

Minority ethnic families caring for a severely disabled child

It is widely recognised that minority ethnic groups experience social and material disadvantage and face barriers in their access to statutory support services. Families with a disabled child have been identified as being particularly poorly served. Research carried out at the Universities of Bradford and York is the first to provide detailed information at a national level of the needs and circumstances of families from minority ethnic groups caring for a severely disabled child, comparing the findings with those from an earlier survey of white families from the same database. The project found:

- f Overall, families from minority ethnic groups caring for a severely disabled child were even more disadvantaged than white families in similar situations. Families' experiences, needs and circumstances varied across ethnic groups.**
- f Low levels of employment, particularly among mothers, meant that many families were living in difficult circumstances. Compared with white families, fewer families were receiving disability benefits. Those receiving benefits were less likely than white families to be awarded the higher rates of Disability Living Allowance (despite both groups having severely disabled children).**
- f Parents wanted more information about their child's disability and, in particular, services for their child and themselves. However, poor interpreting support and limited availability of translated materials could make access to appropriate information difficult, particularly for Bangladeshi families.**
- f Indian and Black African/Caribbean families reported least support from their extended family, with levels of support lower than that found among the survey of white families. Mothers from all ethnic groups represented reported lower levels of support from their partners than white mothers had reported.**
- f Just over half of parents described their contact with professionals as positive and supportive. Families with a key worker were more likely to say they had a positive relationship.**
- f Two-thirds of parents said they needed more breaks from care, yet only a quarter of families received short-term breaks. Many families were unaware of such schemes. Indian and Black African/Caribbean families were more likely to use short-term break services than other minority ethnic families.**
- f Reported levels of unmet need – both for the children and their parents – were greater than those found in the study of white families.**

Introduction

What is known about minority ethnic families caring for a severely disabled child remains limited compared with research findings on white disabled children within the United Kingdom. This research sought to address this imbalance. It explored: families' living circumstances; levels of informal support; experiences of using services; and particular unmet needs. The research follows a 1995 study which explored the experiences of about 1,000 white families caring for a severely disabled child. In comparing the findings, the current study shows that, with few exceptions, minority ethnic families were much more disadvantaged in all areas explored and had higher levels of unmet need than the white families in the 1995 study.

Living circumstances

Most families reported *incomes* of less than £200 per week. Overall, families in this survey reported lower income levels than the white families in the 1995 survey. Pakistani and Bangladeshi two-parent families had much lower incomes than Black African/Caribbean and Indian two-parent families. Lone parents suffered greatest disadvantage: two-thirds of Black African/Caribbean families were headed by a lone parent.

Low levels of *employment* – especially among mothers – contributed to the difficult financial circumstances in which many families were living. Three-quarters of mothers had no paid work. Black African/Caribbean and Indian mothers were more likely than Pakistani and Bangladeshi parents to be in paid employment or to want to be working.

In terms of *benefits*, fewer parents were receiving Disability Living Allowance (DLA) and Invalid Care Allowance compared with white families in the 1995 survey. Minority ethnic group families were less likely to be awarded benefits at the higher rates for both components of DLA, even though all the children represented in the survey were severely disabled. Parents who understood English well had much higher levels of benefit take-up than those with little or no

understanding. However, the generally low access to benefits suggests that the inability to use English was not the only barrier to access.

Six out of ten families said they lived in *unsuitable housing*, with nearly half reporting three or more housing problems. Lack of space and problems relating to access around the home were the main concerns. Importantly, parents who considered their house to be suitable reported fewer unmet needs for their child and themselves. Moving did not necessarily resolve housing problems: of those families who had moved because their previous home was unsuitable, over half reported that they were still living in unsuitable housing.

Communication and information

Access to information is crucial to accessing and using services. For this reason, the survey explored the languages used by its respondents (see Table 1).

Overall, a third of Asian parents said they needed an *interpreter* when talking to professionals, with Bangladeshi parents most likely to report this need. However, only six out of ten of these parents were provided with an interpreter. Parents valued interpreters because they allowed them “to say what they wanted” and it avoided reliance on friends and relatives. However, almost all families felt such support was inadequate in some way. Problems in professional interpreting included: lack of availability of interpreters; limited knowledge of the child's impairment; and concerns about confidentiality.

Professionals failed to provide an equal service to speakers of languages other than English. Little knowledge of English, poor interpreting support and limited availability of translated materials make access to appropriate information difficult. Parents reported unmet needs for information about their child's disability and, in particular, services for their child and themselves. The most preferred information sources were directly from a professional and written material. Telephone help lines (in English and other languages) were not popular.

