

“We want to understand their ‘virtual’ world better, so we can make them happy”: Pakistani children use participatory action research to explore their disabled siblings’ support needs.

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Introduction

This chapter describes the role children played in a participatory action research project that aimed to explore the support needs of Pakistani families with disabled children living in the United Kingdom (UK). The children living in a multi cultural urban area of UK were brought together for this project when their families decided to participate, so that they did not know each other before, they were of different ages and studied in different schools. A range of creative and fun activities were used during the fieldwork spread over a period of ten months. The chapter reflects on both the successes and challenges of this project, with implications for using this approach in an educational setting.

This project was carried out in the context of my PhD studies at Brunel University, West London, UK. Before embarking on the PhD studies, I had worked with Pakistani disabled children and their families, communities and schools for almost 15 years, nine of which in Pakistan and six in the UK. I worked in a number of different areas i.e. occupational therapy, community development, project evaluation and planning, teacher education, research. These experiences gave me a good knowledge of the Pakistani culture, majority religion and language, as well as of the highly disadvantaged position of disabled people in Pakistani society. In addition I observed that Pakistani families with disabled children in the UK also face a wide range of challenges, which were different, but not necessarily easier.

A small number of earlier studies into the situation of Pakistani families with disabled children in the UK was available and provided a broad overview of issues faced by these families, confirming my own observations. There is a higher incidence of childhood disability in the Pakistani community in the UK than among other ethnic

groups (e.g. Morton et al, 2002), and among the different population groups these Pakistani families are the most disadvantaged (Chamba et al, 1999). The Pakistani community as a whole faces a range of marginalizing factors, such as high levels of poverty (National Statistics Website, 2002) and unemployment (The Poverty Site, online), poor housing, limited English proficiency (Modood, 1997) and religious discrimination (Khan, 2006). On top of these general factors, families with disabled children battle with additional disability related issues, such as the high extra costs of raising a disabled child (Every Disabled Child Matters, 2007), difficulty accessing health and social services (Bywaters et al, 2003) and benefits (Chamba et al, 1999), and negative attitudes towards their child and the family as a whole in the Pakistani community (Bywaters et al, 2003).¹

The need for an emancipatory approach

When comparing the outcomes of earlier studies (e.g. Beresford, 1995; Chamba et al, 1999) and later ones (e.g. Hatton et al, 2004) little improvement can be seen in these Pakistani families' circumstances. Therefore, rather than repeating these descriptive studies, I saw the need for a participatory study that aimed not only to provide deeper insight into their specific needs, but also invited the participant families to take an active role in the research process. This gave insight into the way meeting support needs may depend as much on appropriate services being available as it does on the families' ability to help define, access and receive them. This approach fits into a critical social paradigm of research which has emancipatory goals, aiming to bring empowerment to oppressed groups. It seeks to expose injustices, give voice to the participants and support them in gaining more insight into and control over their difficult situation (Henn et al, 2006).

In recent decades disabled activists and academics have argued for the need to engage disabled people and their families in emancipatory research, in which the participants have as much control over the research process as possible, and disability issues are studied from a social model perspective (Barnes, 2002). The social model locates the problem of disability in the restrictions imposed on the disabled person by society

¹ For a more detailed description of these issues please refer to Kramer-Roy (2007).

through physical and social barriers which leads to limited participation in the community, rather than in the particular impairment or functional limitation that that person may have (Riddell and Watson, 2003).

The design of the study

Within the critical social paradigm I used participatory action research to engage six families with disabled children actively in identifying and starting to address their support needs within their families, in the community and/or through the service system. There are very few examples of emancipatory research with Pakistani participants (see for example Seebohm et al, 2005) and none were identified that engaged whole families with disabled children in participatory action research.

The families, living in a multi-cultural urban area in the UK, were identified and invited to participate through announcements made and leaflets distributed at the local Mosques, and through special schools and voluntary projects passing on invitation letters to Pakistani families. The recruitment process was slow and difficult and out of the 18 families identified over a period of five months six agreed to participate in the project. Each family had one disabled child, two of which had severe intellectual impairment and autism, three had moderate intellectual impairment and one had mild physical impairment.

