	April	May '08
1 (July)one-off 1	1	1	1	1	1	1	1	1
2 (July) F3 Intro	2 F4 F5 Intro	2	2	2	2 MEN - 3	2	2	2
3	3 F7 M	3	3	3	3	3	3	3
4	4 F4 M, F5 M, F	4	4	4	4	4	4	4
5	5	5	5	5	5	5	5	5
6 F1 Intro	6 F4 D	6	6	6	6	6	6	6
7 F7 Intro	7	7 F3 Sa, D	7	7	7	7	7	7
8 Fam meeting	8	8	8	8	8	8	8	8
9	9 F5 D, Sa, Sb, Sc	9	9	9	9	9	9	9
10	10	10	10	10	10	10	10	10
11 F2 Intro	11 F7 Sa, Sb	11	11	11	11	11	11	11
12 F1 M	12	12	12	12	12	12	12	12
13 F2 M	13	13	13	13	13	13	13	13
14	14	14	14	14	14	14	14	14
15	15	15	15	15	15	15	15	15
16	16 F3 Sa	16	16	16	16	16	16	16
17	17 One-off 2	17	17	17	17	17	17	17
18 F1 F, Sa	18 One-off 3	18	18	18	18	18	18	18
19	19	19	19	19	19	19	19	19
20	20	20	20	20	20	20	20	20
21	21	21	21	21	21	21	21	21
22	22	22	22	22	22	22	22	22
23	23	23	23	23	23	23	23	23
24	24 KIDS - 1	24	24	24	24	24	24	24
25	25 KIDS - 2	25	25	25	25	25	25	25
26 F1 Sb, Sc, D	26 KIDS - 3	26	26	26	26	26	26	26
27 F2 Sa, Sb, D	27 Eid Party	27	27	27	27	27	27	27
28 F3 M	28	28	28	28	28	28	28	28
29	29 One-off 4	29	29	29	29	29	29	29
30	30	30	30	30	30	30	30	30
31	31	31	31	31	31	31	31	31

F = Father
 M = Mother
 G = Grandmother
 D = Disabled Child
 One-off = one-off interviews/visits with other mothers of disabled children (5 Pakistani, 2 Indian Muslim: 4 with signed consent)
 S = sibling (a = oldest, b = second, etc)
 F1 to F7 = families in order of signing up (apart from the one that dropped out, which is no. 7)
 photos = looking at photos taken by family members with camera provided
 eval = evaluation

June '08	July	August	September	October	November
1	1	1	1	1 F1 all Eid	1 MEN - FB2
2	2	2	2	2 F6 all Eid	2
3	3	3	3	3 F3 M Sa Eid	3
4	4	4	4	4 F2 all Eid	4
5	5	5	5	5	5
6	6	6	6	6	6
7	7	7	7	7	7 WOMEN - FB2
8	8	8	8	8	8
9 F4 M	9	9	9	9	9
10	10	10	10	10	10
11	11	11	11	11	11
12	12	12	12	12	12
13	13	13	13	13	13
14 WOMEN - FB1	14	14	14	14	14
15	15	15	15	15	15
16	16	16	16	16	16
17	17	17	17	17	17
18	18	18	18	18	18 F2 Sa picture
19	19 MEN - FB1	19	19	19	19
20	20	20	20	20	20 Conference
21	21	21	21	21	21
22	22	22	22	22	22
23	23	23	23	23	23
24	24	24	24	24 F3 M picture	24
25	25	25	25	25	25
26	26	26	26	26	26
27	27	27	27	27	27
28	28	28	28	28	28
29	29	29	29	28 KIDS - FB2	28
30	30 KIDS - FB1	30 F4 all Eid	30 F4 all Eid	29	29
			F5 all Eid	30	30
				31	31

Family composition:

Family	Adults	Disabled child – age and impairment	Other children and ages	Number of home visits
F1	F, M, Sa (22), Sb (19)	14, learning disabilities	Sc (11)	6 + Eid
F2	F, M	10, severe learning and communication difficulties	Sa (12), Sb (8)	7 + Eid
F3	M	11, severe autism and learning disabilities	Sa (13)	5 + Eid
F4	F, M	3, physical impairments	-	5 + Eid
F5	F, M	14, learning disabilities	Sa (13), Sb (9), Sc (6)	5 + Eid
F6	F, M, G	9, learning disabilities	Sa (13), Sb (7)	5 + Eid
F7	F, M	4, learning disabilities	Sa (11), Sb (9), Sc (6)	3

Total number of group meetings:

Kids 8 + 2 feedback (7 children participated)
Men 7 + 2 feedback (5 fathers and 1 older brother participated)
WOMEN 7 + 2 feedback (5 mothers participated)
All 3 + conference presentation

Appendix K
Leaflet produced by women's group



Are you a
PAKISTANI mother?

Do you have a
SPECIAL NEEDS child?

Do you need **HELP** or **FRIENDSHIP**?
Would you like to meet with other
mums like you?



*Let miracles find you.
Make a difference in some one's life.*



کیا آپ ایک پاکستانی خاتون ہیں؟

کیا آپ کا کوئی بچہ/بچی

خصوصی توجہ کا مستحق ہے؟

کیا آپ کو صرد یا کسی بیماری

کی ضرورت ہے؟

اصید آپ کی منتظر ہے!

آج ہی غبر ملائیں

**Appendix L:
PowerPoint presentation for Inclusion & Exclusion 2008
Conference**

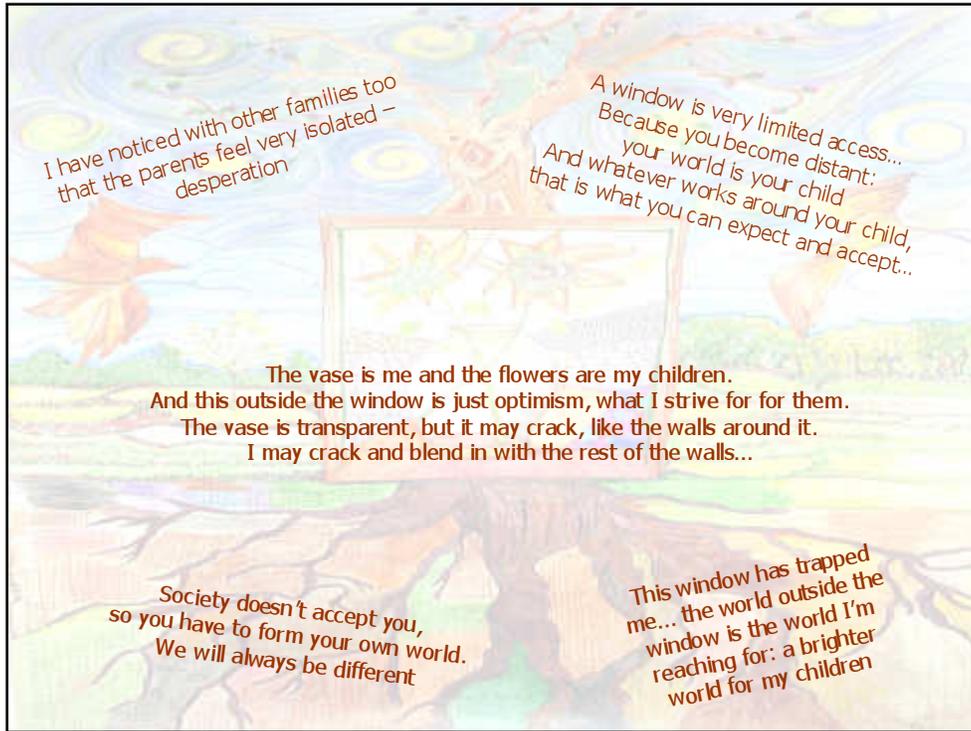
**The outcomes of a participatory
action research project exploring the
support needs of Pakistani families
with disabled children in the UK.**

A collaborative presentation by research participants
(names omitted due to confidentiality concerns) and
the lead researcher, Debbie Kramer-Roy

Inclusion and Exclusion Conference: 2008



This picture was made by
one of the mothers who
participated in the project.
On the next page some
quotes from her explanation
are given to help you
understand the depth of the
picture.



I have noticed with other families too
that the parents feel very isolated –
desperation

A window is very limited access...
Because you become distant:
your world is your child
And whatever works around your child,
that is what you can expect and accept...

The vase is me and the flowers are my children.
And this outside the window is just optimism, what I strive for for them.
The vase is transparent, but it may crack, like the walls around it.
I may crack and blend in with the rest of the walls...

Society doesn't accept you,
so you have to form your own world.
We will always be different

This window has trapped
me... the world outside the
window is the world I'm
reaching for: a brighter
world for my children



**Do you know anyone with these
feelings?**

Someone with a disabled child?

Someone from a Pakistani background?

Scheme of Presentation



- Introduction
- Study plan & methods
- Issues studied
- The three action research groups
- Problems identified
- Recommendations
- Conclusion

Why this study?



