

## Researching the support needs of Pakistani families with disabled children in the UK

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### 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 29<sup>th</sup> 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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