The action research process was participatory and democratic, and consisted of an exploratory phase lasting three months followed by action research cycles of reflection, planning and action (Kemmis et al, 2004) lasting seven months in total. All family members were invited to play their part in telling their family story in the exploratory phase, in which interviews as well as non-verbal methods were used, as described below. For the 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. For example the men's group contacted Islamic scholars and Imams to find out what the Quran teaches about disability, and the women identified the value of meeting other mothers from their own cultural and religious background and planned to set up a local support group. Each group met around eight times over a five month period each and determined their own research focus and actions. The researcher offered activities to facilitate each group's research

process, based on their discussions and actions in previous meetings, so that the design of the study emerged throughout the process.

The children's research activities

In this family-centered research project the children's participation was very important at all stages and the remainder of the chapter will concentrate on this aspect.² The choice of activities was crucial during the exploratory phase as well as for all three action research groups, as they were designed to make it easier to start expressing feelings and views about family life with the disabled child, and to trigger open communication and deeper reflection in the groups and families. The activities the children engaged in will therefore be described in some detail. Important positive outcomes of the children's participation in the project will be indicated in relation to these activities. Key challenges and their implications for future studies will be discussed at the end of the chapter.

The disabled children

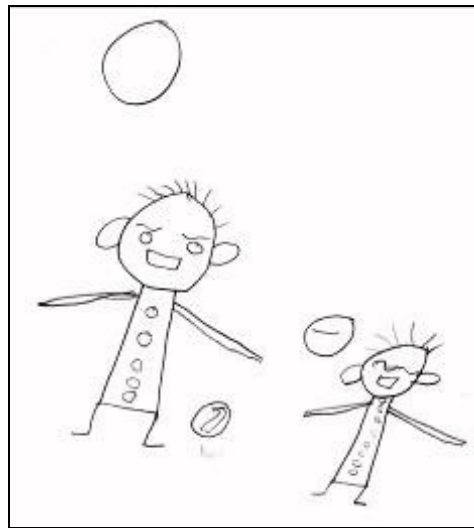
The active participation of the disabled children consisted of engaging in interviews and interactions during the exploratory phase, and joining in the all-family meetings throughout the project period. Most disabled children had had very limited opportunities to express their own views before, and interviewing and otherwise obtaining their views was challenging. Overall three children could not respond to verbal questions about disability issues at all, whilst the remaining three could to a limited extent. Therefore non-verbal modes of communication were more important in enabling their participation in the project and exploring 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. This 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,

² For a complete overview of the study, particularly of the parents' role and of the full range of findings and implications, please refer to the thesis online (Kramer-Roy, 2009).

in some cases it made the parents realise that their child was much better at drawing and expressing their ideas than they realised, as in the case of Sultan (14), who drew a picture of himself and his little brother playing football.



Photography

Another activity that some of the disabled children used to express themselves, was taking photographs with the camera I provided to each family. One girl with intellectual impairment took many pictures, both of her family members and of herself, and was very happy to see the prints and explain what she had photographed and why. She took a number of pictures of herself and her doll, which was very important to her (see picture).



Alternative ways of communicating

Once I had built up a relationship of trust by spending time engaging in play, I was able to engage one of the autistic children in a card sorting activity using symbols familiar to him, in which he sorted symbols representing activities into “I like” and “I don’t like” (see picture).



I was unable to achieve this with the other child with autism. However, he used a small number of signs, actions (such as walking away or hitting) and single words to express his feelings and preferences spontaneously (i.e. not in response to my verbal questions). Inviting his parents and siblings to reflect on the way he communicated and what messages he tried to get across helped them to recognise his need to be engaged in purposeful activity and how this might help to prevent his aggressive behaviour. For example during evaluation activities one of his siblings said they now knew better “how to deal with him and stop him from hurting himself”.

At the end of the project the disabled children got another opportunity to participate actively in the same activities as their siblings in the closing party. The activities will be described later in this chapter.

Issues identified through interactions with the disabled children:

The most noticeable problem the disabled 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. Their parents and siblings talked about how 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.