- Both previous research studies and Debbie's own professional experience indicate that Pakistani families with disabled children in the UK face many challenges and have many unmet needs
- Despite this being an identified problem for well over a decade, services have not improved significantly

For full details see Kramer-Roy (2007). Researching the support needs of Pakistani families with disabled children in the UK. *Research, Policy and Planning* 25(2)

Why Participatory Action Research (PAR)?



- The lived experience and knowledge of people are directly valued and central to the process. Aims are to produce knowledge and action that are directly useful to the participants and to empower them through the process of constructing and using their own knowledge (Reason, 1994, p6)
- Bundling of practical and academic knowledge in order to improve the situation
- The long and action-based group process in collaboration with experience-experts makes it possible to study a complex situation in depth.

Reason, P. (1994). Three Approaches to Participative Inquiry. In: N.K. Denzin and Y.S. Lincoln, eds, *Handbook of Qualitative Research*. Thousand Oaks, California: Sage Publications, pp. 324-339.

Study design

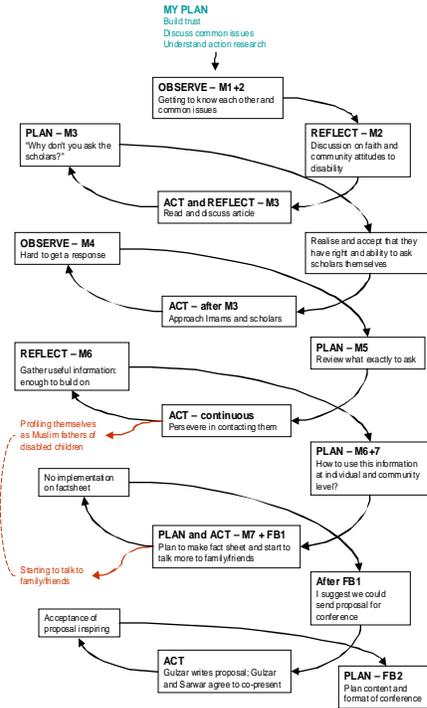


- Exploring support needs through individual interviews and home visits
- Action research study
 - Active debates
 - Participants' discussions, reflections, plans and actions
- Sample size: 6 families – very difficult to find!
 - 3 groups of men, women and children respectively
 - Action research for every group

Study Plan & Methods

- Each group engaged in their own action research cycles of observing, reflecting, planning and acting
- This is the process the men's group went through

(M = meeting
FB = feedback meeting)



Overview of Key Issues Discussed



- Men: Islamic beliefs and myths about disability
- Negative and positive attitudes towards disability
- Role of service providers and access to services
- Women: found the action research group very supportive and decided to set up a support group to include more Pakistani mothers of disabled children
- Children: “to understand our disabled sibling better so that we can help them to be happier”

The Women's Group: main focus



- Glad to be out of isolation & meet new mothers with same problems
- Glad to be able to talk openly to someone & to express all fears, thoughts, anxieties, etc.
- Idea of setting up a Support Group – to include more mothers

Inviting other Pakistani mothers to join a support group




Are you a
PAKISTANI mother?

Do you have a
SPECIAL NEEDS child?

Do you need **HELP** or **FRIENDSHIP**?
Would you like to meet with other
mums like you?



*Let miracles find you,
Make a difference in some one's life.*

کیا آپ ایک پاکستانی خاتون ہیں؟
کیا آپ کا کوئی بچہ/بچی
خصوصی نوبت کا مستحق ہے؟
کیا آپ کو مزہ یا کسی پلررد
کی ضرورت ہے؟
امید آپ کی منتظر ہے!
آج ہی غیر ملائیں

Women's group: other thoughts



- Everyone has something to contribute:
 - Enjoyed creative activities, and they brought out hidden / unconscious thinking
 - More / deeper exchange of information and ideas through time
- Worry about future care for the child, but many Pakistani children seem to have inbuilt commitment to their sibling's future care
- Accessing services is very difficult. More so if English is poor because interpreters are expensive and don't always convey the right message.
- Difficult to accept overnight respite care

“My child is like....”



a beautiful but incomplete rainbow lighting up her parents' life

a sun providing an overwhelming source of energy, yet breaking my heart because of the anguish of looking after him

an open book

an angel

an island in the sea



The Men's Group: main focus



- Noted negative attitudes in the Pakistani community were often expressed in religious terms
- Decided to find out if these negative perceptions are based on the Quran and Hadith
- Approached Islamic Scholars and Imams (this took much time and effort!)
- Found out that the Quran and Hadith provide no basis for either moral judgments on disabled people, but rather require Muslims to respect and care for them.
- Intend to use this information to raise awareness of disability issues in the Pakistani community

The Men's group: other problems identified



- Information problem
 - Lack of information
 - Irrelevant information overload
 - Unknowledgeable support staff
- Immigration status
- Financial circumstances
- Housing Issues

Problems identified (cont'd)

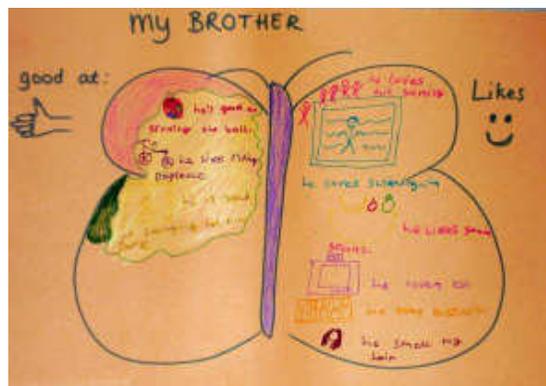


- Social services barriers
- Eligibility-lead as opposed to needs-led approach
- Services providers not committed to helping
- Relationship problems between siblings, husband & wife - lack of communication
- Confusion over the impact of cousin marriage on the incidence of disability

The children's group



- Engaged in games and activities that increased their understanding of their sibling's strengths and needs.
- They also learned how to plan things and work together.



“It’s like he’s in his own, virtual world and he is on a mission to find the way out”



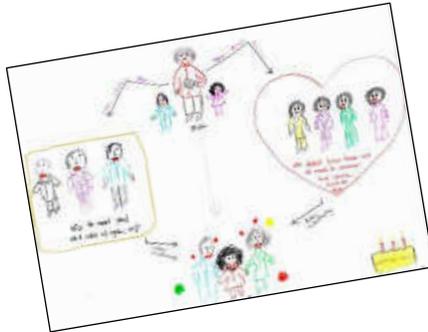
This picture, made by 'Jamil', expressing how he imagines his brother 'Imran' experiences his world:

“The picture shows my brother in his virtual world. He is in a room, which is filled with water. The arrows show that there is a way out, but the way is blocked. The only way out is the path of stepping stones in the water, but if he steps on them he will be drowned. If he solves the puzzles on the walls, then there will be a safe path. The other two people with him are 'holograms' who try to lead him in the wrong direction. Once he crosses this water, he has achieved 'level one' of his mission and there will be more levels to solve before he can escape from his virtual world.”

The children’s message to you



Bringing the groups together



Recommendations



- For Service Users
 - Know and assert your rights
 - Do not take no for an answer
 - Always ask for the alternate course of action
 - Keep regular checks, call/visit every single day until problem is solved
 - Use support groups to meet others like you

Recommendations



- For Service Providers
 - Feedback, Feedback, Feedback
 - Consider the individual/family and their context/worldview: not just another 'case'
 - Understand the importance of the individual/family's religious beliefs, as these have a major impact on how they deal with disability
 - Considerate view of the relevant issues and not only the main problem
 - Specially trained knowledgeable support staff

Recommendations



- For Policy Makers
 - Government's duty to provide a school space for special needs child must be implemented
 - Precise and to the point information for users on various issues including housing, Disabled Living Allowance, carer allowance, etc.
 - Needs-led criteria instead of eligibility-led

Conclusion



- Pakistani families with disabled children are at risk of becoming very isolated.
- Bringing parents together for peer support from those who share the same culture, language and religion can be an effective way of becoming more assertive and able to access existing services.
- Encouraging Muslim leaders to be involved in community awareness raising and support for families with disabled children is difficult, but necessary.
- Statutory services, the voluntary sector and Pakistani community leaders need to join efforts to improve the support offered to these families

Acknowledgments



- This participatory action research project was undertaken as part of the PhD studies of the lead researcher, Debbie Kramer-Roy.
- Debbie fully acknowledges that the outcomes of the project were only possible because of the co-researchers' willingness to engage in the project and their generous gift of time, hard work and deep insights.
- Debbie studies at the School of Health Sciences and Social Care of Brunel University, West London, where her supervisors are professors Peter Beresford and Judith Harwin.
- Contact: debbie.kramer-roy@brunel.ac.uk
- Phone: 079 60820560

Discussion



- Time to ask questions and give us your valuable feedback!
- Thank you for your attention and interest!

Thank you!

Appendix M
Evaluation Forms

Evaluation Questions: Adults - Name: _____

How would you describe the purpose of the project?

What did you like best about the project?

What did you like least about it?

What were the reasons for not attending some / all of the group activities?

What could I have done differently to make the groups better for you?

Did you learn anything from the activities we did at home and in the group? If yes, what?

