

## A Health Needs Assessment of Black and Minority Ethnic Children's Needs



Report prepared for:

Leeds Children & Families Modernisation Team and Leeds Health Action Zone

By:

Barnardo's, the Centre for Research in Primary Care, and the Centre for Disability Studies (University of Leeds)

**JUNE 2002** 

This report is available online at: www.leeds.ac.uk/disability-studies/projects/leedshna.htm

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## Acknowledgements

The presentation of this report arises from the contribution of many people. We would particularly like to thank all of the young people, parents and professionals who contributed their views and experiences during the research process. The process was made possible by the active co-operation of staff within NHS Leeds, Education Leeds, and Leeds City Council. The writing and editing of the report was also a collective effort by members of the research team. Specific credit is therefore due to:

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### 1. Introduction

The aims of this initial study were:

• to carry out a health needs assessment of children and young people (0-19 years) from minority ethnic communities in Leeds, in order to provide an evidence base for future development and improvement of services

• to obtain a baseline profile of the health needs of ethnic minority children in Leeds, in order to ensure that the services planned for them in future are appropriate and culturally acceptable.

The key objectives in addressing these aims were to:

- report on the nature of the population of ethnic minority children in Leeds
- provide a review of literature and shared learning
- obtain the views of parents, children and concerned professionals
- obtain an overview of services for children
- establish key priorities for addressing unmet needs and service developments

In preparing this report we have conducted a review of research and policy documents on the health needs of ethnic minority children, barriers to current provision and examples of good practice. The sources of information have included research studies, service evaluations, organisational policies and strategies from a variety of statutory and voluntary organisations, such as health authorities, health action zones, local authorities, community health councils, independent health think tanks and charity groups. We have gone on to examine the nature of the ethnic minority population in Leeds through a review of the available statistical information and have consulted with children, parents and professionals on the health needs of ethnic minority children and the range of available service provision. In addition we have undertaken a mapping of existing services via a postal questionnaire to agencies across Leeds.

#### Health needs assessment

It is important to be clear about the purpose of a health needs assessment and about the scope for this study. Several definitions of health needs assessment are possible. In general terms, the purpose of a health needs assessment is to improve the health of a whole population and to target resources towards improving the health of those at specific risk or in under-served population subgroups. The priority for Leeds NHS is to identify different populations, to determine their similar and differing needs, and to assess their ability to benefit from interventions to meet those needs.

The two essential determinants of a population's ability to benefit are the extent of the health problem (incidence/prevalence), and the effectiveness of interventions to deal with it. These interventions will not just be diagnosis, treatment and palliation but will include preventative measures and health promotion (LHA, 1999: 8).

Our study offers an initial contribution to this task in relation to the health needs of minority ethnic children in Leeds. Consequently, the key tasks have been to identify

and define that population, to identify priority groups within it, and to gain an insight into the current state of affairs regarding their health and use of health services.

Stevens and Raftery (1994) define health needs assessment as 'the assessment of a population or community's ability to benefit from health care'. Although this definition is based on 'health care' it does implies more than a narrow clinical focus. In this sense, 'health care' includes treatments but also prevention, diagnosis, continuing care, rehabilitation and palliative care. Thus, the 'benefit' may also include reassurance, supportive care and the relief of carers. Many individual health problems have a social impact via multiple knock-on effects or the burden to families and carers. Hence a list of beneficiaries of care may extend beyond the patient. Consequently, our study includes not only the health experiences of minority ethnic children themselves but also the perspectives of parents, health professionals and agencies involved in health activity within the city.

Mackintosh *et al.* (1998: 18) consider the assessment of health needs to be a strategic process, providing the background information required to make sound decisions. 'It informs, educates and (hopefully) supports service providers and consumers in developing or sustaining services. Health needs assessment should thus be considered as an ongoing, cyclical process'. Our study offers a contribution to this process and suggests how it might be developed and extended. It should not therefore be viewed as an end product but as the beginning of a strategic process. In this sense, many of our findings are indicative rather than definitive, suggesting as many questions as they answer. For example, in conducting the study we were often hampered by the lack of existing research in this area, the absence of reliable or comparable data, and the lack of follow-up studies to help us to identify trends.

Health needs assessment for the *ethnic majority* in Britain has been ongoing for decades, if not for centuries, but only recently has the attention focused on the needs of *ethnic minority* groups. Thus, there is a wealth of relevant health needs information available in the general context but often much less 'hard' information about minority subgroups. Although the awareness among policy makers of the importance of ethnic minority children's services is increasing, the past few years have seen little change in patterns of service provision. In the case of children from ethnic minorities, the absence of concrete local information is often striking. In addition to providing indicative information about this population from existing data it is therefore necessary to view the study as highlighting potential areas for the development of future knowledge and the gathering of information not currently available. Consequently, many of the report sections include recommendations for the development of monitoring and evaluation systems alongside summaries of existing knowledge.

SUMMARY: The health needs assessment should be considered as the starting point for an ongoing process of information gathering and analysis, in order to target future interventions and investments to improve the health of minority ethnic children in Leeds.

#### Determinants of health

To underpin the context of health needs assessment it is relevant to consider what we mean by health and what we understand to be its primary determinants. Similarly, Leeds Health Authority (1999) believes that any health improvement programme must address not only the provision of services but also the determinants of health. Existing literature points to a number of determinants of health, which might need to be addressed in order to improve the health of minority ethnic children.

The World Health Organisation (WHO) glossaries present three definitions of health:

Health is a state of complete physical, mental and social well being and not merely the absence of disease or infirmity (WHO constitution).

Health is the reduction in mortality, morbidity and disability due to detectable disease or disorder, and an increase in the perceived level of health (WHO/EURO's Health21).

Health is a resource for everyday life, not the object of living. It is a positive concept emphasising social and personal resources as well as physical capabilities (WHO, Health Promotion Glossary).

Health determinants are the personal, social, cultural, economic, and environmental factors that influence the health status of individuals or populations. People's health may thus be influenced by *individual* factors such as age, gender and family history; *social and economic* factors such as ethnic background, education, employment, poverty and social exclusion; *cultural* factors such as diet, physical activity, sexual behaviour, drugs, smoking and alcohol intake; *environmental* factors such as housing, air and water quality, and working conditions; and also the *services* that are available locally, such as education, NHS, Social Services, transport and leisure. These factors can vary from place to place and from person to person. They come together to influence health and health inequalities (DoH, 1999).

SUMMARY: Health needs assessment demands a broad definition of health and its determinants that includes individual, social, economic, cultural, environmental, and service factors.

#### Health inequalities

Within the context of these definitions and health determinants, it is clear that we can identify a number of areas in which health inequalities may exist, especially with reference to young people and people from minority ethnic communities. Even in the richest countries, the better off live years longer and have fewer illnesses than the poor (WHO, 1998). Such differences are an important marker of social injustice, and reflect some of the most powerful influences on health. People's lifestyles and the conditions in which they live and work strongly influence their health and longevity. Poor conditions lead to poor health. Health is profoundly unequal. Health inequality runs throughout life, from before birth into old age. It exists between social classes, different areas, between men and women, and between people from different ethnic backgrounds. However, the underlying picture is that the poorer you are, the more likely you are to be ill and to die younger (DoH, 1999).

In the UK there are large social class, regional and ethnic differences in life chances related to health. Children born into poverty and disadvantage miss out on important opportunities for health gain, and accumulate health risks as they grow into adulthood. Among those most at risk of suffering the effects of health

inequalities are 'looked after' children, children in single parent households or households with low incomes, children experiencing abuse and/or domestic violence, children from homeless families, children with learning difficulties and/or impairments, travellers, refugees, asylum seekers and children from some minority ethnic groups. Children born into poverty are more likely than their better off counterparts to: die in the first year of life; be born small, be born early, or both; be bottle fed; die from an accident in childhood; smoke and have a parent who smokes; have poor nutrition; become a lone parent; have children of their own at a younger age; and to die younger (e.g. Roberts 2000)

One of the first acts of the new Labour Government in 1997 was to commission an independent inquiry into inequalities in health, chaired by Sir Donald Acheson, a former chief medical officer. This resulted in the *Independent Inquiry into Inequalities in Health* (The Acheson Report), published in 1998. The terms of reference were to review the latest information on inequalities in health, and to identify priority areas for future policy development where scientific and expert evidence indicated the potential for cost effective and affordable interventions to reduce inequalities. In terms of children's health the report contained some good news: we live longer than we did 50 years ago, fewer babies die at or shortly after birth, and there are fewer childhood deaths. But there remain unacceptable inequalities between rich and poor. The report (Acheson, 1998) made three major policy recommendations:

Policies likely to affect health should be evaluated in terms of their impact on health inequalities.

Steps should be taken to reduce income inequalities and improve the living standards of poor households.

A high priority should be given to the health of families with children.

Of the specific recommendations, ten are of particular relevance in reducing health inequalities for children and young people:

• Reduction in poverty in women of childbearing age, expectant mothers, young children and older people by increasing benefits in cash or kind.

• The development of high quality pre-school education so that it meets, in particular, the needs of disadvantaged families.

• Measures to encourage walking and cycling and the separation of pedestrians and cyclists from motor vehicles.

• Policies which reduce poverty in families with children by promoting material support; removing barriers to work for parents who wish to combine work with parenting; and enabling those who want to be full-time parents to do so.

• An integrated policy for the provision of affordable, high quality day care and pre-school education with extra resources for disadvantaged communities.

• Policies which improve the health and nutrition of women of childbearing age and their children, prioritising the elimination of food poverty and the prevention and reduction of obesity.

• Policies which increase breastfeeding.

• Policies which promote social and emotional support for parents and children.

- Policies which reduce psychosocial ill health in young women in, disadvantaged circumstances, particularly those caring for young children.
- Consideration of ethnic minority groups in needs assessment, resource allocation, health care planning and provision (our emphasis).

Similarly, the British Medical Association report *Growing Up in Britain: A Healthy Future for All Our Children* (BMA, 1999) recognised that inequalities in health will not be solved by medical interventions alone, recommending:

• A Children's Commissioners for England, Wales, Scotland and Northern Ireland.

- An annual report on the health of children from the Chief Medical Officer.
- No further cuts in lone parent benefit.
- Tax and education measures which tackle social exclusion.
- Action to tackle teenage pregnancy and smoking in pregnancy.
- Co-ordinated long-term support for families under pressure.

Clearly, such conclusions also frame the context for this study and suggest a number of areas, within a broader definition of health, which might be addressed. However, it was beyond the scope of this study to make recommendations or observations on the national policy agenda or its social context. Consequently, strategic planning arising from the study findings (relating to local circumstances and perspectives) should be considered within the bigger picture and informed by larger political debates.

SUMMARY: Health needs assessment for minority ethnic children in Leeds should be set in the context of a wider knowledge and appreciation of national health inequalities.