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

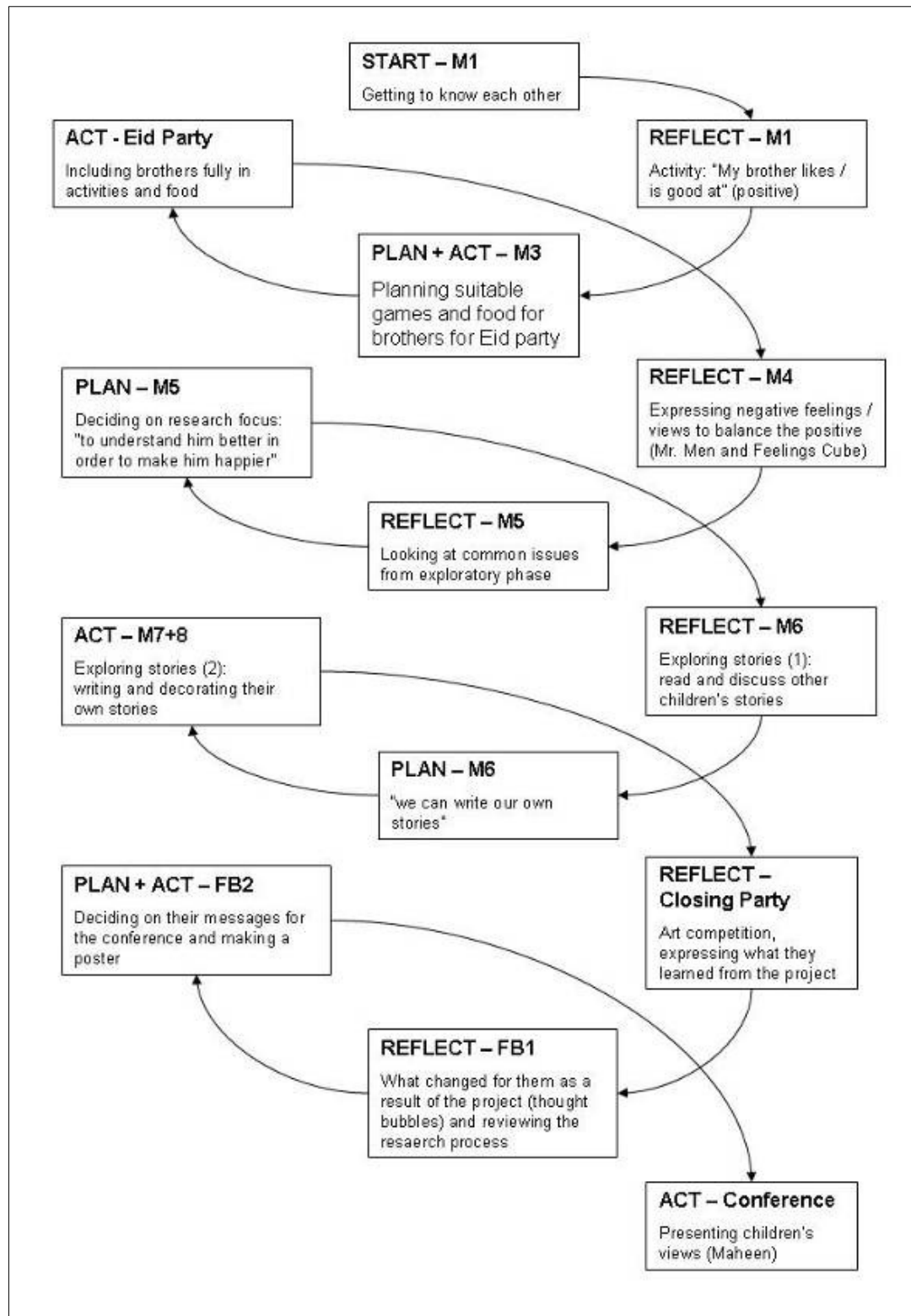
directly, but the children did not indicate this awareness when answering questions, for example about why they did not go to the same school as their siblings.

Only one child expressed disappointment in the interview 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 families the siblings did spend time playing with their disabled sibling. Later in the project the parents of the non-disabled children who attended the action research group most regularly (two families), reported spontaneously that their children's behaviour towards their disabled sibling tended to be better after their Kid's Club meetings (which were also a part of this project and are discussed later). Whilst they still found this difficult to sustain, this suggests their increased awareness of their sibling's needs enabled them to reflect on the effect of their own behaviour towards them as well.

The non-disabled siblings

In addition to the same activities as their disabled siblings, seven non-disabled children participated in a 'Kids Club', which met eight times. As several of the children attended daily Quran classes the Kids Club met during school holidays and on Saturdays.

The action research process the children's group went through can be summed up in the following diagram, details of which will be presented in the following pages.