About disability in general

About your own disabled child / family

About yourself

About research

How would you describe the focus your group chose for its own research?

Did you learn something new about that focus?

Has anything changed in the way you think about disability / your child?

Has anything changed in the way you say or do things at home?
With your disabled child

With other family members

Did you tell your family members what you did at the group? If yes, what?

What would you like people in the Pakistani community to know or understand about your child, his/her disability, or family life with him/her?

Do you think taking part in the project will help you to deal with disability issues in the future? In what way?

How will you continue the process we started in the group?

Dear ...



I realise some things are difficult to put down in words. Thinking of all the things we have talked and thought about, the things we have shared, the things we have done, the image of a lovely Pakistani tapestry came to mind.

Please use the art materials provided to make your own tapestry of important, interesting, surprising things that you thought / talked / learned about during the project.

It could be a picture, or you could use just colours, or mix in words, or anything that will help you express your ideas.

You will be invited to show and talk about your artwork to everyone at the closing party, but you don't have to do this!



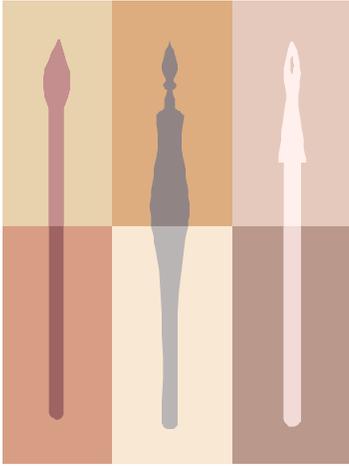
I hope you enjoy yourself doing this and I look forward to seeing the result!

Debbie.

And now for the real challenge!

Dear ...,

This part of the evaluation will give you the chance to express in a more creative way what you got out of the project – please give it a go, I'm sure you'll enjoy it once you get started!



Please write a poem about the MOST important / interesting / surprising thing (or person!) you did or thought about during this project.

Feel free to choose what to write about, how long or short, to write it in story form instead, to write it in Urdu or English, and whether or not to decorate it in any way.

You are invited to share your poem / story with all the others attending the closing party – but you don't have to do this.



I look forward to hearing / seeing your poems!

Debbie

Evaluation Questions: Children - Name: _____

Why do you think I did this project?

What did you like best about the project?

What did you like least about it?

Had people asked you questions about your ideas about your sibling's disability before?

Did you learn anything from the activities we did at home and in the group? If yes, what?

About disability in general

About your own sibling / family

About yourself

About research

Do you remember what research focus we had chosen?

Did you learn something new about that focus?
Has anything changed in the way you think about disability?

Has anything changed in the way you say or do things at home?
With your sibling

With your parent(s)

Did you tell your parents what you did at the group? If yes, what? If no, why not?

How could you tell your parents about what you learned?

What would you like your friends to know or understand about your sibling, his/her disability, or family life with him?

Do you think taking part in the project will help you to deal with disability issues in the future? In what way?

Did you enjoy coming to the group? Why (not)?

What were the reasons for not attending some / all of the group activities?

What could I have done differently to make the groups better for you?

Competition!

Dear ...,

As part of the closing party there will be an art competition – everyone who comes to the party will vote for the best entry, which you need to prepare beforehand.



Make a picture, story, poem, or anything else about the MOST important / interesting / surprising thing you did or thought about during this project.



You can use any of the art materials I have given you.

Please help (*name of disabled sibling*) to make a picture to enter into the competition as well!

See you at the party!

Debbie.

Appendix N
Conference proposal:
first draft by Gulzar and final draft by me

Exploring the support needs of Pakistani families with disabled children in the UK: An action research study

Aims & Objectives of Research

- to identify required needs (social, material & non-material needs) of Pakistani families with disabled children living in UK
- to identify information on, access to, and stability and adequacy of facilities.
- Exploring and suggesting new ways to address the issue in more effective way.
- Putting the results in action

Synopsis of the Project

An action research study aimed to evaluate the present scenario of the service providers in UK, involving the Pakistani families living in UK and having disabled children (both physical and mental disabled kids). This is an action research study which was driven by the active debates and discussions of the participants. A sample of eight families from Pakistani ethnic group was involved to drive the research. The participating families were divided into three independent groups i.e. Male, Female and Children Group, who were actively involved in the research with same guidelines for every one of the group.

This action research proved very fruitful in determining many important parameters associated with special reference to UK service providers and users. Lot of issues including reasons and beliefs of the disability in Islam (for which a research through internet sources and face to face meeting with religious Muslim Scholars were also organized) were discussed. Others issue include attitude of social peers, benefits and losses of disability to family, the role of service providers for the families of disabled children were critically evaluated and different measures suggested.

Putting results into satisfactory measurements units, at the end of the project:

- many of the participants were more aware about the research topic than before
- many of them had more clear idea about the support they need in relation to disabilities of their child.
- Quite few of them were more enthusiastic to put the research in action

(Gulzar's Draft)

A collaborative presentation about the outcomes of a participatory action research project exploring the support needs of Pakistani families with disabled children in the UK.

This presentation will be made jointly by research participants and the lead researcher. This proposal has also been prepared together.

This study aimed to evaluate the support needs of the Pakistani families with disabled children living in the UK (both physical and intellectually disabled kids). This is an action research study which was driven by the active debates and discussions of the participants. A sample of six families from the Pakistani ethnic group was actively involved in conducting the research. The participating families were divided into three independent groups of men, women and children respectively, who engaged in cycles of action research about their chosen topic.

This action research proved very fruitful in informing UK service providers about the specific needs and strengths of these families. Issues discussed included:

- reasons and beliefs around disability in Islam (for which a research through internet sources and face to face meeting with religious Muslim Scholars was undertaken by the men's group).
- attitudes of social peers,
- benefits and losses to family as a result of disability, and
- the role of service providers for the families of disabled children.
- the benefit of a support group for mothers: the women's group explored setting this up locally
- finally the children explored how they could understand their disabled sibling's 'different world' better in order to help him/her to be happier.

At the end of the project many participants had a clearer idea about the support they need in relation to disabilities of their child and quite a few of them were more enthusiastic to put the research in action

The presentation will suggest how service providers could support Pakistani families with disabled children more effectively, based on the insider perspective of the lived experience and research efforts of this group of families.

(submitted version)

Appendix O
Volunteer Agreement

Volunteering Agreement

Dear ...,

Thank you very much for your support of my PhD research project, titled “**Exploring the support needs of Pakistani families with disabled children in the UK using an occupational justice framework: a participatory action research study**” and for offering to help me in conducting the children’s “holiday club”. I really appreciate your commitment!

As this is a research project the following issues need to be clarified:

- The children are co-researchers in this project. This means we are not ‘teaching’ them ideas or skills, but rather we offer activities that give them opportunities to express their own ideas and find out how to deal with the issues they face themselves. It is therefore important that we do not guide or direct their ideas by giving suggestions or ideas whilst they work together.
- Whatever the children say, do or make during the sessions is “research data” and therefore confidential. It is very important that neither the identity of the children nor the data resulting from the sessions are disclosed to anyone outside this group of children.
- As we are working with children the university needs to know that you have had a Criminal Records Bureau check. Please could you show me the certificate.

Please indicate that you understand these issues by ticking the appropriate boxes and signing overleaf.

Thanks again for your help and I look forward to working with you!

Debbie Kramer-Roy
PhD Student

Volunteering Agreement

“Exploring the support needs of Pakistani families with disabled children in the UK using an occupational justice framework: a participatory action research study”

	<i>Please tick the appropriate box</i>	
	YES	NO
<p>I understand that this is a research project and that all information I come to know about is confidential. I will not share any information outside the children’s group</p>	<input type="checkbox"/>	<input type="checkbox"/>
<p>I understand it is important to avoid influencing the children’s ideas and responses expressed in the sessions.</p>	<input type="checkbox"/>	<input type="checkbox"/>
<p>I will consider everything the children say, do or make as confidential and will not talk about these to anybody outside the children’s group, including their parents.</p>	<input type="checkbox"/>	<input type="checkbox"/>
<p>I have been checked by the Criminal Records Bureau Reference number:</p>	<input type="checkbox"/>	<input type="checkbox"/>
<p>Signature:</p>		
<p>Name in capitals:</p>		
<p>Date:</p>		

Appendix P
Story from “Views from our shoes”

Amber Cafford-Robinson, 5.

My sister's name is Naomi and my name is Amber. I am five and she is three. We think Naomi has Rett Syndrome and some other things.

I like to play with Naomi. If she cries, I can make her laugh by laughing! Naomi has an electric piano. Sometimes I move her arms and help her push the keys to make music. I love to play with her. She loves me best of all.

Naomi has a g-tube. A g-tube is a tube that goes into her tummy so she can drink a special kind of formula. Naomi throws up a lot, and I don't like it when she throws up. When my parents are dealing with her, I'm alone and nobody pays attention to me. It's like I'm not even there. If she did not have this sickness, I would like it much better.

Last year I when to "Camp Me and My Family" and met some new friends who have sisters and brothers with special needs. We had a lot of fun! One girl had a brother who has a g-tube and was in a wheelchair and couldn't talk, just like Naomi.

