

BRADLEY BORUM

Asian handicaps

The high rate of infant death and disability in the West Midlands Asian community has met with an inadequate response from the health service.



Madhuben Patel, who has lived in Britain for 24 years, has no relatives in the UK other than her husband and her 18 year old autistic daughter. It was 13 years before she discovered that there were such people as social workers.

Lutifa Ali has grown up in both Birmingham and Bangladesh and now lives in west Bromwich with her husband and five children. Two of her children are handicapped, and she regards this as the way things were meant to be: "No one is perfect, I'm lucky I've only got two. Some have three or four. Most mothers with handicapped children probably think alike; a handicapped child needs more time, love and care." Having two, three, or even four handicapped children may sound unlikely, but among Asian families in Birmingham it is not uncommon.

The West Midlands, as a region, has the highest rate of infant death and handicap in Great Britain. These deaths are concentrated among poor Asian families who live in areas badly served by local services. Six years ago the Short Report on baby deaths showed that inequalities in health care were increasingly class and race related; women from India, Pakistan and Bangladesh are most at risk of losing a baby or having a handicapped one. Although there have been some improvements nationally, the position of Asian women, particularly in the north, remains largely unchanged.

Nusrat Begum is 23 and has five children all under the age of eight, including handicapped twin boys and a handicapped baby daughter. Nusrat also sometimes has the responsibility of looking after her husband's handicapped sister and has had only intermittent help from the authorities since her four year old twins were born. Like many Asian women I met, she seems not to

have been told the nature of her children's handicap, or even given a word to describe it. She told me the doctors had said the twins were getting fits because of a high fever: "But we did not believe it because many children get fevers, but they do not have such fits." Nusrat's antenatal clinic experience was no more illuminating. During her visits she never saw anyone who spoke to her in a language she understood. It could be argued that both her time and that of the NHS were wasted.

Investment in primary health care and in community-based services (which are sensitive to the needs of the people they are intended for) could be a big part of the solution. Part of the difficulty is a reluctance on the part of the authorities to identify the problem properly. Statistics are gathered by health districts instead of by neighbourhoods, and the inner city of Birmingham is covered by three such bureaucratic boundaries which obscures the real figures for the inner city, where resources are most needed. The inclusion on records of mothers' ethnic origins, as well as country of birth, would certainly help to define the problem. For example, east Birmingham, which has a large Asian population, has seen an infant mortality rate in recent years similar to that of a third world country, with a correspondingly high rate of handicap. Yet the hospital serving the area has no formal language interpreting service and no maternity unit. So where do pregnant women in east Birmingham go? Until the opening of a satellite clinic this October, they attended a hospital in another district, a two-bus journey away.

Apart from the inaccessibility of health services, there is also the problem of Asian women only attending clinics late in their pregnancies. Sudharshan Kaur, like many women I met, told me that when she was pregnant she attended antenatal clinic three or four times. This is often not enough; it is generally accepted that attendance should start when pregnancy is diagnosed and should be regular thereafter. The single, meagrely funded national initiative to promote awareness of antenatal services among Asian women is the "Asian Mother and Baby Campaign." At a recent conference of the campaign's link workers, I heard that it was not uncommon to find GPs who advise their Asian patients only to start attending antenatal clinics once they have missed three or four monthly periods! The truth is that Asian women are conscientious attenders once they've got the message.

If you ask Paul Rooney, the secretary of the east Birmingham community health council, if this is a problem that Asians have brought with them, he is sharp to point out: "We're talking about British babies, born in Britain's second city to British tax-payers under a National Health Service that is supposed to guarantee equality of access to all. It patently doesn't do so."

The large number of first-cousin marriages among Muslims is often cited as the cause of the high rate of handicap among the Asian community. This is not so. Reducing and confining a reproductive gene pool can increase the chances of a problem gene being present in the offspring, but no study has yet shown that this is the case in Asian first-cousin marriages. One suspected aggravating factor is their numerous and unspaced pregnancies, which carry on well into middle age. But what has been universally demonstrated, and particularly in the Black Report (1984) in this country, is the relationship of low income, poor housing and poor nutrition with poor health, high infant mortality and a higher incidence of some forms of handicap.