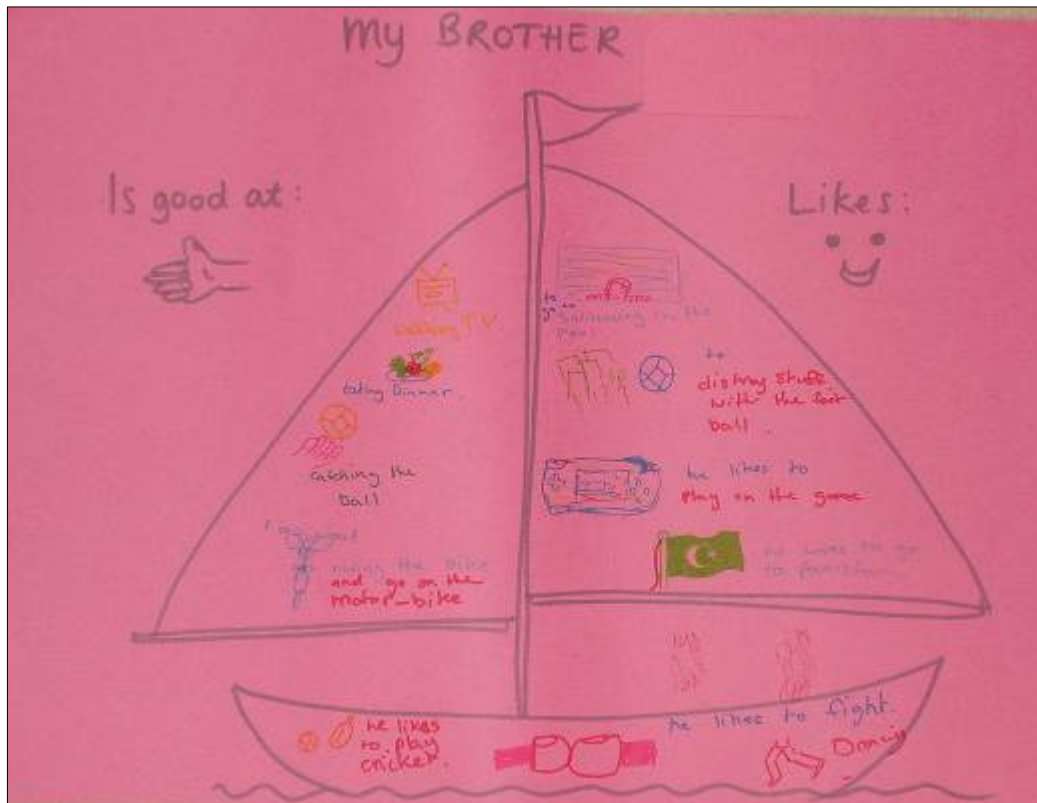


Key: 'REFLECT', 'PLAN' and 'ACT': phases of action research
M = meeting
FB = feedback meeting.

The meetings of the Kids' Club

During the exploratory phase it had become evident that the children found it difficult to open up, and were inclined to give mainly superficial and positive answers to my questions. They were very loyal to their families, which was congruent with Pakistani cultural values that favor family and interdependence on the one hand, but also a strong sense of honor and potentially bringing shame on the family on the other hand. For this reason the main aim of the first Holiday Club (meetings one to three) was for the children to get to know each other and to start sharing positive views on their disabled siblings.

On the first day the children filled in worksheets, writing or drawing all the things their sibling was good at and liked doing. See the picture for an example.



As this Holiday Club took place just after *Eid-ul-Fitr* (the religious festival that marks the end of the holy month of Ramadan during which Muslims fast), we planned to have an Eid party for all families together on the day after the Holiday club. On the second day the main activity was to make a welcome banner for the party. On the third day the children used their worksheets from the first day to think about what activities and food we could have at the party, so that their disabled sibling would be

able to participate and enjoy it to the full. The children took this task very seriously and were able to sacrifice some things – no chocolate because one disabled child was not allowed to eat it as it made him hyperactive; no crayons as another disabled child was likely to eat them – as well as think about activities that all could participate in – ‘pass the parcel’, a target game and eating! The children also made Eid cards for their disabled siblings, based on the ‘likes’ they had identified on the first day, to present to them at the party.