If Naomi didn't have special needs, I would be much happier. Thinking of all the things we could do together fills up my brain with thoughts! We would do all sorts of things – play ball, make up games together or play in the hot tub.

When we go to school, I sometimes like to bring Naomi into my classroom and introduce her to my classmates. Sometimes, if we are early enough I go into her classroom and see her classmates.

I worry about Naomi sometimes. When she is in school I wonder what she is doing and if she is having a good day. When I get home from school, I can't wait to see the art she did in school.

On weekends I like friends to come over to play and meet Naomi.

I wish she will get better sometime in her life. But I do not wish she will get better in days, weeks, months, or years. I just wish she would get better the minute I wish it.

Amber, who loves to dance, swim, swing, roller-skate and read, lives in Forestville, California.

From "Views from Our Shoes: Growing Up With a Brother or Sister With Special Needs"
by [Donald J. Meyer](#) (Editor), [Cary Pillo](#) (Illustrator), 1997.

Appendix Q Publications

Researching the support needs of Pakistani families with disabled children in the UK

Debbie Kramer-Roy, PhD Student, School of Health Sciences and Social Care, Brunel University

Abstract

Pakistani families living in the UK form one of the most disadvantaged sections of the society. Key issues faced relate to poverty, high unemployment, ill health, low levels of English proficiency, rising 'Islamophobia', men feeling misunderstood and misrepresented, and a lack of faith/culture appropriate facilities. When a disabled child is born, additional issues are added to this already challenging situation. These include a significantly higher incidence of disability, high costs of raising a disabled child, being less likely to receive benefits, poor access to health and social care, negative attitudes towards disability within the community and a high incidence of depression and anxiety among primary carers.

Although a considerable body of research-based evidence has been available for well over a decade, no significant improvement in service provision to these families has been seen. The paper suggests that a critical paradigm of research, with emancipatory goals, is needed and that participatory action research be used to help Pakistani families gain better understanding of their own support needs and to provide better skills to be able to ensure that these needs will be met more effectively within the family, in the community and through mainstream services.

Keywords: Pakistani, disabled children, critical emancipatory research paradigm, participatory action research

Introduction

This paper is based on an interactive workshop I conducted at the *Inclusion and Exclusion 2007* Conference organized by the Race Equality Foundation and the Social Services Research Group on 29th January 2007. The participants of the workshop brought a wide range of experience of working with black and ethnic minority families with disabled children and included a Pakistani mother of disabled children.

The paper also consists of a literature review around the situation faced by Pakistani families* with disabled children in the UK, a discussion of the possible reasons why little improvement in their situation has occurred despite the awareness of the issues brought about by this research, and a proposed way ahead in research approach and methodology. During the workshop,

participants were given the opportunity to share their experiences and views on challenges faced by the families and on reasons for research not having had as much impact on service provision as desirable, before findings from the literature on both these issues were presented. Having first secured their consent, participants' input and feedback have been incorporated in the paper. The paper was written at the end of the first phase of my PhD studies, whilst the research proposal was being finalized.

Pakistani families in the UK

When reading relevant literature about the Pakistani community in Britain, the first factor that stands out which has an impact on many of the other issues that will be described in this article, is the disproportionately high percentage of Pakistani families living in poverty: 60% are

low-income families before housing costs, rising to 68% after housing costs, compared to 20% of the total population (National Statistics Website, 2002). An associated problem is the very high unemployment rate, which is twice the rate compared to the white population for men and three times for women (Equal Opportunities Commission, 2004). In addition, Pakistani people, especially men, are less likely to have a professional qualification or degree (Equal Opportunities Commission, 2004). Those men who are employed are more likely to work unsocial hours due to shift work in restaurant and retail jobs, thereby affecting the role of fathers in their children's upbringing, as they are rarely at home from the time the children come home from school until they go to sleep (Khan, 2006a, p. 7).

There is also a higher incidence of ill health among Pakistani people, with the incidence of self-reported ill-health being double and the incidence of disability across the life span being one and a half times that of the white majority population (National Statistics Website, 2004).

Limited English proficiency also impacts on Pakistani families. Modood (1997, p. 60) found that, overall, 78% of men and 54% of women speak English fluently or fairly well, rising to 96 and 84% respectively for 16 to 24 year olds and dropping to 56 and 28% for 45 to 64 year olds. The proportion of those speaking English well increases with the length of settlement in the UK, although those who arrived at a younger age are more likely to develop good English. Another important factor is the 'residential density effect' - people living in neighbourhoods with larger numbers of Pakistani people being less likely to speak English well.

Khan (2006b, p. 2) reports from her research with Pakistani men that they see the rise in 'Islamophobia' in recent years as an important factor in hindering integration in society, leading to more alienation. The

men added that they felt misunderstood and misrepresented in society and that they struggled to redefine their role in the family, as the traditional roles of being the 'provider' and 'authority' figure were lost. In addition, the men in this study considered the lack of faith- and/or culture-appropriate provision of social and leisure activities for youth and families to be an important threat to developing positive family relationships (p. 3).

Workshop participants highlighted the isolation of the Pakistani community from the white majority community, ascribing the reason for this mainly to a lack of knowledge and understanding of Pakistani culture by the majority population. They observed that this led to a lack of participation in the political and wider community spheres. Another important observation they made was that information about accessing care and benefits is often not provided in a way that lets people know their rights. This was seen as an additional problem to poor English proficiency and not merely a result of it. Finally, both overt and indirect racism were seen as pervasive problems for Pakistani families in all spheres of society, hindering access to education, health and social services and to employment.

This brief overview indicates that Pakistani families are significantly disadvantaged in many areas of their lives, as compared to their white majority counterparts. The next section will show that their situation worsens considerably when a disabled child is born into the family.

Pakistani families with disabled children in the UK

Although a number of the problems described in this section are shared with white majority families with disabled children, they have been described because they impact particularly heavily on Pakistani families. Chamba *et al.* (1999)

found that ethnic minority families with disabled children were relatively more disadvantaged as compared to the white majority population and that, among them, Pakistani and Bangladeshi families were worst affected.

The first important observation is that a number of studies report a significantly higher prevalence of childhood disabilities in Pakistani families. For example, Morton *et al.* (2002), in their Derby-based study, found a three times higher prevalence for severe learning disability, six times for hearing loss, four times for sight loss and ten times for genetic causes of disability (p. 89). The latter is also evident in the national study of Progressive Intellectual and Neurological Deterioration (Devereux *et al.*, 2004), which found that 19 % of all reported cases occurred in Pakistani families, whereas the total Pakistani under-16 population constitutes only 1.8% of the UK total (p. 11). The authors suggest that consanguinity is likely to be one of the reasons for this difference in prevalence, with approximately a quarter of cases being children of parents who are related, most of whom are Pakistani (p. 10). A complicating factor in this respect is that genetic guidance for families from ethnic minorities is particularly difficult, and many families do not receive adequate information and guidance after their first disabled child is born, which increases the chances of more than one child with the same genetic disorder being born into the same family (Morton *et al.*, 2002, p. 92). However, it is important not to overemphasize the issue of consanguinity as this leads to an unhelpful tendency to blame families for having disabled children. It needs to be kept in mind that “families which are already poor are more likely to have chronically sick or disabled children” (Reith, 2001, online). As Pakistani families are three times more likely to live in poverty than the general population, this is likely to have a significant impact on the incidence of disability as well.

In the UK, the average cost of raising a disabled child is three and half times higher than the cost of raising a non-disabled child and the available benefits do not cover the difference (End Child Poverty and the Council for Disabled Children, undated). Chamba *et al.* (1999) found that, among ethnic minority families, fewer parents were receiving benefits and, if they did, they were less likely to be awarded at the higher rates. Parents who did not speak or understand English were even less likely to receive benefits (p. 5). As mentioned above, poor English proficiency is a common issue in Pakistani families.

In their study, Bywaters *et al.* (2003, p. 507) report that Pakistani families found it particularly difficult to gain access to health and social services. This was not due to their failure to try to access services for their child, but due to full information not being made available, which was often compounded by the language barrier experienced by many of the families. In addition, the services offered were not always in line with what the families needed. Chamba *et al.* (1999, p. 22) report that many families encounter insensitivity from service providers regarding their religion and culture. This was particularly important in the case of respite services, where needs like a Halal diet and modesty must be addressed before parents feel able to hand over the care of their child. On the basis of my own experience of working in a multi-disciplinary child development team, I have observed a great deal of misunderstanding about both Islam and the Pakistani culture, even among colleagues who were open-minded and willing to serve them as well as possible.