#### Racism and health

There is a considerable amount of research that identifies racism in health and health care interventions, disadvantaging people from minority ethnic groups. It is therefore important to understand the relationship between minority ethnic people and health services in order to improve the health of such groups (e.g. Mir *et al.*, 2001). In addition, institutional racism and more widespread societal racism contribute to minority ethnic groups being over-represented among the unemployed, those on lowest incomes, those socially excluded and those living in deprived areas and in poor housing (Arora *et al.*, 2000). All of these factors are also associated with poorer health.

Overt racism from individuals is also an unfortunate reality in the UK today, as suggested by findings from the Fourth National Survey of Ethnic Minorities, where around one quarter of white people interviewed admitted to racist feelings against those from South East Asia, Africa or the Caribbean (Nazroo, 1997). Racism contributes to a climate of anxiety and fear and nearly one quarter of all ethnic minority respondents in the National Survey worried about racial harassment. Such

concerns can lead to social exclusion, have a major impact on lifestyle and thereby contribute to stress-related illnesses.

The health care system is no less vulnerable to institutional racism, which may operate in several different dimensions to either exclude minority groups or favour white majority groups (Arora, 2000). For example, stereotypical beliefs about South Asian families 'looking after their own' (Ahmad and Atkin, 1996) may reinforce the neglect they experience from service planners, while African and Caribbean cultures are often viewed either as impoverished variants of the British culture and thus ignored, or seen as threatening and therefore in need of control (Ahmed *et al.*, 1998).

Although a 'colour-blind' approach ('we treat everyone the same') is frequently adopted within health care organisations, such statements may disguise the fact that the specific needs of ethnic minority communities have been overlooked (Alexander, 1999). At a grassroots level such attitudes may influence the use of discretionary decision-making and deprive minority ethnic communities of their rights to services (Mir *et al.*, 2001). It has been argued in a number of studies that the situation requires a political solution, as racism is based on power structures rather than simply on cultural differences (Ahmed and Atkin, 1996).

Consequently, it was important not to overlook the potential for institutional or individual racism in our study, for example, in the experiences of minority ethnic children and their families, in service delivery and information systems, or in the assumptions of service providers. At the same time, this was not the primary focus for research and the study did not involve any specific evaluation of existing health care services in relation to this issue.

SUMMARY: Health needs assessment for minority ethnic children should acknowledge the potential impact of personal or institutional racism on health and health care experiences.

#### 2. Nature of the population

The first objective for the study was to report on the nature of the overall population of minority ethnic children in Leeds, and to determine the availability of demographic data relating to this population. Looking at the national picture, there is evidence of considerable variation between different regions and localities across the country, and between different minority ethnic groups. Some groups are growing faster than others, particularly in relation to the number of children concerned, and local circumstances are important. The demographic picture is therefore complex, and considerable caution should be exercised in applying national trends to local planning scenarios.

For this reason, it has become increasingly apparent that planners and providers within health services require accurate and up-to-date information about local communities and community needs. However, the indicative research carried out for this study suggests that such information is frequently unavailable, unreliable, or difficult to access for health planning purposes. In order to target the most appropriate services and resources, it is important to understand how the population of minority ethnic children in Leeds compares with the national picture, and how the local distribution varies between localities within the city. Although Leeds is a prosperous district overall, it contains inner-city areas which are among the poorest in the country as well as smaller pockets of disadvantage in other parts. Thus, the accurate identification of health needs and health inequalities involves a number of complex tasks. The following sections draw on both national and local data in order to highlight the most readily available sources of information, and to provide estimates of the current population of minority ethnic children in Leeds.

#### The national picture

Beginning with the national picture, the following Figure 1 shows the overall proportion of minority ethnic children in the population by comparison with the majority white population. Although the overall proportion of minority ethnic communities in the national population remains relatively small, under 10%, it has been increasing steadily for some time.

Figure 1: Minority ethnic children in the national population (source: 1991 census)



This gradual increase is reflected in the fact that there are larger numbers of minority ethnic children in younger age groups than in older age groups. For

example, there is a larger proportion of minority ethnic children within the preschool age group than within the 15-19 group. Within this overall picture there is considerable variation. For example, while the largest groups of minority ethnic children are of Indian or Pakistani family origin, the fastest-growing groups are those described as 'mixed', of dual heritage or 'other'. By contrast, the number of Chinese children in the population appears to be declining. In addition, there has been a recent increase in migration amongst white populations from central and Eastern Europe. A traditional focus on 'non-white' minorities has tended to mask this latter trend by defining white ethnic minorities or nationalities as 'other'. Figure 2 shows the number of children (in thousands and in the different age groups) from the main minority ethnic communities identified in the 1991 National Census.





Summary: The number of minority ethnic children is increasing nationally and there are more children from ethnic minorities in younger age groups. Pakistani and Indian children form the largest sub-groups, while children of 'mixed' or 'other' parentage are the fastest growing groups. More research into the latter groups is required.

#### The situation in Leeds

Leeds has a total population of around 725,000 and since the local administrative and health boundaries are coterminous, population data and health statistics can be regarded as broadly equivalent. Children and young people under 19 account for just over 170,000 of this population and those aged under 5 number around 47,000. Overall, the ethnic minority population in Leeds is around 5.2%, although this figure is not wholly reliable, particularly in relation to children and older people.

The national age trends, outlined earlier, are underlined by the fact that most of the minority ethnic communities in Leeds have a younger profile than the population

average. For example, in Leeds, 50% of the Bangladeshi community, 44% of the Pakistani community and 30% of the Indian community were aged below 16 in the 1991 Census (compared to 20% for the population as a whole). This is partly due to the fact that more recently settled migrant communities are generally younger than host populations and often have correspondingly higher fertility levels, especially true for Pakistani and Bangladeshi groups (DoH, 1997).

In the absence of up-to-date Census data, the most useful current information on overall numbers is probably from ethnic monitoring of school pupils within the city. Education Leeds collects a variety of data on all known current pupils, including ethnicity as recorded by individual schools. The codes used to record pupil ethnicity vary slightly from those employed in the census and some caution should be attached to the interpretation of pupil ethnicity data, as recording practices and reliability vary between schools. The following table summarises existing data on the ethnicity of school age children in Leeds by primary and secondary age groups using aggregated figures from the 2000-2001 academic year.

Ethnicity	Primary	%	Secondary	%
Bangladeshi	550	0.81	281	0.58
Black African	244	0.36	128	0.27
Black Caribbean	1012	1.50	709	1.47
Black other	944	1.40	537	1.11
Chinese	274	0.41	181	0.37
Greek/Greek Cypriot	30	0.04	24	0.05
Indian	1356	2.01	1135	2.35
Not recorded	621	0.92	364	0.75
Other	1070	1.58	670	1.39
Pakistani	3219	4.77	1870	3.87
Traveller	2	0	0	0
Unclassified	293	0.43	56	0.12
Vietnamese	37	0.05	19	0.04
White other	1003	1.49	1218	2.52
White UK	56881	84.22	41080	85.10
TOTALS	67536	100.00	48272	100.00

Figure 3 shows the relative proportions of children in Leeds primary and secondary schools who were identified with specific minority ethnic communities.



Figure 3: % pupils in Leeds Schools by ethnicity (source: Education Leeds)

Although indicative, these figures provide a useful indication of the current population of minority ethnic children in Leeds. They also confirm some of the demographic trends identified earlier. For example, the weighting of certain minority groups towards the younger age range is evident in the differing percentage figures for primary and secondary schools. In particular, there are significantly larger proportions of primary age children from Bangladeshi and Pakistani groups than in secondary schools. Interestingly, the proportion of children whose ethnicity was identified as 'Indian' or 'White other' was actually lower in the younger age group (although this may be due to classification practices within schools).

Education Leeds also identifies a total of 315 asylum seeker and refugee children in Leeds schools, all admitted since 1999 (almost two thirds have been admitted during 2001). A large proportion of these children (more than half) are of central or Eastern European origin (predominantly Albanian, plus Russian, Czech, Lithuanian, Polish, Slav, Romanian, etc.). Others include children from Afghanistan, Africa, the Middle East and South Asia. One third are in high schools and two thirds in primary schools. Refugee children use a wide variety of minority languages and only 19 are recorded as having English as their primary language.

We were unable to establish, with any precision, the numbers of minority ethnic children in the pre-school age group, although the primary school data should provide a reasonable indication. Similarly, the high school data does not include those young people under the age of 19 who have left secondary school, although the 2001 census data will provide this information when it becomes available.

Summary: The overall population of minority ethnic children in Leeds mirrors some of the national trends. The largest minority group of school age children are of Pakistani origin with significant numbers of children from Black and minority White groups. Bangladeshi and Pakistani children show the lowest age profile, with an apparent decline in younger children of Indian origin (although there may be an error of recording here).

#### Variations between wards

The most densely populated areas are in the 12 inner city wards. Those that have notably high ethnic minority populations are Chapel Allerton (31%), Harehills (28%), University (17%), Headingley (17%), Moortown (10%), City and Holbeck (9%) and Roundhay (9%). Harehills has the largest proportion of Pakistani and Bangladeshi communities, whilst Indian and Black groups are most prevalent in Chapel Allerton ward. University ward has the highest proportion of minority communities described as 'other'. There are also large concentrations of Indian families in Moortown and of Bangladeshi families in Holbeck. However, it is worth noting that these figures are based on 1991 Census data and may be revised with the availability of new data.

Table 2 (on the following page) provides an indication of the distribution of the main minority ethnic communities *across all ages* in the population of Leeds by Ward (numbers include both children and adults using data from the 1991 Census).

Since these data are more than ten years old, it might be misleading to provide too detailed a breakdown of the figures for ethnicity and childhood across the city. However, they do provide an indicative picture of the varied pattern between wards. In the absence of up to date information on the pre-school population, the data can also be used to illustrate the demographic picture in 1991. Considerable caution should be exercised here, bearing in mind the changing profile of different ethnic groups in the youngest age cohorts. However, for the purposes of illustration, it may useful to look at young children in those wards with the highest concentrations of minority ethnic families. Thus, the subsequent three figures (on page 16) show the numbers of minority ethnic children aged under 5 in Chapel Allerton, Harehills and University wards using data from the 1991 Census, divided by gender.

In addition to the 1991 Census, a more up-to-date picture is available for school-age children from the pupil data collected by Education Leeds. Since most primary pupils attend schools close to home (with exceptions) an indicative picture of current ethnicity distributions may be obtained by mapping the proportion of children attending primary schools in the different wards. Since many high school pupils travel a considerable distance to school, this exercise would be much less reliable for older children (although it may be useful in targeting health promotion activities through schools). Table 3 (on page 17) shows the proportion of minority ethnic children attending primary schools in the various Leeds wards, using data from the 2000-2001 academic year. A more detailed breakdown of this data is provided in Appendix A, with reference to the 11 ethnic categories used in schools reporting.

