



Research Findings Register

(ReFR)

Abstract Submission

Project Title : Meeting the Needs of Severely Disabled Pakistani and Bangladeshi Children and their Families

NRR Project Number : N0461088166

NRR Data Provider :

Research Programme : Improving the Health and Social Care of Minority Ethnic Groups by Better Communication

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Aim/ Principal Research Question (Max 200 words) : This study addressed the poor uptake and utilisation of services by Pakistani and Bangladeshi families with severely disabled children. It investigated possible reasons, including linguistic and cultural barriers which impede communication between families, professionals and agencies and limit knowledge and understanding of services; professional stereotyping; lack of sensitivity to 'race' and culture; and the poor coordination of services.

**Factors of Interest
(Max 200 words) :**

The Race Relations (Amendment) Act (2000) places a duty on public authorities to promote race equality and, together with the Disability Discrimination Act (1995) should ensure that everyone has equal access to services, regardless of race and disability.

Among disabled children, it has been estimated that around 16% have severe impairments, commonly a combination of physical, sensory and learning impairments, which may result in complex needs. Consequently, providing for the complex needs of these children requires the use of resources from health, social care and education services.

This study provides a distinctive contributions to knowledge in that it included:

1. Similar numbers of families from three distinct ethnic groups, Pakistani, Bangladeshi and White, living in the same relatively deprived area. This enables comparison of similarities and differences in their experiences and views.
2. The views and experiences of disabled children and young people, and of their siblings, as well as their parents. These views were to be given equal status.
3. The experiences and views of health and social care professionals, and their reflections on the families' views.

**Methods
(Max 200 words) :**

This qualitative study used initial structured interviews to collect data on awareness and use of services and subsequent semi-structured interviews, drawings and worksheets to explore the experiences and understandings of parents and children. We hypothesised that minority ethnic families having a disabled child would share some similar experiences to White English-speaking families in the same position, but that there will be important differences and additional issues. In order to distinguish these, a sample of White families from the same area was included in the investigation. Thematic content analysis of interview transcripts and children's worksheet was undertaken using NVIVO software. The findings from these interviews were then used to formulate semi-structured interviews which were conducted with health and social care professionals practicing in the area.

**Sample Groups
(Max 200 words) :**

The study took place in two adjoining wards of a Northern city with above average South Asian populations and significant social deprivation and child poverty. The sample comprised 27 families, 10 Pakistani, Bangladeshi and 8 White. Between them they had 33 disabled children. One Bangladeshi and one Pakistani family had three disabled children; there were two disabled children in one Bangladeshi, one Pakistani and two White families. In the White families, three of these children were adopted. The children and young people had a wide range of physical and learning impairments.

In most families, the mother was the only parent interviewed. Seventeen disabled children (11 girls and 7 boys) and 20 siblings (5 boys and 15 girls) were interviewed.

Seven professionals (3 Asian, 4 White) working in the area were interviewed. They comprised, 3 GPs, a consultant community paediatrician, a community worker, a specialist social worker and the manager of the social services children with disabilities team.

Not applicable

**Outcome Measures
(Max 200 words) :**

Findings
(Max 400 words) :

White families had better levels of service provision than either Pakistani or Bangladeshi families. Bangladeshi families had better levels than Pakistani families. Three families, one from each of the communities, had no services except for contact with primary healthcare.

There were two predictors of service involvement in families – the presence of a social worker or a family member who worked in the health and social care field. When families had a social worker, they were more likely to have access to a range of other services such as respite care.

Several families had long-term relationships with the same social worker. They were more likely to report satisfaction with the service they received than families who had intermittent contact with a range of social workers. Some families had a number of assessments from professionals which did not result in any service provision.

When children had multiple impairments, they were seen by a range of medical professionals and so had to attend a variety of appointments. One consultant in the city was attempting to have joint clinics with other consultants and involve other professionals to facilitate a more holistic approach to working with families.

Disabled children and young people from across the three communities wanted to live ‘ordinary’ lives. When children attended schools away from their local communities, they often had no friends living nearby and so had a limited social life.

Siblings across the three communities were involved in caring for their disabled brother/sister. Several young Asian women were essential to the care-giving in their families. This was particularly likely when parents had health problems themselves. Some Pakistani and Bangladeshi parents reported experiencing difficulties when an adult daughter left home after marriage.

Professionals interviewed appreciated the need to work more holistically to serve families and pointed to a number of initiatives, including recent legislation and policy initiatives which would facilitate this. Medical professionals were less likely to be aware of legislation and initiatives and their implications than social care professionals.

Conclusions
(Max 100 words) :

The low uptake of services by Pakistani and Bangladeshi families is due more to social and linguistic barriers than to parental beliefs and attitudes about disability. These barriers operate at the agency/institutional level as well as at the level of families and communities. There are many practical steps which agencies can and should take, both singly and together. These include, better provision of information and the development of culturally sensitive services.

Implications for Further Research : This study confirms and extends findings from a large national scale survey (Chamba et al., 1999) and from the two recently published studies of Pakistani and Bangladeshi parents (Fazil et al 2002; Bywaters et al., 2003; and Hatton et al., 2004) as well as an Audit Commission report (2003). We consider that further investigations of parents' and children's views and experiences of existing services should NOT be undertaken. However, new services establish on the basis of existing research should be carefully evaluated.

Primary Keywords : DISABLED-CHILDREN; MINORITY-ETHNIC-GROUPS

HUMAN; CHILD; PAKISTAN Q-ethnology;
BANGLADESH Q-ethnology; HEALTH-SERVICES-
NEEDS-AND-DEMANDS; HEALTH-SERVICES Q-
utilization

Project Report URL : www.dur.ac.uk/cass (not yet available)
Publications (and related URLs) : in preparation