Although negative attitudes towards disability can be seen in all sections of society, they may possibly be more overt in the Pakistani community. The first issue relates to the faith based explanation of the cause for the child’s disability. Although Bywaters *et al.* (2003, p. 505) found that

only a minority of parents in their sample referred to God when asked about the cause of their child's disability, the concept of it being God's will, testing or punishment is nevertheless a recurring theme. In my experience both in the UK and in Pakistan, families often refer to God when they speak about their child's disability and how they deal with it. Although these beliefs about the causes of disability are quite common in the Pakistani community, they are not based on the Qur'an. Al-Munaizel (1995) describes how the Qur'an affords equal human rights to disabled people and that Muslims are encouraged to associate with and care for disabled people as a moral obligation. Morad *et al.* (2001) give a number of examples of the improved services for, and position of, disabled people in early Islamic societies and suggest that negative attitudes seen in contemporary Muslim societies and communities cannot be attributed to the teachings of Islam. Similarly, Bazna and Hatab (2004) concluded from their detailed study of the Qur'an that physical impairments are morally neutral, i.e. they are neither curse nor blessing, but just a part of the human condition, thus removing any stigma and barrier to inclusion (p. 25). Bywaters *et al.* (2003) point out that religious beliefs may be an important element in the coping mechanisms of families and should therefore not be off-limits for service providers who do not share the same beliefs (p. 508). My own experience confirms this and I have often been able to encourage Pakistani families to rediscover what their faith teaches them about disability, helping them to feel more positive about their child.

Nevertheless, in practice, Pakistani families with disabled children face many negative attitudes in their own community. Workshop participants emphasized the cultural impact of having a disabled child, often leading to the mother being blamed for the child's disability. Even if the mother is not blamed for the disability, she is often still seen as a 'victim', and told that she

must carry this burden in the hope that she will eventually be rewarded for it in heaven. These views lead to a sense of shame and isolation, as well as to a lower likelihood of receiving emotional or practical support from her husband, extended family or community. This lack of support perhaps serves to challenge the stereotype of caring minority ethnic families, which is sometimes used by professionals as the reason for the limited provision of services for these families (Chamba *et al.*, 1999, p. 15; Katbamna, *et al.*, 2004, p. 398). Chamba *et al.* found that, compared to mothers from other ethnic groups, Pakistani mothers were least likely to receive high levels of emotional and practical support from their partner. Hatton *et al.* (2004, p. 68) also found low levels of support from spouses in their sample of South Asian families. In addition, they found that support from the extended family was even less frequent, with almost 68% reporting 'no help' and 21% reporting 'a little help'. Reasons for this were that extended family members were too busy, not interested in the child, did not know help was needed, or could not cope with the child. Parents were often reluctant to ask for help (p. 74). Help from friends outside the extended family was even less common and parents tended to feel uncomfortable talking about their disabled child to their friends (p. 77). When asked about support from local communities, parents reported negative attitudes, stigma and a consequent lack of support. Support from religious organisations was not forthcoming and parents, generally, did not take the initiative to try and obtain support from this source (p. 79). Only around 10% of parents had sometimes received help, but 44% had found them unhelpful and 46% had found them unavailable for support services (p. 79). Some parents expressed the view that "our Muslim people aren't doing enough to help Muslim people ... Pakistani Muslims need a push" (p. 114).

In light of the above, it is not surprising that there appears to be a high incidence of psychological distress, including depression and anxiety, among primary carers (most often the mothers) of Pakistani disabled children. Emerson *et al.* (2004) found an incidence of 70% of carers suffering psychological distress versus 47% in the general population. In Hatton *et al.*'s (2004) study, more than 45% of Pakistani parents were affected by depression and almost 35% by anxiety. Parents attributed this to having to care for their disabled child without support (p. 149). The authors point out that this higher rate is unlikely to be due to ethnicity *per se*, but is more likely to arise from the higher level of social deprivation they experience (p. 81).

This review of the literature clearly shows that, not only are Pakistani families relatively more affected by poverty and deprivation in general, they also have higher chances of having disabled children, which increases and compounds this disadvantaged position even further. It could be said that families (of any ethnic background), as a whole, are 'disabled' by the unjust society in which they find themselves, as parents and siblings of the disabled child, subject to stigma, marginalization and discrimination in much the same way as the child (Fazil *et al.*, 2002, p. 238). Pakistani families are particularly vulnerable in this respect as they have a number of characteristics that make society regard them as 'other' - ethnicity (colour, culture, language, originating from a former colony) and religion (the 'dreaded', highly misrepresented Islam).

Nature of research studies and their impact on the families

The research studies on which I have drawn for the literature review, which to my knowledge are the only studies that have been published to date, have yielded a wealth of findings, which clearly show the complex web of marginalization in which

many Pakistani families with disabled children are caught. However, although this has been known from research findings dating as far back as the mid 1990s (e.g. Beresford, 1995), more recent studies (e.g. Hatton *et al.*, 2004) suggest that little progress has been made in either defining the specific support needs of this group more precisely, or in meeting these needs.

These studies have either been large-scale, using questionnaires (Beresford, 1995; Chamba *et al.*, 1999), or smaller, qualitative studies that have mainly employed interviews (Fazil *et al.*, 2002; Bywaters *et al.*, 2003; Hatton *et al.*, 2004). Although the study on which the papers by Bywaters *et al.* and Fazil *et al.* are based described how action research had been used (Fazil *et al.*, p. 389) to ensure the 'right' questions were being asked in the interviews, the research participants did not participate at the level of co-researchers, but rather their feedback was used by the researchers to refine the research tools. A similar approach was taken by Hatton *et al.* (2004), although they do not describe it as 'action research' (p. 169) and acknowledge that their study "falls short of recommendations made for participatory research (which is) a way of doing research that includes people at the receiving end of the study as joint researchers". All of these studies were carried out within traditional research paradigms.

Significantly, Bywaters *et al.* (2003, p. 508) note that none of the families in their study appeared to be aware of the disability rights movement or to be in touch with any organisation for families with disabled children. They point out that this should be a challenge for these organisations to take up, so that ethnic minority families, who currently appear to perceive disabilities mainly from an individualistic model, may become more aware of the social models of disability, which conceptualise disability as being caused by political and social barriers as much as (or more than) by the individual

person's impairments (UPIAS, 1976, pp. 3-4).

The participants of my Conference workshop suggested the following reasons for the limited impact of research findings:

- engaging with service users from ethnic minorities is too challenging for many service providers;
- service providers are not questioning critically enough why current services are under-used by people from ethnic minorities and therefore not taking the initiative to access research findings;
- there are only fragmented attempts to improve services and not enough 'champions', i.e. high profile advocates of racial equality in health;
- there is a lack of political will at higher levels;
- there is a perception that providing more appropriate services will only cost money and not bring financial gain;
- academic studies do not translate into policy, as the findings are often not formulated in practical terms;
- there is a low level of involvement of people from ethnic minorities in planning and evaluating services because, on the one hand, they are not invited often enough to be involved and, on the other hand, they are less likely to have the confidence and skills to do so due to their marginalized position in society at this time.

Although this list of reasons echoes many of the findings from the literature review above, it remains a disturbing collection of issues. The main theme seems to be a lack of willingness at all levels: of politicians to create fairer laws; of service-providing organizations to be informed by research findings and by representatives of ethnic minorities when they plan and implement services; and of individual service providers to be committed to the highest quality of care of their service users regardless of their

ethnicity. By the same token, it appears that the only players who have not been challenged to take on an active role in improving the situation are the families with disabled children themselves. Furthermore, the research has followed traditional research paradigms. Hence it has described the disadvantaged position of Pakistani families with disabled children with the aim to improve service provision, rather than challenging or addressing the oppression faced by the families directly. A critical emancipatory approach to research is therefore needed: one in which the research participants take more control over the research process, reconsider their situation from a social model perspective and gain the skills to start addressing their own challenges, rather than merely describing them. This should enable people to take a more active role in improving policies and provisions: the following section outlines this proposed way forward.

The need for a critical emancipatory research paradigm

The critical research paradigm distinguishes itself from the more traditional positivist (quantitative) and interpretive (qualitative) paradigms in that it focuses on social and political influences on human thought and action and starts from the assumption that social structures have historically served to oppress certain groups in society. Research undertaken within the critical paradigm therefore has emancipatory goals and seeks to bring empowerment to oppressed groups (Henn *et al.*, 2006, pp. 15-6).

With the birth of the social model of disability, which locates the problem of disability in the social and political structures of society rather than in the disabled person, the demand for an adequate research approach to match this radically different view of disability also arose. Stone and Priestley (1996, p. 702) explain that "the focus of disability research will have less to do with the ability of disabled people

to 'cope with' or 'adapt to' their situation and more to do with the identification and removal of physical and social barriers". In the disability studies literature, this alternative approach has generally been described as 'emancipatory disability research'. Some of the key characteristics of this type of research are: (1) the control over the research focus and process lies with the participants as much as possible; (2) the lead researchers are accountable to the disabled community; (3) a social model of disability is adhered to; and (4) the research should have some meaningful practical outcome for disabled people (Barnes, 2002, online). It is difficult to find any literature that prescribes specific methodology and methods that should be used in the pursuit of emancipatory disability research (Mercer, 2002, p. 245), although Barnes (2002, online) points out that it has generally been associated with qualitative, rather than with quantitative data collection strategies. However, he goes on to say that quantitative strategies may be useful too and that "it is not the research strategies themselves that are the problem; it is the uses to which they are put".

