PERSONAL VIEW

Meeting the needs of minority ethnic communities

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Minority ethnic communities make up 5.9% of the population of Great Britain¹; 8% of children under 16 are members of such communities.² The health care needs of these children ought to be part of the mainstream of service planning and provision but at best they are considered as 'other' with emphasis on the differences instead of similarities between them and the majority ethnic population.³ At worst their needs are overlooked or we see the sort of tokenism displayed in *Seen But Not Heard*, with black people being conspicuously present, but only in the illustrations.⁴ Even *Health For All Children* addresses just nutrition and haemoglobinopathy in any significant way,⁵ in effect concentrating on 'traditional generalisations'.⁶ This pattern is repeated in research which, on the general health of minority ethnic children, remains relatively uncommon.⁷ Some general and some specific issues are discussed below in order to illustrate how this marginalisation may be adversely affecting the health care and, indirectly, the health of these children in Britain.

Access to health services

It is widely acknowledged that those with least need of health care use the health services more, and more effectively, than do those with greatest need.^{8,9} This applies equally to preventive health measures, as to delivery of care. For example pregnant women in the lowest socioeconomic groups present later for antenatal care, deliver more low birthweight babies, and are up to twice as likely to die from pregnancy related disease than are their more affluent counterparts.^{10,11} Related to this is a higher incidence of premature birth and congenital abnormality in their offspring.^{10,11} This is highly relevant to minority ethnic populations given that the incidence of socioeconomic deprivation is higher in these groups.^{12,13}

In addition to interaction of poverty and ethnicity in compromising access to services, there are many other obstacles in the way of any attempt to address and answer the health care needs of minority ethnic children.¹⁴ These are among the challenges of providing quality health care in a transcultural setting. The 'medical model' which is central to current health service provision in Britain is based on a Eurocentric understanding of illness. In addition our health service is highly standardised and inflexible and has not adapted adequately to take account of Britain's multiracial, multicultural, and multifaith society.¹⁵

Racism affects both employment practice¹⁶ and service delivery in the NHS. Smaje describes its effects upon service delivery¹⁷:

- *Direct racism*, where a worker treats a client less favourably because of the client's ethnic group or colour.
- *Institutional racism*, the 'colour blind' approach which arises from a faulty notion of the concept of equal opportunities, assuming that equality of care will be assured if the *same* service is provided for all.
- *Ethnocentrism* results in professionals making inappropriate assumptions about clients needs, either on the basis of the majority ethnic experience, or on faulty notions of the clients own situation – cultural stereotyping.

As data on ethnicity has not been routinely collected within the health service there is very little published work from the UK that identifies the detrimental effects of racism on the quality of health care. In adult services research has shown that being of Afro-Caribbean origin and mentally ill significantly affects the quality of care received compared with white controls,¹⁸ and that waiting times for angiograms in patients with ischaemic heart disease were twice as long for British Indian patients than for their white counterparts.¹⁹ From 1995 it will be mandatory to include ethnic data in the minimum dataset, at least in England, so that the information needed for research and audit in this field will be both more accessible and more accurate than hitherto. This provides a great opportunity to ascertain whether or not inequalities in service provision exist within our child health services, and to take appropriate action where necessary.

Health promotion

Health promotion advice is generally based on our knowledge of the ethnic majority. Research on minority ethnic communities has often been based on spurious definitions of race, ethnicity and culture, with meaningless groupings (for example 'Asian'²⁰) and confusion of biological and social variables.²¹ Health promotion messages have sometimes been based on increased relative risk instead of absolute risk⁶ and thus concentrated on inappropriate areas of disease.