Of the refugee and asylum seeker children of high school age, many are concentrated in specific schools targeting their language and social support needs (e.g. Primrose High School, City of Leeds, Matthew Murray). Primary school children are more dispersed but with heavier concentrations in Leeds 7, 8, 9 and 13 schools. The large majority live within walking distance of the schools they attend.

Summary: There is considerable ethnic diversity within and between the various wards, with larger concentrations of minority ethnic children in Chapel Allerton, Harehills and University wards. The availability of 2001 Census data will confirm the current picture in much more detail. However, liaison with Education Leeds over the collection and analysis of pupil ethnicity data would also provide a useful source of dynamic data.

Ward	Bangla- deshi	Indian	Pakistani	Black groups	Other	Irish
Aireborough	0	39	21	54	120	182
Armley	10	320	399	140	190	264
Barwick	0	60	5	55	74	141
Beeston	209	248	388	160	186	346
Bramley	5	93	16	87	91	175
Burmantofts	0	127	86	278	169	466
Chapel	295	1282	1070	3811	955	483
City Holbeck	355	346	940	256	229	454
Cookridge	40	299	40	74	231	247
Garforth	4	64	11	45	50	150
Halton	0	64	4	42	111	245
Harehills	798	944	2449	1485	692	666
Headingley	17	707	1178	521	553	364
Horsforth	0	58	7	67	130	179
Hunslet	2	58	8	90	136	221
Kirkstall	12	410	447	294	306	454
Middleton	0	75	15	61	66	176
Moortown	7	1207	308	290	421	332
Morley North	0	128	18	30	96	111
Morley South	0	143	18	59	90	156
North	13	406	190	128	378	306
Otley	4	58	17	33	72	144
Pudsey North	0	631	117	56	98	105
Pudsey South	0	250	44	52	114	180
Richmond	3	116	26	173	155	376
Rothwell	5	69	14	28	49	100
Roundhay	1	712	604	460	391	470
Seacroft	3	37	10	153	94	319
University	21	324	600	1387	1207	489
Weetwood	2	257	85	187	225	257
Wetherby	0	31	17	20	65	215
Whitmoor	0	122	113	86	115	148
Wortley	2	218	51	121	119	268

#### Table 2: Distribution of Minority Ethnic Groups in Leeds (source: 1991 Census)

Figure 4: Under 5s in Harehills Ward (source: 1991 census)

Figure 5: Under 5s in Chapel Allerton Ward (source: 1991 Census)



Figure 6: Under 5s in University Ward (source: 1991 census)



Ward	Total	% minority	% Asian	% Black
Harehills	2807	57.04	46.63	6.48
Headingley	1048	49.24	36.35	7.73
Chapel Allerton	2266	46.20	18.45	23.96
University	1713	45.88	16.58	19.91
Moortown	2214	35.59	20.96	10.43
Roundhay	1620	28.21	19.57	3.89
Beeston	1854	25.30	22.87	1.08
North	2305	18.83	8.76	5.25
Pudsey North	2301	15.56	13.95	0.56
Kirkstall	1489	14.24	7.99	3.90
City And Holbeck	1793	13.55	10.32	1.34
Weetwood	1275	12.78	4.55	4.63
Armley	2692	10.55	7.10	2.12
Cookridge	1736	9.04	2.71	1.73
Burmantofts	1761	7.10	0.91	4.20
Pudsey South	2154	5.66	3.48	0.97
Whinmoor	1932	4.66	2.23	1.76
Morley North	2250	3.87	1.78	0.67
Richmond Hill	1876	3.62	0.91	1.81
Seacroft	1827	3.56	0.77	2.08
Wortley	2020	3.51	2.08	0.64
Morley South	3176	3.21	0.94	0.54
Horsforth	2071	3.09	0.43	0.72
Otley	1860	3.06	1.24	0.70
Bramley	2258	2.92	0.71	0.89
Hunslet	1417	2.54	0.49	1.48
Rothwell	2218	2.39	0.77	0.63
Wetherby	2182	1.88	0.60	0.55
Halton	2350	1.87	0.43	0.30
Aireborough	2199	1.64	0.55	0.18
Middleton	2714	1.44	0.33	0.59
Garforth & Swillington	2545	1.38	0.28	0.12
Barwick and Kippax	1613	1.36	0.31	0.37
TOTALS	67556	12.93	7.59	3.26

Table 3: Summary of Pupils in Leeds Primary Schools by Ward, ranked by % minority
ethnic pupils (source: Education Leeds 2000)

## 3. Specific Health Issues

This section of the report builds on the preceding demographic data by highlighting a number of key areas of health need or concern for minority ethnic children in Leeds, as identified from existing knowledge and research. The data is drawn from a variety of sources, including major national studies and local research. The intention is to identify themes and priorities and to relate these to the local population. This section does not include details of the actual priorities identified by participants involved in our research as these are provided in subsequent sections.

There are a number of key areas where there may be potentially significant ethnic differences in children's health, or in the reporting of children's health. In particular, self-reported health, psychological health, respiratory health, the reporting of accidents, and the incidence of chronic illness or impairment seem to have significance for some groups of minority ethnic children nationally. There are seven wards in the city where minority ethnic children currently make up more than a quarter of all primary school pupils. These are Harehills, Headingley, Chapel Allerton, University, Moortown, Roundhay and Beeston (see previous chapter). Where general trends of health inequalities have been identified in the national survey data, we might therefore expect to see some similar patterns in these key areas of the city.

The health problems faced by minority ethnic children in Leeds are by no means unique and may often be applied to children in the majority community. However, there are both similarities and differences between ethnic minority children's health and their white counterparts. Where differences exist they may be attributed to a range of causes, including environmental factors, differences in reporting, cultural and behavioural factors and occasionally genetic differences. It is important therefore not to attribute all of the health problems faced by minority ethnic children to their ethnic origin.

#### Poverty and environmental indicators

Poverty is a key factor in indicators of child health, particularly as this relates to the health of minority ethnic children. It is well documented that socio-economic status is a significant contributing factor to ethnic variations in health and is linked to higher rates of chronic illness in the most disadvantaged ethnic minority communities (Smaje, 1995; Nazroo, 1997; Acheson, 1998). For example, national data suggests that more than half of African-Caribbean children live in areas of high unemployment, and that Bangladeshi and Pakistani children are consistently amongst the poorest of the poor. In considering specific health issues affecting minority ethnic children it is therefore important to acknowledge the relationship with poverty.

There is clear evidence that children of families who are less well off suffer poorer health (Lister *et al.*, 1994). The risk of death is small, but it is greater for children whose parents are in semi-skilled or unskilled work, or who are unable to work. The risk of accidents is also greater for these children. There is evidence that children brought up in disadvantaged inner city areas are more at risk of accidents and emotional disorders. A small minority of children have to cope with more serious illnesses, like diabetes, cystic fibrosis, epilepsy, haemoglobinopathies, or with long standing impairments. However, childhood is also a time of much minor illness, such

as flu, fever, food poisoning, and infectious diseases (like measles and whooping cough)

Looking at the local population data for Leeds, it is evident that health and poverty indicators may have a particular relevance for minority ethnic children in the city. Leeds is a vibrant dynamic city that has seen phenomenal growth and prosperity in the last few years. However, the benefits of prosperity have not been shared equally, and least so by those residing in the inner city wards. In fact, deprivation has persisted, polarising differences between locales to the extent that the DETR has categorised 30% of the population of Leeds (residing in 10 wards) as amongst the 10% most deprived in England. The fact that these wards also have a high number of minority ethnic residents inevitably leads to these communities suffering disproportionately the effects of deprivation and consequently high burdens of disease and illness.

The *Leeds Health Improvement Programme 1999-2002* (Leeds Health Authority, 1999) identified some of the main socio-economic factors impacting on health in the inner city area:

• **Poverty:** One-third of households live below the poverty line (with an income below 50% of the national average). Free school meals take-up is nearly double the national average (41% of all children in the inner city, 22.5% in Leeds, and 23% nationally). Nearly half of all households receive Council Tax or Housing Benefit (46%).

• **Unemployment:** 41% of benefits claimants in April 1997 were unemployed for more than 12 months. Unemployment amongst men from ethnic minority groups is over 40%, higher than the national average.

• **Education:** Educational achievement is only about one-third of the national average; from 1995 to 1997 an average of only 14% of pupils in inner-city high schools obtained five or more GCSEs at grade A-C (the average rate for England was 44%).

• **Crime:** There was an increase in the number of reported racial incidents in Leeds in 1997/98. This increase may represent the efforts of agencies to record such incidents rather than an increase in the number of incidents. However the number recorded is still likely to be below the actual number occurring.

• **Housing** is a significant area of concern. More than one in five private houses in the inner city wards are regarded are unfit, nearly three times the national average, and more than 60% of the Council's housing stock presents problems associated with dampness. The incidence of derelict land justifying reclamation recorded in the Government's Derelict Land Survey (1993) was over 13 times the national average.

There are a number of variables within the census data that also have a bearing on health and health indicators. It is clear, for example, that figures for low birth weight in the Leeds area map very closely onto the data for ethnicity by ward and there would seem to be a clear connection here between ethnicity, poverty and child health (no such correlation is apparent for data on infant mortality, since the numbers are too small to draw conclusions). In key areas, such as Harehills, Headingley, Chapel Allerton and University wards, where there are more than 45% minority ethnic children, there are also significant poor housing indicators, particularly in relation to overcrowding and lack of central heating. National data suggests that issues of overcrowding and poor housing may be of particular concern for Bangladeshi children.

Existing census and survey data suggest that there is a considerable overlap between those areas of the inner city with the largest numbers of households with dependent children (both older children and younger children) and those with the largest minority ethnic populations. Issues of child health in the inner city are therefore closely linked to issues of health for minority ethnic children. Action to target environmental factors and poverty in these areas would therefore be linked to outcomes for minority ethnic children.

Summary: Household income, unemployment and poverty are key issues in those areas of the city where most minority ethnic children live. They are also identified as key factors in the ill-health of minority ethnic children nationally. Action to tackle poverty and poor family housing in inner city wards such as Harehills, University and Headingley would have a positive impact on the health of minority ethnic children.

#### Reported health and illness

Taking into account the underlying relationship between environmental health factors and minority ethnic communities in the city, it is then relevant to consider the available information on rates of reported health and ill-health amongst those populations. A considerable amount of data are available from the Health Survey for England 1999, including specific data on of the health of minority ethnic children. The following summary findings provide an indication of the overall picture with reference to specific issues of concern. More detailed information and data summaries are available from the Health Survey website at:

www.official-documents.co.uk/document/doh/survey99/hse99.htm

The data on self-reported health for children aged 2-15 it suggests the possibility of an under reporting of ill-health by minority ethnic young people. For example, Indian, Chinese, and particularly Pakistani and Bangladeshi children were less likely to report long-standing illness by comparison with the general population. Black Caribbean, Indian, Pakistani, Bangladeshi, and Chinese children were also less likely to report acute sickness in the past two weeks. However, Pakistani and Bangladeshi boys were also less likely to report good or very good health compared with the average. Since Pakistani and Bangladeshi children are a significant minority in Leeds (up to 5% overall) this national finding may have local relevance. Given the clustering of these communities in particular wards it may be particularly useful to consider indicators of health reporting amongst Pakistani and Bangladeshi children in Harehills, City, Chapel Allerton, Beeston, Headingley, University and Roundhay wards.