Participatory action research

Participatory action research is congruent with both the ethos of the social model of disability and with the key characteristics of emancipatory disability research and I therefore believe that it can be used as an effective method to achieve the goals of emancipatory disability research. Participatory action research can be described as "an emancipatory practice aimed at helping an oppressed group to identify and act on social policies and practices that keep unequal power relations in place" (Herr & Anderson, 2005, p. 9). Reason (1994, p. 6) explains that participatory action research starts with concerns for power and powerlessness and aims to confront the way in which the established and power-holding elements of societies world-wide are favoured. Secondly

the lived experience and knowledge of people, often oppressed groups, are directly valued and central to the process. The two major aims are to produce knowledge and action that are directly useful to the participants and to empower people through the process of constructing and using their own knowledge, a process described by Paulo Freire (1970) as 'conscientization'. Another important feature is the commitment of the researcher and of the participants to the processes of genuine collaboration. For this to happen, dialogue is very important because it causes the subject-object relationship of traditional science to give way to a subject-subject one, "in which the academic knowledge of formally educated people works in a dialectical tension with the popular knowledge of the people to produce a more profound understanding of the situation" (Reason, 1994, p. 7).

In order to achieve the emancipatory goals of participatory action research, the nature and level of participation of the participants is extremely important. Cornwall (1996, p. 96) presents a useful continuum of modes of participation, ranging from the research being done **on** people, to the research being done **by** them, i.e. Co-option (on), Compliance (for), Consultation (for/with), Co-operation (with), Co-learning (with/by) and Collective action (by). The highest level at which an outside researcher can engage with the participants is at the level of 'co-learning'. Keeping in mind that the participants in participatory action research studies tend to be members of a highly marginalised section of the population, it takes both time and facilitation skills on the part of the researcher to enable participants to reach that level of participation and, through this, emancipation. As Reason (1994, p. 18) states: "There are a whole range of skills required for participatory research which are very different from those of orthodox research, and which include personal skills of self-awareness and self-reflexiveness; facilitation skills in

interpersonal and group settings; political skills; intellectual skills; and data management skills". Maintaining a high level of participation is only possible if the researcher constantly reflects on the status of their relationship with the participants and if the participants are aware of the desired nature of their relationship and encouraged to monitor and give feedback on it too.

The process of participatory action research – and all other types of action research - consists of a spiral of cycles, each of which consists of planning, action, observation of the impact of the action, and evaluation of that action and its impact (Kemmis *et al.*, 2004, p. 3). This is a dynamic process in which these four aspects are not seen as static steps, but rather as moments in the action research spiral. In the process, the aim is to bring together discourse and practice through constructive (planning and acting) and re-constructive (observing and reflecting) processes, so that improvements in practice and understanding can be made systematically, responsively and reflectively (Kemmis *et al.*, 2004, p. 7). Before embarking on the first cycle of the action research spiral, the process begins with a general idea and the sense that some kind of change is desirable. The idea of improvement prompts a reconnaissance, or exploration, of the current situation, in order to understand it better. On the basis of this reconnaissance phase the initial plan of action is decided and the first cycle of the action research spiral has begun (Kemmis *et al.*, 2004, p. 3).

Will it work?

Successful participatory action research studies carried out with South Asian participants in the UK have been described in the literature (e.g. Bowes, 1996; Chiu, 2003). However, I have not been able to identify examples of participatory action research involving Pakistani families with disabled children/members, who face

oppression due to ethnicity as well as disability issues. Nevertheless, successful development projects using participatory approaches have been described (Singh, 2005) and valuable lessons can be learned from them. My own experience of using participatory methods in project planning, in the evaluation of community-based rehabilitation projects and in teaching and researching in inclusive and health education in Pakistan also makes me optimistic about the possible outcomes of participatory action research with Pakistani participants.

At the time of writing, I have gained the cooperation of two local mosques in inviting and encouraging families to come forward to participate in a study which aims to identify the support needs of Pakistani families with disabled children and how these needs can be met more effectively; and to explore how engaging the research participants in undertaking participatory action research in groups of men, women and children can facilitate their active role in achieving these aims.

In gaining access to the community I have found that my previous experience has been very helpful. My nine years in Pakistan and five years of working with South Asian families in the UK not only give me a good knowledge of Urdu, the Muslim faith and the Pakistani culture, but also give people the confidence that I understand them relatively well. Secondly both my professional background in occupational therapy and my experience in using participative approaches in other professional roles have prepared me well to take a facilitating rather than a directive approach to working with the research participants. Finally I believe that not being a Pakistani myself may be an advantage as I do not fit into the social hierarchy and therefore have no fixed 'status' within the Pakistani community. This means I am likely to be perceived as impartial. In addition there is no culturally defined role I

am expected to fulfil and I am therefore no threat to the honour of families in engaging with both the male and the female family members as a researcher. In personal communication Pakistani women have expressed the view that it would have been extremely difficult for a Pakistani female researcher to engage the men meaningfully, but that I stand a good chance of doing so, due to my non-Pakistani nationality and professional background.

In order to 'make it work' it will be important to keep in mind the culturally specific power relationships that are evident within the sample of participants. By working in separate male and female groups an opportunity is created to bring about change within existing power structures. By having meetings for all participants to exchange their findings and ideas people will be able to begin to challenge issues from the inside where they form an identified threat to the health and well-being of the disabled child and/or other family members. Starting to develop the conditions in which communication can improve and positive change can occur is a process that needs to be controlled by the participants as much as possible. Although it is likely that initial developments will focus on relationships within the families, they should prepare participants to be able to describe their needs more effectively to, and negotiate more effective support from, service providers.

Conclusion

This paper has highlighted the situation of Pakistani families with disabled children in the UK and discussed what approach to research might be most effective in addressing the persistent problem of their needs not being met effectively. I have argued that a critical research paradigm is most likely to enable participants to take on a more active and assertive role in policy and service development. Though at the time of writing I can only be optimistic

about the potential outcomes of this approach, reports on this work in progress will become available in due course.

Footnote:

* In this paper the term 'Pakistani families' is applied to all families of Pakistani origin, regardless of their current nationality, or whether they are first, second or later generation immigrants.

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Occupational Injustice in the Lives of Pakistani Families with Disabled Children in the UK: A Participatory Action Research Study

Debbie Kramer-Roy

ABSTRACT

This chapter describes both the processes and the findings of a Participatory Action Research (PAR) project carried out with a group of Pakistani families with disabled children living in the UK. The research was conducted in the context of the author's PhD studies and therefore restricted in scope and length. However it resulted in rich data and its findings are important for occupational therapists and others who work with Pakistani families.

First the research process is described, which indicates how PAR can be used successfully with this population, keeping in mind specific cultural and religious characteristics as well as universal aspects. Then the findings of the study that relate to occupational science are presented, with a focus on occupational injustice and on cultural aspects. Key observations relate to the concept of belongingness and how the families experience a lack of this due to negative perceptions of disability in their community. The positive changes in their own faith led to positive perceptions and the ability to accept their disabled child and deal with community attitudes better. The PAR process fostered important life-skills, enabling participants to reflect on and deal with the challenges of living with a disabled child better.
(end of abstract)

In the light of the recent development of occupational science, Wilcock (1999 p 10) urges occupational therapists to take on the challenge to work not only with people with impairments of various kinds, but “also with those suffering from the disorders of our time, such as occupational deprivation, occupational alienation, occupational imbalance and occupational injustice (in order) to enable occupation for personal wellbeing, for community development, to prevent illnesses and towards social justice ...”. Pakistani families with disabled children are one population that suffers from such ‘disorders of our time’.

Pakistani families with disabled children in the UK

The reasons for choosing to conduct research with Pakistani families in the UK are twofold. My long previous experience of working in Pakistan (9 years) and with the Pakistani community in the UK (4 years) means I have a relatively good understanding of their culture, religion and – importantly – language. The knowledge, skills and attitudes resulting from this experience have been instrumental in building up relationships in the Pakistani community and with the research participants, which have contributed to gaining rich data.

Secondly the limited amount of previous research paints a depressing picture of the Pakistani community in the UK, especially for families with disabled children. Compared to the total population of the UK, the Pakistani community faces higher levels of poverty and unemployment, poorer housing, prejudice based on both racism and Islamophobia, and a lack of faith / culture appropriate provision of social and leisure activities (National Statistics Website 2002; Government Equalities Office 2008; Khan 2006)

Furthermore there is a higher prevalence of childhood disability in the Pakistani community (e.g. Morton et al 2002) and the families of these children face the additional challenges of the high cost of raising one or more disabled children, are less likely to receive benefits at the appropriate rates and face more difficulty in accessing health and social care (Beresford 1995). Although negative attitudes towards disability exist throughout society, some of the specific attitudes met in the Pakistani community, such as blaming the mother for the child’s disability, a belief in disability as God’s punishment and the subsequent lower levels of support received in the extended family and the community cause high levels of distress in the primary carers of disabled children (Bywaters et al 2003; Chamba 1999; Fazil et al 2002; Hatton et al 2004).