We need knowledge of the social and cultural mores of communities that are being targeted with health promotion advice and a

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sense of how this advice will be understood. Does a particular community share our health proprieties? Does the material contain culturally hostile information? If so, does inclusion of this culturally hostile message jeopardise the acceptance of other accompanying information? Promotional material that was intended to reduce the incidence of sudden infant death syndrome (SIDS) in New Zealand included advice against co-sleeping. This was so against the Maori cultural norm that it may have caused Maori parents to reject the whole health promotional package.²²

Accidents cause 43% of deaths for ages 1–19 in England and Wales and take a huge toll in the survivors both in acute distress and chronic morbidity.²³ There are very few published data on the epidemiology of accidental death and injury in minority ethnic populations but without such data it is difficult to see how a coherent, comprehensive, and effective accident prevention programme can be mounted. We cannot be confident that current accident prevention programmes are valid for all children, or that they are appropriately targeted. Do children from these communities face lesser, greater, or different risks to those of the majority ethnic children? The literature is sparse and conflicting, with some studies not demonstrating any correlation between accidents and ethnicity²⁴ while others showed higher risk of burns²⁵ and road traffic accidents²⁶ in Asian children, although teasing out the confounding effects of socioeconomic deprivation and inner city living is difficult. Are accidents perceived as a health priority in these communities? A recent qualitative study suggested that child safety was important to the communities consulted (Chinese, Vietnamese, and Asian) with similar general concerns to those of the ethnic majority.²⁷ Issues specific to these communities included kitchen fires, inability to read or understand safety instructions on appliances and health promotional material, and not being able to afford 'safe' equipment. The study was, however, small scale. There is no UK literature on accidents in refugees. What are the risks faced by these children, whose families are having to adjust abruptly to a hugely different lifestyle and culture, often in grossly inadequate 'homeless' accommodation?

Improving breast feeding rates was identified as one of the major health gain areas by both the Department of Health and the Welsh Office.^{28 29} How do we promote breast feeding in different cultures in which the reasons people fail or choose not to breast feed might be very different to those in the majority ethnic population? In general rates of breast feeding in migrants are lower than in the respective countries of origin.^{30 31} Weaning is initiated earlier among migrants than in the ethnic majority^{30 32} and this is associated with shorter duration of breast feeding.³³ The reasons behind these trends are likely to be a complex mix of attitudes to breast feeding in both country of origin and the host country, with the added influence of class and affluence. However, a recent survey of Welsh Pakistani

mothers identified lack of support from professionals as *the* major factor in mothers failing to breast feed.³⁴

Children in need

CHILDREN WITH DISABILITY OR CHRONIC ILLNESS

Congenital and constitutional anomalies are known to be more common in some minority populations.³⁵ There appears to be a relationship between customary consanguinity and a higher incidence of handicap and chronic disease,³⁶ although whether this is causal is debatable, as others argue that the socioeconomic environment may be the primary factor.^{37 38} Whatever the rights and wrongs of such arguments the reality is that disability, chronic illness, and handicap are concentrated in these communities. In any given health district the absolute number of minority ethnic children with disability or a chronic disabling illness will depend on local demography. South Glamorgan, with a population of 400 000 and a minority ethnic population very near the national average, has over 130 such children (E V J Webb, unpublished data); this is a sizeable number with significant resource implications for purchasers and providers of health care.

There are many problems, both of access and inappropriateness of services, in any attempt to address the needs of such children. Cultural differences in concepts of illness, particularly chronic illness,³⁹ coupled with communication difficulties, may lead to confusion and the development of poor relationships between professionals and clients.⁴⁰ For example consanguineous parents are understandably upset when they are told that their baby is disabled or ill *because* they married each other, particularly if they belong to a community in which consanguinity is customary. Apart from this information being manifestly wrong, it does nothing to help the parents adjust to their new role or to avail themselves of genetic counselling.³⁶ There are also cultural barriers to the acceptance of the type of care or support offered to an affected family, by what appears to be a confusing array of professionals. Rejection of such services may lead to a sense of hopelessness and frustration in professionals who may project this back onto the families. For instance, observant Muslims cannot use their left hand to eat in company; a physiotherapist – unaware of this – may encourage use of the left hand in a hemiplegic child and find the family uncooperative. The 'uncooperative' family easily becomes the 'difficult' or 'uncaring' one in the minds of professionals. An Indian mother who regards washing in her own bath water unhygienic would find her stay in hospital less of an ordeal with the provision of a plastic bucket and jug in the bathroom of the parents' annex. These examples of cultural blocks to access are simply and cheaply remedied with a disproportionate improvement in the quality of care delivered.