#### Psychological and emotional health indicators

In relation to psychological health there were no significant differences between minority ethnic groups and the general population in the national survey data, although girls scored better than boys in every group. However, specific attention was drawn to the psychological health of Pakistani boys, and Indian, Pakistani, and Irish girls (who tended to score higher on the Strengths and Difficulties Questionnaire, designed to pick up emotional, behavioural and relationship problems). The Figure 7 shows the scores of children from different ethnic groups.





There is a lack of research into the mental health experiences of young people from minority ethnic groups in Leeds. There are reasons why minority ethnic young people may suffer from mental illness, for example the effects of racism, unemployment and sometimes differential exposure to substance abuse. In addition, there has been recent concern about the psychological impact of cross-cultural tensions in the lives of South Asian young people (for example, in relation to forced marriage and estrangement from family). This can lead to isolation from participation in both the Asian community and the wider society.

Research into suicide suggests that the relationship with ethnicity is complex and not well understood. For example, there is evidence that people of minority ethnic origin may be more at risk in neighbourhoods where there is a small minority population but at less risk in wards where there are dense minority populations, irrespective of other factors such as gender or poverty (Neeleman et al 1999). Particular concern has also been expressed about the specific case of young women recently immigrating from the Indian subcontinent, for whom suicide rates are considerably higher than those of their male counterparts, of young women in their country of origin, and the host population.

Although not included in the national health survey data, there is also concern about the psychological health of refugee children, who may have experienced traumatic loss, bereavement, persecution or social dislocation. Migrants have consistently been shown at greater risk of mental distress and this situation is exacerbated for the most vulnerable and the least able, including young unaccompanied children and those with existing chronic health conditions. Although there is little collated information on the health of refugee and asylum seeker children in Leeds, there are, for example, local children whose parents have been murdered in ethnic violence and those have been shot themselves.

While refugee children have the same broad educational and health needs as other children, they also have a range of additional needs, many of which may be short term. Refugee children often face problems of poverty, poor quality temporary accommodation, frequent moves and hostility and racism within society. They are

sometimes faced with the daunting task of taking the role of head of household because of their fast acquisition of language skills, or because their parents can no longer fulfil this role due to their own psychological anguish. Hence children are thrust into a position of inappropriate responsibility, lacking parental support and losing out on their own childhood experiences. Many of these children are living with fragmented, reconstituted or new families in this country (Refugee Health Consortium, 1998).

The preceding summary suggests that there may be considerable potential for a targeted review of psychological health, emotional and behavioural difficulties amongst ethnic minority children and young people in the city. This might focus on the high density inner city wards noted earlier but should take account of the potential for mental distress amongst more isolated individuals and communities elsewhere. Educational data on the incidence of recorded emotional and behavioural difficulties in Leeds schools would be one way to explore this relationship (particularly in relation to the exclusion of Pakistani and African-Caribbean boys).

#### Healthy lifestyles and behaviours

In addition to environmental factors and reported health patterns it is important to consider the potential for differences in healthy and unhealthy behaviours amongst children of different ethnic groups – such as those associated with tobacco or alcohol consumption and with physical exercise. National data on these issues suggests that they may be of less concern to the most disadvantaged minority children than for white children, but also illustrates considerable diversity. For example, respiratory symptoms and lung function were of less concern nationally for Indian, Pakistani, Bangladeshi, and Chinese children, with greater concerns raised for white children, and those of Black Caribbean and Irish descent. Amongst older children, this appears to be linked with tobacco usage (where Irish girls were particularly at risk and where Indian, Pakistani, Chinese, and Bangladeshi children were at very low risk). The Figure 8 illustrates the national picture for children aged 8-15 who had 'ever smoked' (where the average probability = 1).

#### Figure 8: Probability of having ever smoked (source: Health Survey for England)



A similar, but more dramatic, pattern is evident for the consumption of alcohol by children. Figure 9 shows those in the same age group who 'ever drank'.



Figure 9: Probability of having ever drank (source: Health Survey for England)

Summary: National and local data suggest that there may be a case for targeted smoking cessation or prevention work with Black children in Chapel Allerton, Harehills and University wards, and amongst Irish girls (who are more dispersed in the city). Similarly, there has been increasing concern about the health impacts of illegal substance use amongst young people, such as the increasingly prevalent and regular use of cannabis and dance drugs. However, given the equal prevalence amongst white children, targeting ethnic minority children may not be the most productive strategy for intervention on these issues (although a case for specific work on smoking with Irish girls might seem to be indicated).

Nationally, systolic blood-pressure was higher for Pakistani boys and lower for Black Caribbean girls than for the corresponding gender groups in other ethnic groups. Diastolic blood pressure was higher for Indian, Pakistani and Chinese boys, and for Bangladeshi, Pakistani, and Chinese girls. However there were few ethnic differences in physical activity (where housework was included alongside recreational exercise). However, Indian, Pakistani, Bangladeshi, and Chinese children had much lower rates of participation in sport and exercise than the general population and this may raise some concerns in targeting health promotion in this area.

#### Accidents

Considering the association between poverty and ethnicity, and between poverty and accidents, we would expect to find a greater risk of accidental harm to children in disadvantaged inner city minority ethnic communities. However, survey data on reported accidents suggests that this is not the case. The incidence of both major and minor accidents varied in the Health Survey for England but was higher for children in the general population, and for Black Caribbean groups, than in other minority ethnic groups. The rates of major accidents reported for Bangladeshi children, Pakistani girls and Chinese boys were particularly low (almost three times less likely, despite indicators of poverty in some of these groups). Figure 10 shows the variance of reported major accidents by comparison with the general population (average = 1).





The reporting of minor accidents was even more skewed and suggests that this may involve differences in both the actual incidence of accidental injury and significantly different reporting patterns. The following figure presents data on the reporting of minor accidents between different groups (scale as previous). This data suggests that Irish girls and Black-Caribbean boys were more than 15 times more likely to report minor accidents than Bangladeshi children or Pakistani girls. There are clearly some significant issues here that might be investigated further in the local context (for example, through GP practice records or the monitoring of Accident and Emergency data).

#### Figure 11: Likelihood of reported minor accidents (source: Health Survey for England)



#### Disability, impairment and chronic illness

Generally speaking, belonging to a specific ethnic group per se does not lead to specific long-term illness conditions. However, there are a few conditions, such as haemoglobinopathies (thalassemia and sickle cell disease) that are strongly associated with particular ethnic groups because of their genetic basis. Sickle cell disorders (SCDs) are inherited diseases that occur more frequently in specific ethnic groups and affect the haemoglobin in red blood cells. SCDs include sickle cell anaemia, the milder haemoglobin SC disease and sickle beta thalessemia. Complications can include 'painful crises', increased susceptibility to infections, risk of stroke and damage to other vital organs (Smaje 1995, Atkin & Ahmad 1998).

The extent to which particular ethnic groups are affected by SCDs differs. The genetic trait for the diseases, as oppose to the diseases themselves, are commonly found in those originating from areas where malaria is prevalent (Smaje, 1995) or in populations who have migrated from such areas. This means that the groups most at risk in the UK from SCDs (sickle cell anaemia, haemoglobin SC) are those of African/Caribbean origin, while thalessemia is more likely to be found in people originating from South Asia, the Middle East and Southern European countries (Atkin and Ahmad, 1998; DoH, 1993 - Ethnicity and Health). There are estimated to be 14,000 people with SCD living in the UK and 800 people with thalassaemia. There are significant numbers of young people with these conditions in Leeds and there has been local research into their experiences of contact with health and social care services (see following chapter on use of services).

National data relating to the situation of minority ethnic disabled children is available from a range of sources. These include the national census and the OPCS disability surveys carried out during the 1980s, which have been recently re-analysed, together with a number of smaller academic studies relating to particular groups or health issues. This data suggests that minority ethnic children, and particularly those from Pakistani or Bangladeshi backgrounds, are more likely to experience what has been defined as 'limiting long term illness'. However, this finding also appears to be closely related to socio-economic factors, noting that apparently better off Indian and Chinese families showed lower rates of prevalence in this respect. There is currently no working register of disabled children in Leeds and no systematic monitoring of children's disability services. Consequently, it is not possible to say with any certainty how the incidence of impairment and chronic conditions links to ethnicity within the city.

Specific attention should be paid to the incidence of childhood impairment in relation to learning difficulties, since this has recently been highlighted as an area of concern within minority ethnic communities. The prevalence of learning difficulties amongst South Asian children and young adults (aged 5-32) is up to three times higher than in other communities (Azmi et al 1996c). Apparently lower rates of prevalence in under-5's are likely to be a result of failure to diagnose problems until school age (CVS 1998). Of South Asian families caring for family members with learning difficulties, 19% had more than one member with a learning difficulty. The higher prevalence of learning difficulties in South Asian communities has been linked to high levels of material and social deprivation, which may be combined with other factors such as poor access to material health care, misclassification and higher rates of environmental or genetic risk factors. Prevalence within other minority ethnic

groups is not as well documented, however fieldwork impressions also suggest a relatively high prevalence within the African Caribbean community (ibid.).

The Social Inclusion Division of Education Leeds hold an increasing amount of data on pupils assessed within the special needs Matrix. Here, individual pupil data can be associated with one of one or more of six bands (cognitive skills, visual impairment, hearing impairment, physical disability, language and communication skills, emotional and behavioural difficulties). Although ethnicity data in this context is regarded as a less than reliable, it would be technically possible to crosscheck special needs records with the pupil database held by the Pupil Assessment Unit. Similarly, the needs of pupils in special schools are well documented but would need to be crosschecked with PAU ethnicity data. The last audit of pupils described by mainstream schools as having special educational needs was conducted in 1999 but there is no reliable from the specialist support services for pupils with visual or hearing impairments, much less so in relation to pupils with physical impairments. Detailed local data on ethnicity and the incidence of special educational needs is therefore lacking at the moment.

Summary: Existing survey and research data provides some useful indications of significant health differences between children of different ethnic groups. These may be associated with environmental factors, reporting, cultural behaviours, and sometimes genetic factors. These differences suggest that there may be a need for greater monitoring, and possibly targeted intervention, in key areas of the city. Such interventions might be targeted at children's knowledge and reporting of their own health, at psychological and emotional health, at promoting healthy lifestyles, the reporting of accidents involving children, and at recording the incidence of chronic conditions and impairments (including the prevalence of young Asian and African Caribbean people with learning difficulties).