The need for Critical (Social) Paradigm research

Although the above has been known from research findings dating as far back as the mid 1990s (e.g. Beresford 1995) more recent studies (e.g. Hatton et al 2004) suggest little progress has been made in either defining the specific support needs of this group more precisely, or in meeting these needs.

A critical social paradigm of research is most likely to be able to start unravelling the complex web of marginalisation, made up of issues related to ethnicity, religion, disability and - for most carers – gender, which these families are caught up in. Within the critical paradigm, I have chosen to use participatory action research (PAR) to

engage the families actively in identifying and starting to address their support needs within their families, in the community and/or through the service system (see Kramer-Roy 2007).

Participatory Action Research

PAR can be defined as “an emancipatory practice aimed at helping an oppressed group to identify and act on social policies and practices that keep unequal power relations in place” (Herr and Anderson 2005 p 9). A very important principle is that the lived experience and knowledge of the participants, are directly valued and central to the process. The aims are to produce knowledge and action that are directly useful to the participants and to empower them through the process of constructing and using their own knowledge (Reason 1994). This approach to research very clearly recognises that many real-life situations can not be accurately described or addressed by academic knowledge only, and can be seen as the bundling of practical-experiential and academic knowledge in order to improve the situation.

Although PAR is generally considered an approach, rather than a prescriptive method (e.g. Meyer 2006), a helpful way of describing action research is as a spiral of cycles, each of which consists of planning, action, observation of the impact of the action, and reflection on that action and its impact. It is a dynamic process in which these four aspects are not seen as static steps, but rather as moments in the action research spiral, (Kemmis et al 2004). An exploratory phase, in which the research participants identify the key issues to focus on in the research process, precedes this succession of cycles. What makes the process emancipatory is the fact that the participants are not only facilitated to address problematic situations in their lives, but also that they gain important research and problem-solving skills in the process.

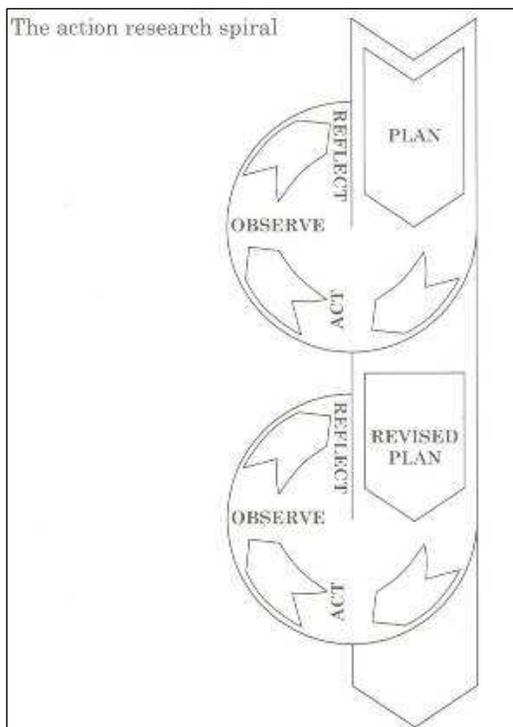


Figure 1: The action research spiral (Kemmis et al 2004 p4)

Congruence of PAR and OT

Trentham & Cockburn (2005 p 440) observe that PAR is “consistent with the values of occupational therapy and occupational justice” and is therefore a particularly suitable choice of approach to researching occupational aspects of individual’s or families’ lives.

Firstly, the participants engage in an occupation that helps them “to develop the skills and knowledge necessary to take greater control over their own lives; in so doing, they promote their own health as well as the health of other community members” (Trentham & Cockburn 2005 p 446).

Secondly, the approach to working as a team of co-researchers is very congruent with principles of client-centred practice, such as respect for people’s skills and insights, taking responsibility for one’s own choices, enabling participation, flexibility, and keeping in view the links between the person, their environment and occupation (Letts 2003).

In both OT and PAR “action” and “collaboration” are central, whether they are implemented with individuals or groups. The successful outcomes of both processes depend much on the therapist or lead researcher’s openness to learn from their partners, rather than viewing oneself as the ‘expert’.

The study

The central research question for this study was as follows: “How can families with disabled children be facilitated to identify their support needs and ensure they are met, within the family, in the community and/or through the service system?” Therefore *the process* of facilitating the participants to engage in the research was as important as *the content*, i.e. identifying their support needs. Within this occupational science offered a helpful perspective, but was not the main theme (see Kramer-Roy 2009 for the full thesis).

Six families participated in this study. In the exploratory phase, carried out in each family’s home, all family members were involved in constructing their family story. For the main action research phase separate action research groups were formed for the men, women and non-disabled children of the families to engage with the issues in ways most appropriate to them. In these groups they identified key issues and planned, implemented and reflected on action taken to address these issues.

Because it was soon evident that this was the first time that participants were invited to reflect on their situation of living with a disabled child, and because recruitment difficulties led to a shorter period being available for the PAR process (around 7 months), the “action” focused primarily on gaining a better understanding of their specific issues and needs. Some steps were also taken towards meeting those needs, which the participants intended to build on beyond the project. An enormous amount of learning was gained from the process, both by the participants and myself.

The action research groups

Each group had its own unique dynamics and processes. As none of the participants knew each other beforehand, initial meetings provided opportunities to share some of their stories and experiences. Once group members were comfortable with each other I explained the principles and purposes of PAR, emphasising that the decisions and actions to be taken needed to be theirs, rather than mine. Even though each group was positive about this in principle, none of them found it easy to act accordingly and frequently asked me to take decisions or actions as I was “much better at it”. Constant reminders that they were the experience experts, or the ones who had the right to ask questions, encouraged them to take over the reigns gradually. I will now describe how this worked out in each group:

The women’s group

For the women the opportunity to come together with other women of their own cultural and linguistic background, who all had a disabled child, was probably the most significant aspect of the project. Introductory activities included making a drawing of an allegory about their child and filling out a worksheet to index their skills. Both these activities led to sharing of very personal stories, which they experienced as a very welcome opportunity for catharsis and mutual encouragement.

On considering which issue to focus on in their own action research cycles, they decided that these meetings filled a gap in their local support system, and should therefore not stop when the research project finished. Their key action was to design and distribute leaflets inviting other Pakistani women to join their support group. The women continued to work on this after the project.

The men’s group

The men started off by sharing one positive and one negative anecdote from their child’s life, which set the tone for much openness in subsequent meetings – much more in fact than I had expected, based on my own experience, and other researchers’ as well as Pakistani women’s predictions. On reflection I recognise several reasons for this openness. The first reason is my unique position as both insider and outsider. The men realised I knew their country of origin, culture, religion, social issues and language rather well and did not feel they needed to hide anything for that reason. At the same time I was not a member of the local Pakistani community and therefore highly unlikely to feedback any ‘gossip’ into the local grapevines. In addition meetings took place in one of the local Mosques, where they felt at ease, as it was a respectable public place and neutral territory.

In terms of their research focus, the men noted that attitudes towards disability in the Pakistani community are overwhelmingly negative, whilst their own attitudes towards their own and other disabled children are largely positive. As the negative community attitudes are mostly expressed in religious terms, they decided to consult Islamic scholars to find out what the Quran and other early Islamic scriptures actually teach about disability, so they could use that knowledge in challenging community attitudes. This information was not at all easy to come by and required much

perseverance in getting appointments to see local scholars, emailing those in other countries and searching the internet.

Their search confirmed their expectation that the Quran does not provide a basis for negative attitudes towards disability. For example the only place in the Quran where disability is directly referred to, the verse serves to remove any stigma experienced in society: “No blame will be attached to the blind, the lame and the sick. Whether you eat in your own houses, or those of your fathers, ... or any of your friends’ houses, you will not be blamed” (Quran 24:61, translation by Abdel Haleem 2004). Eating together in Arabic culture implied a close association at equal footing and this verse is the clearest indication in the Quran that no moral judgment is applied to disabled people. Other issues like the concept of God testing believers and the duty to support the ‘needy’ are not described with explicit relation to disability, but general verses imply positive views on disabled people. A key message is that “in God’s eyes, the most honored of you are the ones most mindful of Him” (Qur’an 49: 13), i.e. that in Islam people’s abilities are relatively unimportant in comparison with their faith in God.

By the end of the project the men were considering how to use this information to encourage more positive attitudes in their community.

The children’s group

The children took much time to open up and were initially both superficial and exclusively positive about living with a disabled sibling. I offered a number of activities to encourage more sharing of the other side of the story, for example the ‘feelings cube’ (adapted from Gibbs et al 2002), which had three positive (happy, excited, proud) and 3 negative (sad, angry, embarrassed) feelings on its six sides and was rolled like a dice; the child then told a story about a time their disabled sibling had caused them to feel that way or had felt like that themselves.

The children had quite a lot of knowledge about what research entails, but initially did not think children could carry out research themselves. Referring back to their own description of research as ‘finding out information’, ‘observing’ and ‘asking the right questions’ helped them to realise that they did indeed possess the required skills. Once the children were ready to start their research, they had clear ideas about their focus, i.e. to understand their disabled sibling better, so they could make him/her happier. They took a step towards this by writing stories about their sibling.