Do we overdiagnose or underdiagnose communication problems in children from families

whose first language is not English? In South Glamorgan children whose mothers do not speak English are twice as likely to have a language disorder diagnosed than are other minority ethnic children with English speaking mothers (E V J Webb, unpublished data). When we correctly identify disordered language development in a non-English speaking child, what kind of service will s/he receive from a monoglot therapist, whether or not the support of an interpreter is available? How appropriate are our assessment methods in children from other cultures? Cultural mismatches in assessment can give misleading results, and we need culturally appropriate assessments standardised on the population group for which they are designed.⁴¹ Can methodologies based on patterns of language development of monoglot English speaking children be applied to other languages, or to bilingual children? Surely we need norms for languages whose structures and grammar may be fundamentally different from those of English. Norms are only now being identified for Gujarati (P Chavda, personal communication) and for Welsh. There is some information available on language development in Punjabi⁴² and Bengali.⁴³ It seems unlikely that we can offer effective intervention to language disabled children with English as a second language given current levels of knowledge and service provision even with the help of health advocates with training in this area, of which there are very few. This has serious implications both for the emotional well being and the educational outcomes of these children.

Inadequate health advocacy services, communication difficulties, and inappropriate speech and language therapy pose tremendous challenges both in early diagnosis and in the provision of appropriate therapeutic and support services to hearing impaired children from these communities. Most published work in this area comes from the United States where such children have depressed educational achievement levels as compared with their white peers.⁴⁴ Profoundly deaf children may be isolated from their hearing families. Presumably where the home language is not English this isolation is more profound. Does this mean they are isolated from their cultures as well? In the United States there exists the view that deafness precludes ethnic minority group status.⁴⁴ Poor educational outcomes and social isolation may appear to be more a problem for providers of social care and education but there are implications for health services both in the possible contribution of late diagnosis and inadequate therapy to these outcomes but also in behavioural problems arising from them requiring intervention. It is an area where the need for research and audit is urgent.

CHILD PROTECTION

Effective child protection in a transcultural setting is difficult. Notions of what is good parenting and what is abuse will vary consider-

ably between cultures. Some traditional practices will masquerade as abuse – for example coin rubbing lesions in Vietnamese children.⁴⁵ Others such as female genital mutilation are clearly abusive, although they may not be regarded as such by the communities themselves.⁴⁶ Protecting children while maintaining the trust of the communities poses a dilemma to service providers which is far from easy to resolve.⁴⁶

A second dilemma, illustrated by the following quote, is that of maintaining cultural awareness and sensitivity while avoiding cultural deficit: 'Physical punishment as a form of parental discipline has traditionally been used by Afro-Caribbean families. The use of a belt or strap ... does not indicate a disturbed family relationship or a sadistic parental attitude and should not normally be dealt with as "child abuse" ...'.⁴⁷ The danger of cultural deficit is that minority ethnic children are not protected in consequence of professionals accepting different standards of care from the families of these children than from those of the white ethnic majority. If it is unacceptable for a white child to be beaten with a strap it is unacceptable for any child to be so treated.

It is inevitable that sometimes in the context of child protection procedures professionals will be accused of racism. Professionals need support, clear guidelines and protocols, with the *best interests of the child* foremost. At the same time professionals do need to be aware of racist practices. Within a population of children in New Zealand killed or hospitalised as a consequence of child abuse, being Maori or Samoan significantly affected the diagnostic categories to which they were assigned.⁴⁸ It is hard to explain such a finding without concluding that professional responses were influenced by attitudes to the ethnic groups as much as by the abuse *per se*. Absence of ethnic monitoring as a more likely reason than absence of racism in accounting for the lack of British data in this area. We have no cause for complacency.

Conclusion

Concentrating on exotica and cultural differences³ merely allows commissioners and providers to ignore general health needs and blame the communities themselves when they receive poor quality services.⁴⁹ We now have to move forward if we are to achieve an improvement in their health care. We are not talking of an insignificant minority, but nearly one in 10 of all children. Clearly real differences in health needs do exist, for example haemoglobinopathy associated illness; these need to be addressed and adequate provision made.¹⁵ It is in meeting the general needs of minority ethnic children that we face the greatest challenge. These are no different to those of the white ethnic majority. However, meeting them may require different – sometimes radically different – response strategies on behalf of both purchasers and providers of health care to children, supported by appropriate training, audit, and research.

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