### 4. Use of Services

This section of the report concludes our review of existing knowledge on the health needs of minority ethnic children and their families by addressing issues in the use of health and health-related services. As with previous sections, data are drawn from existing research, in the national context, and from local information gained during the project. The specific service experiences of children, parents and professionals who took part in the study are then reviewed in the subsequent chapters. The findings of our initial review suggest that there are some considerable issues of inequality associated with the use of health services by minority ethnic children and that there is currently a lack of specific local knowledge in this area, but that the potential exists for development.

#### Primary care

The National Health Survey for England and Wales provides some indication of the use of health services and prescribed medication by minority ethnic children. This data suggests that there is a wide variation in the use of GP services, with Indian and Pakistani children being much more likely to have consulted recently with a GP. However, the same groups were less likely to be taking prescribed medication (Black Caribbean boys were much more likely to receive prescriptions). By contrast, some minority ethnic children were less likely to have made a routine visit to the dentist, but more likely to have consulted with dental problems. This was particularly the case for Pakistani and Bangladeshi children.

The following figures summarise the data on GP visits from the national health survey, illustrating the likelihood of children having visited a GP in the preceding two weeks.



#### Figure 12: % children visiting GP in past two weeks (source: Health Survey for England)

By comparison with the general population, Indian children and Pakistani boys were the most likely to have made a recent GP visit (around 50% more likely). Pakistani and Irish girls were slightly more likely to have made a visit than the average and Bangldeshi children slightly less likely. Irish boys were considerably less likely to have made a recent visit (less than half as likely as the general population). Clearly there are both ethnicity and gender differences here. In particular, it is relevant to note that this data shows a substantial difference in attendance between South Asian communities with similar exposure to the environmental health risks associated with poverty and housing identified in the previous chapter (i.e. Pakistani and Bangladeshi children). This merits further investigation in the local context and could be explored using ethnic monitoring data from GP practices involved in the MIQUEST data project (an example of indicative data from one practice is included in the Appendices).

Taking these national trends into account, it is relevant to note that the pattern of recent GP visits does not correlate with the prescription of medicines. Figure 13 illustrates the national survey data in this respect.

#### Figure 13: % children taking prescribed medicines (source: Health Survey for England)



Here, it is evident that those groups making the most frequent GP visits are also the least likely to be taking prescribed medication. In particular, Indian and Pakistani children were considerably less likely to be taking prescriptions than the average despite having the most frequent GP visits. By contrast, Bangladeshi children were slightly more likely to be taking prescriptions although their GP attendance was lower. These figures might suggest different cultural patterns of attendance or readiness to use medication for children but might also reflect different illness patterns. The most striking feature is that African-Caribbean boys were considerably more likely than the average to be taking prescribed medication than the general population, despite similar patterns of GP attendance. The marked gender difference in this group raises clear questions about the prescription of medicines to African-Caribbean boys and merits further investigation.

# Summary: There should be some concern about the apparently high level of prescribed medication for African Caribbean boys suggested by the national health data.

Marked differences are also apparent in the national data on attendance at dental surgeries, as the following figure illustrates.



Figure 14: % children ever visited dentist (source: Health Survey for England)

Here, it is evident that Bangladeshi children were considerably less likely to have ever visited a dentist, with Pakistani children at slightly less risk in this respect. The different is considerable, with Bangaldeshi children half as likely as the general population to ever have made a visit. There is much less difference for other minority groups and this suggests that targeted health promotion work in the Bangaldeshi community may be required in order to increase attendance rates. Given the considerable concentration of Bangldeshi children in Harehills, Chapel Allerton, City and Beeston wards there may be a case for targeting such interventions via primary schools in these areas.

These findings become increasingly significant when we consider the national data on the incidence of dental problems amongst children of different ethnic groups. Figure 15 shows the proportion of children presenting with dental problems at their most recent visit. It is clear from these figures that the pattern is a direct reversal of the trend in dental check-up attendance. Children from those groups least likely to have ever attended were the most likely to present with dental problems. Pakistani children, especially boys, were more likely to have dental problems and the rate of problems for Bangladeshi children was very significantly higher (almost five times higher than the average). These findings underline the importance of dental service usage in the prevention of dental problems and confirm the need for targeted action with particular communities. Ethnic monitoring of local dental attendance rates and problems would assist in targeting interventions in this area. In Leeds, there is also evidence that some refugee families have been reluctant to make use of dental services (Wilson, 1998).

This theme is underlined by findings from local studies in Leeds, pointing to an association between childhood dental caries and socio-economic status (Beal & Prendergast, 1995; Dental Public Health Unit ,1998). Such studies also suggest that young Asian children continue to experience the highest levels of dental caries (while African Caribbean children have the lowest rates). This complicates the simple association with poverty and suggests that diet and access to services may also be contributory factors.





Although refugee and asylum seeker children are not identified in the national health survey data, there is evidence of widespread concern about their use of primary care services. All refugees, regardless of their status, are entitled to NHS services free of charge (including the right to register with a GP, dentist or optician and to receive NHS prescriptions). However, under-registration is common and may be associated with a range of contributory factors (such as preoccupation with housing, employment and money, language problems, and the limited availability of translated information in uncommon minority languages). There may be cultural uncertainty about charges and about the means to obtain services, low expectations and concern regarding confidentiality between government departments and the NHS (Refugee Health Consortium, 1998). Leeds has established a 'Health Access Team' for asylum seeking families and children.

In reality, some GPs remain confused about refugee entitlements and some continue to offer temporary rather than permanent registration, which prevents acquisition of medical records by the practice and therefore hampers continuity of care. Many GPs find working with refugees time-consuming and stressful in the light of their overwhelming needs. A number of services have evolved specifically to address refugees' special needs, located within general practices or run by health authorities as outreach ventures in hostels or community centres. Since primary care settings generally provide the first point of contact with British health care, they are important. Pharmacists are often seen as a non-threatening source of advice about health problems, along with dentists and opticians are therefore in a good position to provide information on accessing NHS services. Studies, however, have found that these practitioners are in need of good quality culturally appropriate materials for health advice, both visual and written (Refugee Health Consortium, 1998). It is also important to note that school registration may be a refugee family's first contact with outside institutions in this country, providing an important opportunity for children to access health services. It is particularly important for young refugee children to be able to socialise with other children from an early age. Good quality nurseries and pre-school childcare can also be a valuable source of health advice and

materials, especially concerning immunisation programmes (Refugee Health Consortium, 1998).

Summary: There is clear evidence of national differences between children of different ethnic groups in attendance at GP and dental services, in the incidence of dental problems and in the prescription of medicines. This merits further investigation locally, through increased ethnic monitoring, and suggests in particular that Bangladeshi and Pakistani communities in Harehills, Chapel Allerton, City and Beeston should be targeted for health promotion work relating to the take-up of dental care. There is also a case for targeting refugee and asylum seekers to increase attendance. In addition, concerns about the apparently high rates of prescription to African-Caribbean boys should be further investigated in the local context.

#### Hospital services

A second area of significant service usage in child health is that of hospital services. National data on overall hospital attendance rates for adults (including outpatient, day patient and inpatient visits) shows relatively little variation by ethnicity, although there were significantly fewer visits by Chinese people and lower than average usage by those of Pakistani or Bangladeshi origin. However, there are variations. For example, Bangladeshi and Pakistani men were less likely to attend as outpatients and more likely to attend as inpatients, while for women in the same groups this pattern was reversed (excluding maternity services). These differences were less clear cut for Indian men and women. For young men and women (aged 16-34) those in the Chinese and Bangladeshi groups were around half as likely to attend hospital. This raises particular concerns about the low attendance of Bangladeshi young people.

Further information on ethnicity and children's hospital attendance is available from analyses of the 1999 Health Survey for England. The following three figures summarise this data in relation to outpatient, day patient and inpatient attendance (showing the percentage in each group that had attended during the past year).





The national outpatient attendance data for children shows considerable ethnic variation, with South and South East Asian children less likely to have visited a hospital as outpatients in the preceding year. The rates for Chinese girls, Pakistani girls and Bangladeshi children were considerably lower than the general population. While differences in the Chinese population may reflect real health differences, the figures for Pakistani and Bangladeshi children differ considerably from their pattern of attendance at GP surgeries (where the relative incidence was much higher).

The data on day patient and inpatient visits is more difficult to interpret, since the overall numbers of minority ethnic children involved are much smaller. However, the national survey data highlights some apparently significant differences. The following figure deals with the national data on attendance as day patients.





The most striking differences here are in relation to gender. While, the proportion of boys attending as day patients shows relatively little variation between ethnic groups, attendance for girls differs dramatically (although Black-Caribbean, Bangladeshi and especially Irish boys were more likely to attend than the average). For example, day patient attendance for Bangladeshi girls was less than half that for the general population and, amongst Pakistani and Chinese girls, four times lower. Significantly, girls within these groups were similarly less likely to attend than boys of their own ethnic origin. The most striking example in the data is for Indian children, where boys' attendance as day patients was similar to the general population but girls' attendance was close to zero (in the general population there was no gender difference).

A different and slightly less gendered pattern of hospital attendance was evident in the national data on inpatient visits from the 1999 survey, as the following figure shows.



## Figure 18: % visiting hospital as inpatients in the past year (source: Health Survey for England)

Here, the gender variations amongst minority groups tend to mirror the overall gender difference in the general population (where boys are much more likely to visit hospital as inpatients than girls). There were no gender differences in the Chinese group, with boys less likely to attend and girls more likely. Overall, Black-Caribbean and Pakistani children were more likely to have been inpatients, while the rates for Irish boys were particularly high. Unlike the data on day patient admissions, reviewed above, the proportion of Indian girls attending as inpatients was reported as similar to that for the general population.

There are clearly some anomalies in the national self-reported data on hospital attendance that merit further investigation in the local context. It is important, for example, to ask whether such differences reflect real gendered patterns of illness, differences in service usage, or differences in recording and ethnic monitoring. One approach to this problem is to examine the existing data from Leeds hospitals in order to establish ethnic differences in children's service usage (discussed later).

Summary: Existing national data on children's patterns of hospital attendance shows variation between different ethnic groups, including significant gender differences. South and South East Asian children appear less likely than the general population to have visited a hospital as outpatients but there are fewer differences in inpatient admissions. The biggest gender differences are in day patient attendance, where there is a striking under-attendance (or under-reporting) in the case of Indian and other South Asian girls. A more detailed investigation of ethnicity data for Leeds hospital admissions is required to investigate the local implications of these trends.

#### Ethnic monitoring

In order to further the goals of health needs assessment with minority ethnic children in Leeds it is necessary to establish who is collecting ethnic monitoring data for local health services and child health issues. Our research highlights a need to collect more local information about children's specific health needs and experiences in Leeds.