There were two very important aspects of this first holiday club. The first was that the party was planned around the strengths and needs of their disabled siblings, through which they learned that inclusive thinking does not necessarily take much extra effort whilst it does make the occasion more enjoyable for everyone. The second was that this was the first time the children had an opportunity to plan any event together, giving them the confidence that they were able to reflect, plan and collaborate. The children often talked about the Eid party in subsequent meetings and wrote about it in their evaluation forms, for example Inam (8) described the Kids’ Club as follows: “we played, we organized the party and had fun!”

All but one of the participants of the Kids’ Club attended the party, along with four of the five disabled children (the sixth family had not been recruited at this stage). 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 Eid-cards with personal messages were an important way of the members of the Kids’ Club expressing their appreciation of their disabled siblings and reminded all family members that the disabled children were at the core of the project

The next three meetings took place on Saturdays. In meeting four I encouraged the children to start expressing negative feelings and views through two activities. In the first activity the children drew “Mr. Men” characters, inspired by the series of books and videos by Roger Hargreaves (see <http://www.mrmen.com>). They first drew characters to represent themselves, for example, Maheen (13) drew Little Miss Bookworm as she loved reading, and Haroon (6) drew Mr. Wiggly as he had difficulty sitting still. After that they drew characters to represent their disabled sibling. They really enjoyed this activity and there was indeed a mixture of positive

and negative pictures made. For example Inam (8) represented her brother Imran as Mr. Feely because he enjoyed sensory play, like handling a spiky ball, smelling foods before eating them and stroking and smelling her hair. In contrast her brother Jamil (12) drew Imran as Mr. Slappy, because he often hit others when feeling bored or anxious (see pictures).



The second activity during this meeting was a group game in which the children took turns to roll a dice with the symbol for a different emotion on each side, i.e. happy, sad, excited, angry, proud and embarrassed (the ‘feelings cube’). The children were allowed to ‘pass’, so that a light-hearted atmosphere could be maintained. After rolling the dice the child told a story of a time their disabled sibling had made them feel that way. For example when Maheen (13) landed on ‘happy’ she said she felt happy when her brother “Sultan bought me a gift on Eid”, and when Inam (8) landed on ‘embarrassed’ she told a story of the time they went to the supermarket and “Imran ... just started shouting and all the people started looking at me. That was so embarrassing!”.

Both these activities created a degree of openness between the children, as it helped them realize that they shared similar experiences and that it was helpful to express their mixed feelings about having a disabled sibling in this safe, confidential setting, which was something they had not been invited to do before.

With this realization fresh in their minds I reminded them of the fact that the purpose of the Kids’ Club was to conduct research and asked them to discuss their understanding of what research is. After an initial emphasis on scientific research, which they felt could only be carried out by experts, they agreed that the main

purpose of research is to find out new information. From that position they were able to think of ways of gathering information, such as observation through all senses, and the importance to talk about and write down their observations. They decided these were all things children could do. To clarify how this process might work for them I showed them a diagram which depicts the action research process as a staircase (taken from Gibbs et al, 2002), with the following steps: group work, our ideas, choose an issue, find out more, plan and take action and think it over. We discussed how we had already gathered a lot of ideas during the exploratory phase and the first few meetings, and that we now needed to choose an issue.

In the next (fifth) meeting I brought a flipchart with an overview of the issues they had raised during the exploratory phase in their individual interviews. The issues were organized in themes, such as ‘positive points’, ‘caring responsibilities’, ‘frustrations’, ‘what are the issues from the perspective of the disabled child’, ‘dealing with feelings’ and ‘effect on friendships’. After talking through the themes, each child was given a different colour marker to indicate which issues they found most important, which ones they did not agree with and to add any extra issues. Whilst they talked about the theme about their disabled siblings’ perspective on the issues, the children referred back to the ‘feelings cube’ and I suggested we could play one more round, this time to tell a story about a time when their disabled sibling might have 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), and excited: “when visitors come, he gets excited and he behaves well” (Zohaib, 11). Based on their discussions and on their reflection on how their disabled sibling might view things, the children were able to decide on their research focus, describing it as follows: “to understand our sibling and the different, virtual world they live in better, so that we can make them happier”.

In meeting six the children read and discussed some stories written by other siblings of disabled children (Meyer, 1997). I suggested they could try writing their own stories in the next meeting.