Table 1: Proportion of sample using English by ethnicity

Use	Black African/Caribbean (%)	Indian (%)	Pakistani (%)	Bangladeshi (%)
Speaking	72	81	68	47
Reading	63	72	54	42
Writing	82	71	52	35
	N=133	N=214	N=155	N=71

Table 2: Use of support groups across ethnic groups

	Black African/ Caribbean (%)	Indian (%)	Pakistani (%)	Bangladeshi (%)	White parents (1995 survey) (%)
Member of a support group	24	24	17	26	29
Unaware of support groups	30	31	40	38	17
No support group nearby	29	15	20	17	22
Chosen not to belong to a support group	18	30	24	20	32
	N=132	N=199	N=149	N=66	N=1112

Family support

Despite stereotypes suggesting the existence of extended supportive families among minority ethnic groups, there was little evidence to support this assertion. Fewer mothers in this survey received practical help and emotional support from *partners* than white mothers in the 1995 study.

Black African/Caribbean and Indian families were most vulnerable to low levels of support from the *extended family*. The most cited reason for a lack of support was that no family members lived nearby. Half of the Bangladeshi and Black African/Caribbean parents said they did not have family living nearby. Some Asian parents expressed the belief that they should bear full responsibility for their child and this prevented them from asking for help from their extended family.

Membership of *support groups* for parents with disabled children was low. More parents were unaware of support groups than belonged to one (see Table 2).

Experiences as service users

Families had contact with numerous professionals, many seeing ten or more different professionals in a year. These were chiefly health (hospital doctors, health visitors) and education professionals (teachers). Half the families had seen a social worker in the previous twelve months. Black African/Caribbean families were most likely to have social work support, while only one in four Bangladeshi families said they had seen a social worker in the past year.

Just over a third of families said they had a key- or link-worker (one worker who acted as a central point of contact). These families reported fewer unmet needs for information and experienced fewer difficulties as service users. Many families had low expectations for support – this was especially true of Bangladeshi families.

Parents across all ethnic groups broadly agreed on the most serious problems they faced as service users. They included: delays in service provision; having to 'fight' for services; lack of information and a sense that professionals do not understand what daily life with a disabled child is like.

Over two-thirds of parents said they did not have a break from looking after their disabled child as often as they needed, but only one in four parents currently had access to short-term breaks. Those families with a better understanding of English were more likely than others to be using short-term breaks. Families in this survey were more likely to be using short-term breaks in residential units (as opposed to family-based schemes) compared with the white families in the 1995 survey.

The needs of parents and children

Parents were asked about what needs were not being met for their children; the following key areas were identified:

- Skills for future independence;
- Help with learning abilities;
- Access to social/leisure activities;
- Help with communication;
- Help with physical abilities;
- Help with learning about culture/religion;
- Emotional/counselling support.

The number of unmet needs increased with age and peaked among children aged 8-11 years. The types of unmet needs reported by parents in this survey were similar to those found in the 1995 survey. However, the extent of unmet need was far greater among minority ethnic groups compared with white families. Half the parents said their child had seven or more unmet needs (among white parents in the 1995 survey, half reported their child as having four or more unmet needs).

Parents who lived in a home that was suitable for their disabled child were likely to express fewer unmet needs. Parents who received a lot of help from their extended family also reported fewer unmet needs for their child than those who received no help.

When asked about their own unmet needs, parents identified similar areas to those named by white parents in the 1995 survey:

- Money;
- Help planning child's future;
- Help during school holidays;
- Personal guidance about available services;
- Skills to help the child;
- A break from care;
- Help with behaviour/sleep problems.

However, the levels of unmet need were higher. Twice as many parents in this study reported ten or more unmet needs compared with the white parents in the 1995 survey. As with the children's needs, living in suitable housing and/or receiving help from extended family was associated with parents reporting fewer unmet needs.

About the study

Just under six hundred parents caring for a severely disabled child took part in the study. Black African/Caribbean, Indian, Pakistani and Bangladeshi parents across the UK were represented. To allow comparison with the needs and experiences of white families with a severely disabled child, this study used a comparable research design to a survey conducted by Bryony Beresford in 1995. The sample was drawn from the Family Fund Trust database of families with a severely disabled child. The response rate was 66 per cent. The study, which was conducted in 1997, took the form of a postal questionnaire. The questionnaire was translated into Urdu, Punjabi, Gujarati, Bengali and Hindi.

How to get further information

The full report, **On the edge: Minority ethnic families caring for a severely disabled child** by Rampaul Chamba, Waqar Ahmad, Michael Hirst, Dot Lawton and Bryony Beresford, is published for the Foundation by The Policy Press (ISBN 1 86134 134 2, £12.95). It is available from Biblios Publishers' Distribution Services Ltd, Star Road, Partridge Green, West Sussex, RH13 8LD, Tel: 01403 710851, Fax: 01403 711143 (please add £2 p&p). The report of the earlier survey of white parents, **Expert opinions: A national survey of parents caring for a severely disabled child** by Bryony Beresford, is also published by The Policy Press (ISBN 1 86134 004 4, £10.50).