While the scope of our study did not permit a detailed or comprehensive analysis of existing statistical data it was important to identify the potential contribution of a range of data sources relating to service usage of minority ethnic children in the city. The following brief examples illustrate the patchy nature of ethnic monitoring but also highlight significant initiatives where more detailed analysis could be carried out for planning purposes in the future (for example, in relation to primary care, hospital admissions, out-patient clinics, and educational provision for children with special educational needs). Further information on ethnic monitoring practices is also included in later sections of this report.

Ethnicity data are not currently collected in any routine way from practice registers. However, the potential exists to incorporate such monitoring within existing systems. In particular, the Practice Information System (PRIMIS) is available to support and collate a wide range of information in primary care, and to provide training in this area. Codes exist for the monitoring of ethnicity, although the collection of such data by individual practices is very patchy. Where ethnicity is monitored, the data is likely to be comprehensive and potentially useful for planning purposes. In addition, PRIMIS staff would be keen to support further developments in this area. The increasing use of MIQUEST software will facilitate the retrieval of such data within individual practices and this could provide the basis for exploring some of the attendance and prescription anomalies identified earlier.

Until recently no ethnicity data was recorded for hospital in-patient admissions in Leeds. However, this data has been collected from April 2001. An initial investigation of data from the first three months suggests that there may be some potential for monitoring in this area. For example, it is possible to interrogate the data on ethnicity both by age and with reference to the International Classification of Disease codes (ICD10). In this way there is at least the potential to monitor hospital admissions for minority ethnic children in terms of significant diagnostic labels (e.g. respiratory conditions, surgery, and so).

Similarly, ethnicity data does exist for hospital outpatient clinics, although regrettably this does not currently include St James (where the might expect to find a some of
the highest concentrations of minority ethnic children). The outpatient data has potential for interrogation by medical speciality or by individual consultant, as well as the age of patient and so could prove useful in investigating the kind of ethnicity and gender anomalies outlined earlier with regard to the national survey data for day patient attendance. Ethnic monitoring in relation to accident and emergency data has also been patchy, although work is currently in progress to redesign data forms with a view to including ethnicity fields in a more consistent and routine way. Regrettably, we have so far been unable to obtain indicative data summaries on hospital outpatient or inpatient admissions to include in this report, despite our requests.

No reliable ethnicity data is currently available on the use of children's therapy services (e.g. physiotherapy, diatetics, speech and language) although this was previously collected but never used. Similarly, we were unable to locate reliable ethnicity information on the use of occupational therapy services, disability services or early years services.

Summary: The task of local health needs assessment for minority ethnic children in Leeds is considerably hampered by a lack of reliable ethnic monitoring data on the usage of relevant services. However, the development of new systems for monitoring in both primary care and hospital admissions offer the potential for further more detailed investigation. This should be considered as a next step in the needs assessment process.

# Experiencing services

The preceding examples illustrate the potential use of quantitative data in highlighting areas of concern to the local health needs assessment. However, it is important also to look beyond the figures and to think about minority ethnic children's use of health services from a more qualitative perspective (a considerable amount of this kind of information is provided in the subsequent sections of this report). There is an expanding body of published research examining the health care experiences of young people from minority ethnic communities, highlighting their differential experiences of service usage.

For example, disabled people from minority ethnic communities, including children, may experience a double discrimination in both health and health care, and an absence of culturally competent support systems is widely reported in empirical studies. In addition, minority ethnic families with disabled children are more likely to report unmet needs and less likely to receive disability benefits when compared with white families. Minority ethnic children make up approximately six per cent of disabled children living in private households but Asian disabled children are more likely to live at home, while African, Caribbean, and Arab children are more likely to be living in residential settings than the general population (including overnight respite care).

The following two case studies, in the area of haemoglobin disorders and learning difficulties, suggest more general concerns. There is evidence of mistrust within some minority communities of the motives of health service providers (Brent CHC 1981, Chamba et al 1998) and a number of studies address the importance of thinking beyond cultural differences to include a consideration of institutional power and racism (Ahmad and Atkin 1996, Priestley 1995).

### Case Study: Haemoglobin Disorders

The high incidence of haemoglobin disorders amongst minority ethnic children was highlighted in the previous chapter and local research into service experiences provides a useful case study here. Many of the concerns and worries of young people with haemoglobin disorders are similar to all young people. Having a chronic illness, although complicating the process of 'growing-up' does not fundamentally alter it. Nor is ethnicity always central in making sense of young people's experience.

Broadly speaking, young people with a haemoglobin disorder feel that health professionals do not understand fully the difficulties they face in their day-to-day lives. They are, for example, sometimes reluctant to talk about their illness and this can be misunderstood by health professionals, who feel they are not facing up to the consequences of the condition. Similarly, non-compliance with chelation therapy is common in thalassaemia and is an important factor in morbidity and premature death. Although health professionals often explain the problem in terms of young people not understanding the value of their treatment, the real reasons for non-compliance are more likely to be the consequence of emotional and cognitive barriers.

Concerns about the future are common. These included worries about life expectancy; future prognosis; the continued use of medication; physical maturity and development; marriage and having a family; achieving independence; and future employment prospects. Being like their peers is very important for young people with a chronic illness. Nonetheless, 'normality' is easily challenged by the consequences of both illnesses and all young people say there are times when the illness gets them down. Life becomes a struggle as the illness affects daily living and social relationships. This is when the young person requires greater support, although they feel health professionals do not always understand their vulnerability and at times, can contribute to it.

Young people adopt various coping strategies to limit the impact of the illness on their life. Health professionals have an important role in underwriting young people's existing strengths, and important resources include accessible information, the availability of good quality practical and social support from health professionals and appropriate service provision. Young people describe many positive relationships with health professionals, valuing medical competence, an ability to listen, an understanding of their situation and the ability to put them at their ease.

However, insensitive interventions (for example, in hospital procedures) can contribute to the young person's vulnerability. These occasional problems are extremely upsetting, often undermining confidence in hospital provision. More generally, one of the biggest difficulties faced by young people is engaging with practitioners who do not seem to listen to them. Consequently, young people feel they have no say in their illness or the support they receive.

Young people's experience of pain during sickle cell crisis illustrates many of these difficulties. With the onset of pain young people are at their most vulnerable. Pain can evoke a real fear and panic, reinforcing concerns and anxieties about the future. Young people feel that health professionals are especially poor at recognising their emotional responses to pain. Young people also complained of not being listened to and felt some hospital staff were insensitive to their pain. Research evidence suggests that institutional racism contributes to this problem, with some health professionals

still holding the view that African-Caribbean people have 'lower pain thresholds'. This is supported by another racial myth, suggesting that powerful pain killing drugs should not be given to African-Caribbean young people, as they are likely to become addicted to them.

Some young people lack confidence in expressing their needs and often require permission from the health professional before they do so. Other practical difficulties include not always being able to see the same practitioner. Young people, for example, would prefer to see the same doctor and nurse when they visit hospital. Those who tend to see the same doctor are more likely to ask questions about their illness and engage in general conversation with the practitioner. As the child grows older they become worried about being transferred to adult provision and evidence suggests the transfer is not especially well handled, with young people feeling unsupported and isolated.

Haemoglobin disorders easily become characterised as a 'health care' problem, ignoring the important role of social care agencies in supporting healthy lives for these young people. For example, young people had little contact with social workers and when this did occur it was often characterised by lack of knowledge. This lack of knowledge also prominent in contact with housing departments or social security agencies. Young people and their families were often denied appropriate housing or benefits because of the ignorance of the worker involved in their case.

Overcoming disruption to schooling was far from easy and schools did not seem to offer much proactive support (for example, with extra work). Young Black people became annoyed when they felt that teachers had 'written off' their chances of academic success. Teachers were also criticised for not believing the child when they said they were ill: a particular problem for Black children with sickle cell conditions. In addition, there is concern that NHS services are not well focused on providing services to young people and that complications in transitions to adult services can impact negatively on minority ethnic young people.

Generally, young people were satisfied with their contact with health and other practitioners, although this was often a consequence of their low expectations. They described many examples of unmet need, including non-recognition of their support needs; lack of information; and poor quality care. A joint agency strategy is essential in meeting these needs, yet there is little current joint-working (for example, between health and education). Many of these issues are generic problems facing all young people, although racism sometimes characterised the young person's experience.

Summary: NHS services not well-focussed on providing services to young people in transitions to adult services and young people from minority ethnic communities may be particularly disadvantaged in this respect.

#### Case study: learning difficulties

In a commissioned study for the Department of Health, The Centre for Research in Primary Care reviewed services for minority ethnic people with learning difficulties. The report examined the needs of people with learning difficulties, the needs of their carers, and the services available to meet those needs (drawing on the available literature as well as interviews with service providers, users groups, carers organisations and researchers). The main points highlighted by the report are as follows:

• Minority ethnic communities face substantial inequalities and discrimination in employment, education, health and social services, and people with learning difficulties experience simultaneous disadvantage in relation to race, impairment and, for women, gender. Negative stereotypes and attitudes held by service professionals contribute to the disadvantage they face. Within service provision, stereotypical opinions about South Asian families 'looking after their own' (Ahmad and Atkin 1996) can exacerbate invisibility and reinforce neglect from service planners.

• The principles that underpin service planning and provision need to take account of the particular needs and the values of people from different ethnic communities. Partnership with minority ethnic community groups is needed in order to influence service planning, monitoring and evaluation and to meet local needs. Groups may need support to take part in joint ventures. The concept of advocacy needs to be developed in some communities and advocacy or self-advocacy need secure resources in order to develop. An understanding of independence that emphasis individuality may run counter to the values of collectivism and close family relationships that exist in some communities. Barriers to independence in education and employment result in limited choices and low expectations. Restrictive attitudes towards disability within minority ethnic communities and in the wider context need to be addressed. Support groups can increase participation and control for minority ethnic people with learning difficulties and their carers but such groups are generally small-scale and isolated from mainstream services.

• The younger age profile of people within some, particularly South Asian, communities, has been highlighted as an important factor in the future planning of services for people with learning difficulties and their carers (Emerson 1998). Current projections show that the number of South Asian adults with learning difficulties will have more than doubled by 2007 (ibid) reflecting the current high incidence among children. Demand for primary healthcare services is already high within these communities (Nazroo 1997), yet there remains a considerable level of unmet need for health and social care services generally, which is higher than in the majority community (Chamba et al 1999).