The final two meetings were again organized as a holiday club. During meeting seven the children first did the “two bug activity” (based on Meyer and Vadasy, 2008), for which they filled in one activity sheet with a dragonfly to write things on each wing which “bug them” about family life with their disabled sibling, and one sheet with a butterfly, or “love bug” to write things they love about it. This activity aimed to help them reflect on their sibling and was thus a preparation for the second activity, which was to write their own story or mini-book about their life with their disabled sibling. The final meeting was spent finishing and decorating their stories. The stories clearly reflected the children’s different levels of awareness and understanding of the impact their sibling’s impairment might have on their relationship and family life. Maheen (13) used both the style of the story we had read from the book, and a conversation we had had about her relationship with her brother Sultan, to write her story. 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 emphasize that right from the start of the story. Importantly she also showed an awareness of the fact that Sultan felt excluded sometimes:

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 to 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.

Maheen's younger brothers Abid (9) and Haroon (6) did not at all mention Sultan's impairment in their stories and chose to write about incidences in which its relevance was not immediately obvious.

After this holiday club it was decided not to have any more meetings as the attendance had been poor in the last four meetings and the children of one of the regularly attending families were going to be away on a long holiday in Pakistan until the end of the project. Each family was visited at home in order to give the children who had not attended an opportunity to complete some of the activities and give their views on the issues discussed.

The closing party

At the end of the action research phase a closing party was organized, in which family members of five of the families participated. The purpose of the meeting was firstly to mark the end of the project, so there was a clear point of closure, and secondly to give an opportunity to evaluate the project together. The children engaged in two different activities to achieve the second purpose. Based on experience from two earlier family meetings, I offered creative activities to facilitate sharing of their experiences and views, as I had realized that this setting did not lend itself well for sitting down and talking.

The first activity was an art competition, for which each child - disabled and non-disabled - prepared a picture at home before the party, with the art materials provided to each family, expressing the most important, interesting or enjoyable things they did during the project. All pictures were put up on the walls with feedback sheets underneath, on which all participants could write positive feedback. Each person was also given three stickers to put on the feedback sheets of the pictures they thought were the best, so that the winners could be decided. This democratic process worked very well, as it required all participants to move around and mingle, and to think about and learn from each other how to give positive feedback to encourage the children.

The other activity the children participated in was to make a giant (1m²) 'snakes and ladders' game. I provided the grid, number stickers and cut-out snakes and ladders to position on the grid, with the instruction to think of reasons for climbing up the ladders, i.e. a positive action that would be helpful in including disabled children, and for sliding down the snakes, i.e. a negative action that would exclude or ignore the needs of disabled children. The fathers of the children supported them in completing this task, whilst I had some time with their mothers to share the evaluation artwork they had produced and brought to the party. After this the families played the game together.

The final activity was to have a meal together, sharing the food that each family had brought. We sat on the floor around a '*dastarkhan*' (a large sheet with the food set out on it) in good Pakistani style. This further fostered the interactions between and within the families.

Feedback meetings

Apart from the evaluation activities during the closing party all children also filled in individual evaluation forms. However they found the questions about what they had gained from participating particularly difficult to answer on their own and in written form. I therefore used the two feedback meetings that were already planned to take place during the thesis writing process to obtain feedback from the participants on my analysis of the data, to gain more of their views. In one activity which was very helpful in this process, the children responded to five statements presented in 'thought bubbles', such as "things I know now that I did not know before the project" and "things that changed in the way I talk and play with my disabled sibling". The sheets were put up on the wall, so that each child could write ideas on each sheet, and be inspired by the other children's ideas to know what kind of things to write. The focused and concrete phrasing of the statements helped the children to identify what they had learned. All children felt that their understanding of their disabled sibling had improved and that they knew better how to support them. For example Zohaib (11) 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". Maheen (13) observed that "he just wants to be like us; whenever we are watching something on TV he laughs when we laugh".

The action research process itself was also evaluated. Although the children were able to remember all the activities they had done, they could not identify how they fitted into the action research cycles. Despite my constant invitations during the project to give ideas for what activities to undertake, the children had depended on me to structure the research process. Despite this limited awareness of the research process, key decisions, such as choosing a research focus (i.e. “to understand our sibling and the different, virtual world he lives in better, so that we can make them happier”) had been taken by the children themselves, and they were now able to evaluate the outcome of their activities in light of that. In addition they showed their awareness of the fact that their team work and behavior during meetings had not always been ideal, showing an ability to evaluate their own performance.