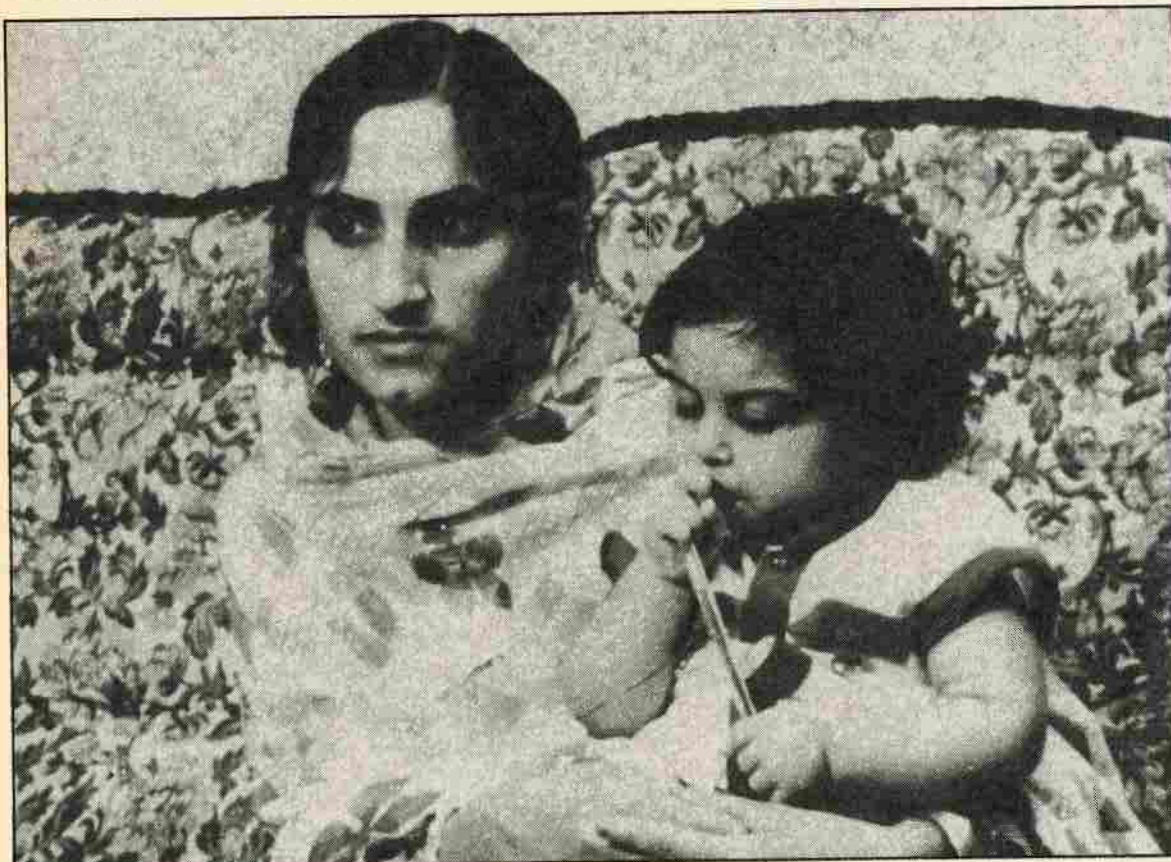
Mohinder and Pargan Singh are well into middle age and are not first cousins. Of their five grown-up children, three are handicapped. All need feeding and two are partially incontinent. The couple are dedicated Sikhs and devoted parents. I asked them whether, had they known that they stood a good chance of having

more handicapped children after their first, it would have altered the size of family they chose to have. Astonished, they both asked if one could tell whether a child would be handicapped and said had they been aware of the risk, they would have sought medical advice. Prenatal and genetic counselling are almost unheard of among the Asian community. This is not intended as an argument for a genetically perfect world, but as an argument for access to information. A genetic counsellor working in Birmingham explained that what often happens with Asian women after they've had a handicapped child is that they're told they have a one in a million chance of it happening again. When it does, the health service throws its hands up in horror and says the woman should be sterilised.

Unequal health care is one side of the problem. The other is lack of support once a handicapped child is born. Asian women are isolated, but the popular press tends to exaggerate this, denying their resourcefulness

The misconception that all Asians live in extended families still prevails, even though logic should tell us that the process of migration must have led to the break-up of many families. Another misconception is that all Asian husbands object to their wives being seen by male doctors. For some Muslims this is true, but the Asian community is diverse and often the objection is seen to come from husbands because they interpret for their wives. Some white women also prefer women doctors. Recent demonstrations to keep open special women's hospitals like the Elizabeth Garrett hospital in London are testimony to white women's feelings on the subject.

Language is indisputably a barrier. Asian women are learning, and want to learn, English, but—as all mothers know—running a home and raising children leaves little spare time. Two years ago, when I began to meet Asian women who had handicapped children, I used almost to dread going into their homes and trying



Nusrat Begum (left, with her baby daughter) has three handicapped children. During her visits to the antenatal clinic she saw no one who spoke to her in a language she understood.

and giving the impression that they are a subjugated and separate race. Darshan Kaira, for example, took her son with cerebral palsy to the world-famous Peto Institute in Budapest for a year's treatment. Much of the Asian community rallied round and raised the money to fund this. But more characteristic is Madhuben Patel's experience. She and her husband came here 24 years ago and their 18 year old autistic daughter was born here. They have no relatives in Britain and it was 13 years before Mrs Patel learned that there were such things as social workers. In the absence of family and statutory support, one might assume her religious community would have stepped in. But no. She said: "I sometimes take her to the Temple... they say it is her fate. She may have done something in her previous life. She has to live it through. No one is interested." Sudharshan Kaur, whose eight year old daughter is handicapped, says: "Sometimes the health visitor came, but nobody helped me properly. They never gave me any consolation, or told me there were other children like this. They just worried me saying Indians do not look after their daughters properly."

to talk to them. Communication was always through an interpreter and was always awkward. The etiquette for meeting strangers does not include the familiar non-verbal cues like eye-to-eye contact and smiles, and this disarmed me. In the beginning I felt an intruder, and was overwhelmed by what seemed to be vast differences and insurmountable difficulties.

However, once the effort is made to break through the barriers of language, colour and custom, the issues and needs become clear. Information on benefits needs to be made more accessible, perhaps through announcements at the start of Indian video films. Voluntary organisations have a large role to play, but so far they have appeared reluctant to do more than carry out pilot projects. The longer they procrastinate, the more ethnic minorities will feel forced to set up separate groups, further splintering the disability movement. Certainly, the scale of the problem demands more imagination and effort on the part of the health service, statutory bodies and voluntary organisations. The Asian community will also have to organise and lobby for their rights.

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