• More bilingual staff and interpreters are needed to improve communication and access to services. Recruitment of minority ethnic staff is needed at all levels in service organisations, with adequate support and training to help them perform their roles. For example, this was raised as a particular concern for speech and language services. Service providers need accurate and ongoing information form and about minority ethnic communities to meet their needs adequately. The report identified that monitoring procedures are currently insufficiently able to identify unmet need, general patterns of use or comparative service performance. Integrated services are likely to be better resourced and given a higher priority than specialist services. Although the ideal is a quality mainstream service that is sensitive to the needs of all users, the cultural needs of some minority ethnic service users are currently more likely to be met in specialist provision, though this is generally under-resourced and insecure For users from different ethnic backgrounds, there is the additional issue of cultural competence in service provision. Training is certainly a prerequisite, but consultation with other community members is likely to be needed as well in order to explore the nature and implications of people's cultural heritage in doing so, it is important to take account of the views of people of, say, a similar age-group to the potential service user as well as community elders. As with any person with learning difficulties, consultation with other family members is likely to be a prerequisite but, again, more so when roles within family and community networks are different from those of the professional's own community

Summary: It is important to look at the qualitative experience of service use in order to appreciate many of the specific health needs of minority ethnic children. There has been an increasing amount of work in this area. The examples of recent work in the area of haemoglobin disorders and learning difficulties suggest some key areas of concern. These include the assumptions of service providers, the cultural competence of services, the significance of services outside the traditional realms of 'health' care, and the role of community based self-help groups.

# 5. Background to organisational concerns

This section of the report provides background information from the postal questionnaires, in order to highlight the involvement of statutory and voluntary sector organisations with minority ethnic children in Leeds. The aim of the questionnaire was to obtain the views of concerned professionals and to provide an indication of services provided by statutory and voluntary organisations in Leeds. The sample was identified via contact with statutory and voluntary organisations across Leeds and was drawn up to ensure representation by:

- different types of organisation working in Leeds;
- different professional groups including medical practitioners, other clinicians, social workers and youth workers;
- statutory and voluntary organisations, including smaller community and voluntary groups
- senior mangers within organisations, middle managers and front-line staff.

More detailed data from the sample is included in subsequent sections. It should also be remembered that many of the issues raised here are covered in more detail when we present material from our face-to-face interviews with service practitioners and managers.

A total of 104 questionnaires were distributed to organisations in Leeds and 64 organisations replied to the questionnaire. The response rate was 61%. In total, 75 (67%) questionnaires were sent to statutory organisations and 29 (48%) to voluntary organisations. More statutory than voluntary organisations responded to the questionnaire (50 and 14 respectively). All of these organisations were based in the city of Leeds. A copy of the questionnaire is included in Appendix B.

# Type of organisation

A range of organisations, statutory and voluntary organisations responded to the questionnaire, the majority of whom were statutory organisations. A number of individuals did not indicate the organisation in which they are employed but we were able to find out who these organisations were from cross-referencing the numbering of the questionnaire with our original distribution list. This applied more to those individuals working for statutory rather than voluntary organisations.

Type of Organisation	Number of respondents
Statutory	50
Voluntary	14
Total	64

Table 4: Questionnaire respondents by t	type of organisation
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### Geographical location

As shown earlier in the report, Leeds has a large and ethnically diverse population, with considerable variations between wards. The concentration of minority ethnic communities is particularly high in some areas and these populations have a younger age profile than the majority, with 55% of the Bangladeshi community; 44% percent of the Pakistani community and 30% of the Indian community were aged under 16 in the 1991 Census, compared to 20% of the rest of population of Leeds [DoH, 1997].

All areas of Leeds were well represented in the questionnaire sample. The majority of organisations provide a citywide service. This was important in terms of a representative sample. In total 40 respondents mentioned that their organisations provided a city-wide service and 20 indicated that their organisation provided services on a smaller scale. (Four did not answer the question).

In addition to city-wide groups, there was good representation from those organisations operating in areas of the city with larger minority ethnic populations (such as Harehills, Beeston, Woodhouse, Chapletown, Armley, and City). We should not, however, automatically associate large numbers of minority ethnic children with 'need' since young people from all backgrounds can be 'disadvantaged' or have greater needs than minority groups. The needs of minority ethnic minority young people, therefore, have to be carefully assessed on an individual basis.

There were other districts in Leeds that were not well represented, these include Horsforth, Middleton, Seacroft and Pudsey. There are minority ethnic children living in areas with small numbers. Their needs, however, are the same as those living in areas where there are large numbers. People of many different backgrounds use services provided by statutory and voluntary organisations in many districts of Leeds. The needs of minority ethnic young people, therefore, have to be considered as part of a city-wide issue rather than the concern of specific areas. This comes out of the general findings of the study and is linked to previous chapters.

## Involvement with minority ethnic children

On a very general level, the vast majority of respondents recognised their organisation's contact with minority ethnic children.

Organisations who work with minority ethnic children	Number
Yes	52
No	8
Did not indicate	4
Total	64

Of the eight respondents who answered 'no', the majority worked for organisations that would be expected to have regular contact with minority ethnic communities. These were Leeds NHS [2], Leeds Health Focus, Newton Surgery, Headingley Community Centre, Leeds Involvement Project, St. Mary's Hospital and Leeds Irish Health and Homes. In some cases, the response may be explained by the fact

respondents who completed the questionnaire did not work with children at all, and in some cases by differences of perception in defining minority ethnic status.

A number of organisations and groups provide services specifically for minority ethnic children and their families. Most, however, provide more general support for families. Most of the respondents indicating that they worked specifically with minority ethnic children were from statutory organisations (reflecting the overall balance of organisations in the sample).

Table 6: Number of organisations providing services specifically for minority ethnic
children

Provision of targeted services	Number
Yes	17
No	39
Did not indicate	8
Total	64

The responses suggest that organisations are currently working with a range of individuals, from diverse ethnic backgrounds. The most frequent users of services included Pakistani, Bangladeshi, Indian, Black-African, Black-Caribbean, Irish and white-UK children. In addition, some respondents identified Kashmiri, Arab and Middle-Eastern communities amongst their recent service users. This underlines the diversity of minority ethnic children in Leeds, and the many different groups/individuals who use statutory and voluntary organisations in the city. It would, therefore, seem that organisations require an increasingly responsive knowledge of different communities and families in order to provide the most appropriate help.

It is also important to note that many respondents indicated that Refugee children had used their services within the last three months. This reflects the recent influx of refugees/asylum seeker families from communities not traditionally represented. It also suggests that refugee families are perhaps more willing to access services provided by both statutory and voluntary organisations than has been suggested by anecdotal reports.

### Under-representation

When asked about under-representation, respondents mentioned specific groups of minority ethnic children and some explanations for their under-representation. A number of groups were identified. The most commonly mentioned included: Bangladeshi, Pakistani, Black-African, Chinese, Vietnamese, Travellers and Refugees and asylum seekers. A variety of explanations were suggested in the questionnaires.

For example, one respondent from a statutory organisation noted, "sometimes professionals may hesitate making referrals due to appropriate resources not being available". Another pointed to cultural barriers in working with Asian young women in youth group settings. Others made more general comments, recognising the difficulties for families where English is an additional language, and suggesting that non-English speakers did not receive the same level of support as the majority.

More generally, respondents were aware that their organisation was better at providing support for young people from some minority ethnic groups than others.

### Ethnic monitoring

Nearly half of the organisations used ethnic monitoring in their work, and all of these said they had some access to the information. The difference is small but statutory rather than voluntary organisations are more likely to use ethnic monitoring in their work and have access to this information. The results also suggest that health agencies are slightly more likely to use ethnic monitoring more than social care agencies.

The work of organisation that use ethnic monitoring is varied and included assisting with service development for ethnic minorities, working with children and their families offering therapeutic intervention, public health, and running educational projects in partnership with schools.

The work of those organisations that do not use ethnic monitoring included providing assessment and treatment for children with difficulties including cerebral palsy, developing health services for people from minority ethnic backgrounds and supporting families whose child is aged 0-5 years with multiple impairments.

Use of ethnic monitoring	Number
Yes	30
No	29
No response	5
Total	64

#### Table 7: Organisations using ethnic monitoring

### Identifying and responding to needs

Respondents identified a wide range of significant needs for minority ethnic children, with the majority of categories on the questionnaire ticked as either 'very important' or 'important'. These included four main areas:

- Service issues: including access to information, cultural competence and interpreting,
- Environmental issues: including housing, social exclusion, discrimination and lack of employment
- Health promotion issues: including dental health, dietary health, mental health, sexual health and smoking
- Specific health issues: including breastfeeding, diabetes, disability issues, emotional issues, emotional and behavioural issues, HIV/AIDS, Sickle Cell/Thalassaemia and skin diseases.

There was consensus among statutory and voluntary organisations in terms of the priority issues identified, suggesting that the three most important were: access to information, interpreting, and the cultural competence of services. Other issues considered as being 'very important' included dietary health, discrimination, and emotional and behavioural issues.

# Contribution to services

When asked about the main contribution of organisations in meeting the health needs of minority ethnic children, a number of themes were mentioned. These included: interpreting; needs assessment; encouraging social inclusion; helping mothers to find support; developing independence in caring for children; access to information, and general support.

It was also clear that, in order to help minority ethnic children, organisations perceived a need to support their families, particularly parents. As part of this, organisations seemed to associate meeting the needs of parents with meeting the needs of young people. In order to meet the needs of children and families from diverse backgrounds, it was also important for organisations to develop their knowledge of the contribution of other specialist or mainstream services and groups. Consequently:

- Children are not the only group requiring help and support; health is a family concern.
- Joint working partnerships between statutory and voluntary organisations are essential in providing responsive support to individuals and communities.

### Knowledge of other organisations

Respondents had a good knowledge of other service providers in the city and the majority were in recent contact with others working in the field. When asked about contacts with projects targeting minority ethnic communities, the most frequently mentioned services were: interpreting services, Haamla, ASHA, Black Mental Health, Circumcision, Leeds Health Focus, and Asylum/Refugee services groups. Of these, the demand for interpreting services was most marked.

There was a clear need for inter-agency referrals and communication. In particular, the data suggest that:

- There is a continuing need to meet language interpreting needs (and that the diversity of language needs poses a challenge for existing services).
- There is continuing concern over the issue of circumcision and the need to preserve funded services in this area.
- There is a need to encourage health and social care agencies that can respond specifically to the needs of minority ethnic children in the city.
- The specific needs of asylum seeker/refugee families appear to be a significant concern to organisations.
- 'Need' is increasingly defined as an individual concern, and ethnic diversity challenges the historical tendency to homogenise organisational responses to minority communities.

It is clear that initial contact services and statutory sector organisations are frequently called upon to guide individuals to other organisations better suited to meeting their needs. This suggests that knowledge of other organisations and groups in the city is essential in developing more responsive services. There is a general and continuing need for contact with services relating to interpreting and translation, and new demands for contact with services responding to the needs of asylum seekers and refugees.

This brief review of the questionnaire data, suggests that there are a wide range of statutory and voluntary sector organisations seeking to respond to the health needs of minority ethnic children in Leeds. It is also clear that working in partnership, or at least developing knowledge of other organisations, is essential in providing appropriate help and support to children, families and communities. In addition, this theme is underlined by the increasing ethnic diversity of the local population, and specifically by the case of recently arrived asylum seeker and refugee families from minority ethnic communities not traditionally served by existing groups.