Conference presentation:

Just before the final feedback meetings a call for papers was received for a conference which aimed to explore research on racism and ethnicity and the implications for policy and practice in the public health and social services. As the conference took place on a school day I invited the children to think about the messages they would like to send to the conference participants and to make a poster to be displayed during the presentation. I explained that some of their parents were going to co-present with me at the conference. Maheen (13) then asked to be included in the team of presenters. I suggested she would need to ask her parents to seek permission from her school to have the day off to attend the conference. As her father was also one of the co-presenters he agreed to her participation and had no difficulty convincing her teachers of the educational value of this activity. Maheen confidently represented the children’s group at the conference, leading to encouraging feedback from the audience, which provided a great boost to her confidence. The conference presentation can be viewed in the appendix of the thesis online (Kramer-Roy, 2009)

Challenges faced in facilitating the children’s participation and implications for future research

In spite of the positive impact of participation on the children’s personal skills and family lives described in the previous section, there were a number of challenges that limited the successful outcome of the Kids’ Club, some of which have already been

alluded to above. This section briefly describes these challenges and identifies implications for the design of future studies.

Group composition

There were two issues around group composition. The first was that due to the nature of the impairments of some of the children (severe autism and intellectual impairment) and the very young age of others, I was unable to guarantee their safety and well-being in a group context as a lone researcher operating in borrowed venues. For this reason the disabled children were not part of the children's action research group as had been my intention. However their well-being and participation in family life was the focus of all the other groups' research activities and by the end of the study the families reported some improvements in relationships and communication with their disabled child.

The second issue was that the group members were very diverse in many respects, such as age, ability, gender, fluency in English, socio economic background and willingness to engage in the group process. Importantly they did not live close to each other or the venue, so did not meet in between group meetings and depended on their parents to bring them to the club. Not all parents appeared to understand that their children would be able to contribute to the research process, or that that was an important component of the overall project. All these factors had a strong impact on attendance and only the children of two families had a regular commitment to the club.

Group dynamics

There was an issue with group dynamics that was partly influenced by the wide age range of the participants. In addition, the fact that this was a voluntary and fun club to take part in, the children were not inclined to be disciplined. Two young teenaged participants, a boy and a girl, constantly challenged each other and put each other down. This behavior tended to affect the younger children as well, as it became very difficult to keep conversations focused. In addition the dynamics between the siblings of one of the families were very negative, with particularly the older child giving a lot of negative, discouraging feedback to the younger ones, which adversely affected their level of confidence to participate and express their views. Despite these

challenges the five children (from two families) who attended regularly often said they enjoyed coming to the club and showed their disappointment when it finished. However two other children (from two families), who attended the club initially, showed their discomfort with the group dynamics and were later reluctant to come. Whilst the children who did attend benefited from reflecting on the impact of their behavior on the group process as well as on their family relationships, this factor limited the level of participation in the actual research process for the group as a whole.

Poor attendance

As described above the attendance at the Kids' Club was very variable and quite poor overall. Only the three children of one family attended every meeting. This variable attendance made it difficult to keep the research process moving along, as the group was inclined to wait for the others before taking decisions. In order to keep children who were absent from meetings involved in the research process, I spoke to or wrote to them after each meeting to inform them of what we had done and talked about.

Level of participation and control

An important purpose of using participatory action research was to give the participants as high a level of control as possible at all stages of the research process. This was particularly difficult in the children's group, as they reported that they had never been asked to reflect on their experience of having a disabled sibling, or to contribute to making decisions within the family context. Although every effort was made to explain the purpose of the project and the nature of participatory action research, and although the children were given opportunities to make choices and decisions at every juncture, their expectation remained that I should lead the research. Their inability to describe the research process they had gone through during evaluation confirmed that they had difficulty keeping the overview over the process. However they were able to identify the way and extent to which the research question they formulated had been answered. In addition some of the most frequent feedback related to their active role in organizing the Eid party, which evidently gave them a sense of control they had not experienced before.