The children indicated that this was the first time anyone had asked about their ideas and feelings about having a disabled sibling, or encouraged them to take decisions and plan and implement activities themselves. Organising a family party, in which their disabled siblings could be fully included, was a very important opportunity to reflect on their disabled siblings’ likes, strengths and limitations, to look for new ways of supporting them and to practice decision-making and planning skills.

Through the processes described above, the participants reflected on and shared with me their individual and family lives in much detail. The next section presents some of the findings from an occupational science perspective.

An occupational science perspective on the findings of this study

When I reflected on what this study has taught me about concepts of occupation relevant to these family's I took as my starting point Wilcock's (2006) 'formula': $d + b^3 = s h$. Or, put in words: doing, being, becoming and belonging equal survival and health. In the women's group I asked the participants to reflect on the relative importance of and interplay between doing, being, becoming and belonging in their lives, by manipulating four coloured paper circles, cut along one radius, to form a pie chart. They found this very helpful. The circle in the picture shows how little one woman felt she was allowed to 'belong', or think about 'becoming'; she felt she was always 'doing' and that that was expected of her. However her sense of 'being' was very important to her and had been influenced by her strengthened faith and resilience through raising her disabled child.

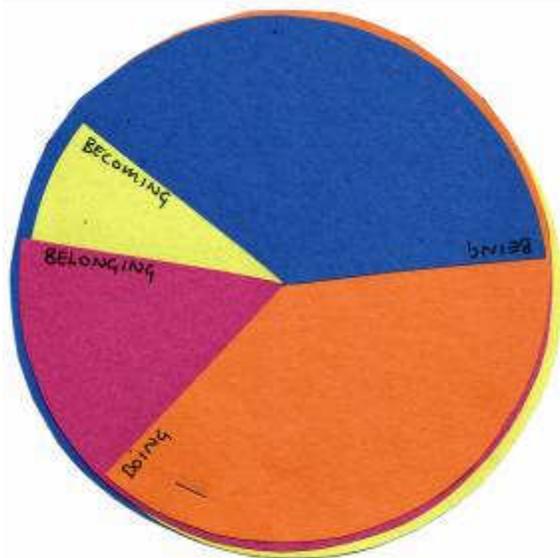


Figure 2: Paper circles used to explore $d+b^3$

Some key findings related to these aspects of occupation follow, and implications for occupational justice will be pointed out where appropriate.

Belonging

The 'belonging' aspect was vitally important for these families. In the Pakistani cultural context interdependence is very important, in many respects more important than independence. There are advantages as well as disadvantages to this. When a girl gets married, the contract entered into is not just between her and her husband, but between the two families. In most cases the bride moves into her husband's home, but even if they live on their own, she still is responsible for keeping her in-laws happy, as that will also ensure a good relationship with her husband. Intimacy or support are not necessarily expected in the husband-wife relationship, although it is often present. The importance of being a good daughter in law also reaches beyond the family, as it affects the family's position in the community. 'Good' entails good housekeeping and cooking, raising respectful children and avoiding anything that might blight the honour of the family. In a good, supportive family, this can be a very positive and safe situation, but in

many cases the woman is constantly aware of having to maintain the family's stability – not an easy task in a culture where gossip and shame have much influence (see Campbell & Mclean 2003).

When a disabled child is born, community attitudes mean that the mother is often made to feel responsible for or guilty of this – the child's disability is seen as a punishment or a 'test' from God. All but one of the families report that this issue caused them much grief in the early months or years of their disabled child's life, but despite this they have all been able to accept their child and gradually come to the opposite point of view of seeing their child as a blessing. However the contrast between the child's positive sense of belonging within the immediate family and the lack of acceptance in their extended family and community, including the Mosque, is an ongoing source of frustration and grief as it has significantly reduced the social contacts and support the families have.

In this family context, the non-disabled siblings tended to be very loyal to their parents, which meant they willingly shared in the care for their disabled sibling. At the same time they were initially extremely reluctant to express any negative views about their sibling or parents until they realised that the other children in the group had similar experiences, and acknowledging and dealing with them did not mean a betrayal of their family.

A final observation on belonging is the feeling of 'homecoming' the women experienced in their research group – they strongly expressed how safe and accepted they felt in the group due to the shared background and issues, saying "we don't need to defend ourselves" and "it is so uplifting to share each other's problems".

The significant lack of belongingness within the extended family and community created a situation of occupational injustice for the disabled child as well as the family, as it restricted their choice of occupations significantly. For example, culturally highly valued activities like attending weddings, visiting relatives and friends, and attending Quran classes and religious celebrations at the Mosque were greatly restricted for the families, particularly for those whose children had intellectual impairments or behavioural difficulties.

Being

Parents talked about how their faith had changed through the process of accepting their disabled child. Initial negative reactions from relatives and community members, which implied that the child's disability was a divine punishment for their sins, were distressing, but despite that they started to see their disabled child as a blessing, who brought them closer to God. As the men's group found out through their research, the negative community attitudes towards disability are not based on the religious scriptures, which do not suggest any value or moral judgment on disability (see Bazna and Hatab 2004). However, the Islamic concept that God presents all Muslims with challenges to test or refine their patience and perseverance in faith (e.g. Qur'an 2:155), was considered a positive aspect in this process, as expressed by one mother who said that God only tests those He wants to enter into Heaven. The negative connotations that

the community appears to have with the idea of disability as a 'test' was turned around into a positive opportunity to become a better human being through the experience. This reasoning and personal growth was expressed by all mothers and several of the fathers and their Muslim faith was central to their sense of identity. It also helped them to accept the child as they are, or in other words to allow them to 'be'.

Doing

In all families the mothers were the main carer of the disabled child, although most fathers also took on a significant role in practical caring and decision-making. All mothers indicated that they had no time for themselves and regretted the loss of certain hobbies or relaxing habits. They also all indicated the importance of having something else, like work or study, to provide balance, distraction and contact with the 'real world', but not all had actually achieved this. Balancing work and caring tasks was also described as a challenge by several of the fathers.

Most siblings also took on caring responsibilities for the disabled child, which was perceived to have both positive and negative outcomes. On the one hand they had limited opportunities for socialising and engaging in their own play and hobbies. On the other hand they valued the maturity and sense of responsibility their situation caused.

Importantly none of the parents or siblings expressed any resentment towards the disabled child for the resulting occupational imbalance, as they said it was natural to do this for their 'own flesh and blood'. Where dissatisfaction was expressed it was about the division of tasks within the family or about the insufficient level of culturally appropriate respite care facilities.

Caring for a disabled child led to considerable occupational imbalance (one of the aspects of occupational injustice), particularly for the mothers, but to a lesser extent also for the fathers and siblings of the child.

Becoming

To some extent the way family life with a disabled child impacts on each family member's personal development and hopes for the future has already been alluded to in the sections on belonging, being and doing above. Dominating themes when participants talked about the future, related to not knowing what to expect from their child's abilities in adulthood; worrying about who would care for them after their own death; and a desire to look for ways to support other Pakistani / Muslim parents in the same position. As described above in the section on 'doing' most mothers had no time to think about, or work towards personal future goals.

These limitations on participants' sense of becoming were caused mainly by external social factors and the resulting limited scope for personal development for the disabled child and their family members thus constitutes a form of occupational injustice.

Occupation and culture

Iwama (2005 p 247) cautions that “current definitions of occupation demonstrate a valuing that is particularly reflective of Western experience and worldviews” and that the concept of occupation must be re-defined in each new cultural context. For this group of Pakistani families with disabled children living in a Western context the aspects of ‘belonging’ and ‘being’ were relatively very important and strongly influenced by their cultural and religious background. In meetings of the women’s group participants remarked repeatedly that many aspects of family and community relationships were universal, but the way they presented in their own culture was often very different. This illustrates the importance of finding a balance in recognising the differences in people’s cultural background whilst also expecting many similarities, as it is the latter that are instrumental in creating relationships of trust that enable collaborative work and effective intervention.

This study also illustrates the importance of recognising that some of the cultural differences are an important positive source of support and inspiration for the families. Examples of this are the role of faith in accepting and allowing the disabled child to “be”, and the way the interdependence or loyalty within the family makes it easier for family members to share the burden of care. Enabling people to build on the strengths in their cultural background in this way can contribute to increased occupational justice.

Conclusion

This project provided the participants with an opportunity to engage in a meaningful occupation - participatory action research - which led to a deeper understanding of their situation, and facilitated the development of valuable skills like problem solving, collaboration, and taking action to improve their situation.

Despite the limited scope of a project undertaken for doctoral studies, participants reported a range of positive outcomes for them as individuals (e.g. improved understanding of community perceptions of disability and increased assertiveness to address them) and families (e.g. improved communication between family members).

The practical and participatory nature of the project lent itself well to exploring occupational aspects of their experience, giving occupational therapists more insight into the particular strengths and needs of Pakistani families with disabled children, as well as inspiration for working with them in ways that capitalise on their strengths, so that their needs can be met more effectively.

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