Implications for future research

As it had been difficult to recruit enough Pakistani families with disabled children for this study, I had little choice about the group composition. As a PhD student I was also restricted in the duration of the project. However, in different circumstances, a more consistent group might be formed by striving to have more commonalities between the group members. For example siblings of disabled children who all attend the same special school could have been invited to attend a research club at that school. This would have enabled the researcher to invite school staff to support the project and to make it possible for the disabled children to be linked in with their siblings' group process. Alternatively non-disabled children in the same school, who live with a disabled sibling (or other family member) could be invited to be part of a research project within their own school. This would enable the researcher to link in with the curriculum being taught at the school and ensure consistent attendance. Working in existing settings would also make it easier to form age groups, to sustain the project over a longer time period, and for the children to recognize acceptable behavioural norms. In addition, a higher level of control over the research design at the very early stages of project planning could be achieved.

In summary it would be more effective to facilitate a group of children of similar age, who already know each other and are situated in a more structured setting, to focus on an extended project that requires much collaboration and critical thinking.

Conclusion

The six families and the individuals within them benefited from participating in the project in a number of ways, related to gaining knowledge (e.g. about disability, Islamic teaching related to disability, and available services), skills (e.g. reflecting critically 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).

Despite a number of significant limitations and challenges, the children who participated in the project discovered they were more able to think critically and take decisions than they realized, and became more proactive in supporting their disabled siblings. The children indicated that they and their families had benefited from their participation in the range of creative activities used in the project, but their understanding of the research process overall remained limited. The chapter has indicated that engaging children in a participatory action research process around a sensitive subject like disability has good potential, but that the effectiveness would be increased if the research took place in a more structured and/or formal context, in age-based groups, and over a longer period of time.

References:

Barnes, C. (2002). 'Emancipatory disability research': project or process? *Journal of Research in Special Educational Needs*, 2(1).

Beresford, B. (1995) *Expert opinions. A national survey of parents caring for a severely disabled child*. Bristol: The Policy Press.

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

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

Gibbs, S., Mann, G. and Mathers, N. (2002). *Child-to-Child: A Practical Guide. Empowering Children as Active Citizens*. London: Lambeth, Southwark and Lewisham Health Action Zone and Groundwork Southwark. Available: <http://www.child-to-child.org/guide/guide.pdf> Accessed 21/03/11.

Hatton, C., Akram, Y., Shah, R., Robertson, J. and Emerson, E. (2004). *Supporting South Asian Families with a Child with Severe Disabilities*. London: Jessica Kingsley Publishers.

Henn, M., Weinstein, M. and Foard, N. (2006). *A Short Introduction To Social Research*. London: Sage Publications.

Khan, H (2006). *Working with Muslim Fathers: A Guide for Practitioners*. London, An-Nisa Society and Fathers Direct.

Kramer-Roy, D (2009). *Exploring the support needs of Pakistani families with disabled children: a participatory action research study*. Doctoral thesis. London: Brunel University. Available: <http://bura.brunel.ac.uk/handle/2438/4377>

Kramer-Roy, D. (2007). Researching the support needs of Pakistani families with disabled children in the UK. *Research, Policy and Planning*, 25(2), pp.143-153.

Meyer, D. (ed) (1997). *Views from our shoes. Growing up with a brother or sister with special needs*. Bethesda: Woodbine House.

Meyer, D. and Vadasy, P. (2008). *Sibshops. Workshops for siblings of children with special needs*. Baltimore: Paul H. Brooks Publishing Co.

Modood, T. (1997). Qualifications and English language. In: Modood, T., Berthoud, R., Lakey, J., Nazroo, J., Smith, P., Virdee, S. and Beishon, S. *Ethnic Minorities in Britain: Diversity and Disadvantage*. London, Policy Studies Institute, pp.60-82.

Morton, R., Sharma, V., Nicholson, J., Broderick, M. and Poyser, J. (2002). Disability in children from different ethnic populations. *Child: Care, Health & Development*, 28(1), pp.87-93.

National Statistics Website (2002). *Ethnicity: Low income for 60% Pakistanis / Bangladeshis*. Available: <http://www.statistics.gov.uk/cci/nugget.asp?id=269>
Accessed 21/03/11.

Riddell, S. and Watson, N., eds. (2003). *Disability, Culture and Identity*. Harlow: Pearson Education Ltd.

Seebohm, P., Henderson, P., Munn-Giddings, C., Thomas, P. & Yasmeen, S. (2005). *Together we will change. Community development, mental health and diversity*. London, The Sainsbury Centre for Mental Health.

The Poverty Site (online). *Work and Ethnicity*. Available: <http://www.poverty.org.uk/47/index.shtml> Accessed 21/03/11