SUMMARY: Initial data from the questionnaires suggests that the majority of existing organisations and providers are currently working with minority ethnic children but that many do not have a detailed knowledge or monitoring of this contact. However, there is evidence that some minority communities continue to be under-served, and increased monitoring would assist in confirming this. Organisations are generally able to identify their own needs for additional input and to develop contacts with other, more specialist, agencies. Building this kind of interagency knowledge and partnership will be increasingly important in responding to ethnic diversity. There may be a case for the greater coordination or collation of citywide information on existing organisational expertise to facilitate this.

# 6. The views of key informants

A central component of this health needs assessment has been gathering the views and experiences of key informants. These have been professionals from a range of services providing agencies across Leeds including representatives of statutory organisations, voluntary organisations and community groups; parents of children from ethnic minority groups and young people themselves. Here we summarise the main themes arising from our consultations.

The views of professionals were obtained in three ways:

- An initial consultation event attended by 46 staff from a range of agencies in June 2001. This event was used to introduce the Health Needs Assessment and to obtain the views of staff through facilitated group discussions which were recorded, transcribed and analysed
- The postal questionnaire sent to 104 agencies (64 returned)
- Face to face and telephone interviews conducted with individuals or teams of staff who were regarded as having a particular remit to work with minority ethnic children

The following section summarises the main themes arising from discussions with professionals. We have used quotations to illustrate the points made but have left these unattributed to respect respondents' anonymity.

### Communication

Language and communication issues were universally identified as being of critical importance. Communication problems were identified at all stages of service delivery from accessing information about services (and health promotion) in the first place, to the first point of enquiry (e.g. reception) and at each subsequent stage of service provision. However, there was some confidence that recent service developments (such as the advocacy and interpretation service) were steps in the right direction.

Many professionals pointed out the challenges to communicating information about health and healthcare services. For example, over 30 languages are spoken in Leeds and (not including variations of dialect). The production of leaflets in several of these languages, whilst important, cannot meet the needs of all potential services users and does not take account of the different levels of literacy. As one voluntary sector worker pointed out:

Talking about leaflets, because we used to have like a Home Start leaflet in all of the major languages and that was stopped because there are just so many languages and in fact people who don't often read English don't read the other languages, then who do they go to have them translated?

There were several examples given of communication problems between patients and healthcare practitioners. These can be compounded by the need to communicate medical terms, difficult even with an interpreter. Some respondents also pointed out that there can be cultural differences in the way people communicate. The use of metaphor, for example, can lead to misunderstanding.

### The use of interpreters

There was a range of views expressed by professionals about the use of interpreters. Although most staff were committed to the principle of using them, there were several difficulties highlighted. Scarce resources are a key issue here and affect the availability of appropriate interpreting. In addition, there was the problem of knowing when an interpreter would be needed:

You don't know you need an interpreter until you're in the situation you are coming to or what's going to walk through our door.

Second, some respondents pointed out that language skills alone were not always enough and that within a specialist healthcare field it is important to have interpreters who have some grasp of the subject under discussion:

...interpreters must also have knowledge of the subject area they are working in. It is no good having someone who is fluent in Hindi and English acting as interpreter in the mental health field if he/she has no knowledge of this subject area.

It was also acknowledged that some medical terms have no direct equivalent in other languages:

And it's medical issues that translating in Bengali is not easy

Most respondents were uncertain what qualifications interpreters should have, and would not readily know the difference between a qualified and unqualified one. Although accredited training for interpreters does exist, many staff appeared unaware of this.

The value of good interpretation was highlighted by several people:

It is quite obvious that nobody is able to get to know how the patient is really feeling because they (the patient) use metaphors and codes we (as indigenous workers) are alien to. These may often be signals which family members may be too distressed to interpret, and ordinary (unqualified) interpreters too naïve to understand. We now know what the issues and communication problems are, and precisely what we need to do. It is high time we did it!

Several people, however, felt that interpreting is under-resourced, leaving professionals to make the best of a situation:

Good quality interpreting is hard to find when you need it, and it is an area which is hugely under-resourced, therefore inevitably, you end up circumventing the process and using a family member

The issue of using family members, particularly children, as interpreters generated considerable debate. Several people felt that the use of children as interpreters for their parents or other family members was unacceptable and examples were given of the confusion and even distress it can cause, particularly where the topic is sensitive. A Health Visitor gave an example of a GP who asked a 9 year old to tell his mum that her bleeding was excessive, and that she would need to return in a weeks time to have the situation monitored. The child ended up worrying that his mother was about to die.

Less alarming examples were given of health staff using a child as an interpreter but being left in considerable doubt exactly what was being communicated:

Often [with] the use of young children to translate to a parent...you'll spend ages telling the child...you've spent ages and she's said it in 3 words.

Despite these concerns, many professionals said they used children as interpreters both in respect of their own health and that of parents. Some respondents were quite sanguine about this:

We don't find much of a language barrier from the children because the majority of them have been brought up and educated so their English is quite good, it is actually explaining back to parents that is usually done through the child, we don't often get interpreters for things like that, or the young person signs, or sometimes actually we just deal with the young person, it is up to them what they actually feed back to their parents.

Others felt it was not ideal but sometimes occurred because of the lack of an alternative in the particular situation.

The use of staff as interpreters was also raised. Some people felt that staff who speak other languages in addition to English were a huge asset in both reaching out to different communities and saving resources.

There are lots of staff within staffing groups and organisations who can speak different languages so if they're provided with the support to learn to interpret then I mean, they themselves can then be used by other staff.

Others pointed out that such staff are not necessarily properly trained as interpreters and can be placed in a difficult position. Such staff may find themselves under an additional pressure over and above their main job.

A lady who is actually a health visitor and she speaks six different languages but she doesn't, she's not recognised for the fact that she does that, I mean she basically feels used because she's just taken along and being paid as a health visitor but she's not actually seen as being an interpreter because in that situation she is interpreting, she's not doing her health visiting, so I mean I think staff need to support other staff.

### Access to services

Communication difficulties can be compounded by practical barriers to accessing health care. This was primarily a concern related to parental access (rather than children themselves):

So if you haven't understood the letter that came to tell you that your appointment, plus you haven't got somebody to look after the kids, plus you haven't got anybody to take you to the hospital

There was a general view that many services have improved their quality of care towards minority ethnic families and that there is now a wider recognition that health services need to meet the needs of all diverse users. There was however, still a widely held view that minority ethnic families continue to receive a 'poorer' service than their white counterparts.

There was a view that ethnic minority parents are less likely to know about services, even when those services are specifically targeted. Other access problems include opening times and practicalities such as location and availability of transport.

From our point of view one of the faults with our service is it's so inflexible, I work from 9.00 until 5.00, I don't work Saturdays and Sundays I don't work in the evening and I think we need to actually re-think the hours that we work as well to make it.

If patients cannot access a service when they need it the most then I'm afraid that things will just get worse. I'm not saying I have the answers but travelling from one end of Leeds to another can be quite a tricky thing to do, especially if you're on low income and you have children to look after.

Respondents felt that those who needed the service the most frequently failed to benefit from them. There may be a lack of knowledge about existing services and routes of access. For some services, such as immunisation, rates of access are very good but less so for more complex or specialist services. It is not uncommon for children with complex difficulties to slip through the net until they are identified at school or nursery. Refugee children may also be of particular concern in this respect (for example, some families from the Balkans have been very reluctant to avail themselves of services for children with impairments or complex health needs).

In addition to practical barriers to access, other barriers may be attitudinal. Although the attitudes and behaviours of staff have changed positively in the last few years, some respondents felt that there were still a need for a change of attitude and culture in services. As one respondent put it:

We have not got the message across with the conviction and clarity required that all users irrespective of background, belief, behaviour, or colour are entitled to, and have a right to our service as any other. We need to accept and show understanding that behaviours, customs and habits of users will differ. We must not judge the status of a person by an out-dated euro-centric value base. At the end of the day we are all human beings.

## Staff composition and cultural competence

A number of respondents expressed the view that health services need to review its policy on recruitment and selection to attract more staff from ethnic minority groups and to better reflect the diversity of the Leeds population. Greater staff diversity, it was argued, would be a major step forward in reducing access barriers. For example:

I was recently working with a young girl who has a physical disability from an Asian background and she specifically wanted resources in the Asian [community]...she wanted to make the first step in more familiar surroundings.

However, even this notion had some drawbacks with concerns raised about confidentiality:

I still had a problem of the non-Asian professions in the medical field but again I felt like I wasn't feeling very confident with my Asian doctors...because I knew them in the community, I don't want to discuss my personal problems.

Several respondents felt that the staffing ratio in an organisation should better reflect the community they serve, for example, by actively recruiting people from ethnic minority groups. It was felt that this may be a way of encouraging ethnic minority groups to access health services.

It's about recruiting staff from a diverse range of backgrounds, I mean that would hopefully address issues around language and interpreting and these sorts of things and also give different communities the confidence to come forward and actually use services facing people they can actually identify with and I know that there are models, not just in health but in other areas like education where staff from different backgrounds have been actively and positively recruited and that has paid dividends in terms of improving access and that is something that agencies need to consider.

...as soon as we began to have a staff group that much more reflected the population that we were serving...the whole thing fell into kilter and actually reflected the health need of the population.

It was also pointed out, however, that erroneous assumptions should not be made about staff's knowledge levels about different ethnic minority groups.

You can't expect that a member of the mixed workforce who happens to come from an ethnic minority background is going to actually have the knowledge because after all, the person presenting the issues might come from a completely different ethnic minority.

The cultural competence of staff was raised by several people and it was pointed out that this should be a requirement across the board, not an optional extra for those with the interest:

It is interesting [that in] nursing and health visiting learning [has become] either rightly or wrongly, very much become self directed now so people control their own learning so if you've not particularly got an interest in ethnic minority you could go through your training and not really address that and then you end up getting a job in a number, with a high number [of patients from ethnic minority communities] Although professionals recognised that ethnic minorities should not be presumed to be a homogenous group, many believed that it would be useful to have more training on cultural awareness so that staff can be more sensitive to service users needs.

If there was more training and awareness around the issues it would certainly help, there's very little around.

## Information pooling and co-ordination

Many staff felt uninformed about what services are available to users across Leeds. Several highlighted the need for better information pooling and exchange between agencies, perhaps through a directory of services.

There's all sorts of different groups that are doing all sorts to promote the health needs of ethnic minority groups, but you do sort of stumble across them by accident, there's no sort of central resource, you know directory with all these groups and organisations in.

At Voluntary Action Leeds they host 3 forums, learning disability, physical disability and mental health and I think that's interesting...they are there to try and co-ordinate the work of small voluntary sector agencies working with these groups, but there isn't a similar forum functioning around ethnic minority needs.

The need for better information links to the issue of ethnic monitoring. Several people highlighted the lack of reliable ethnic monitoring systems in Leeds so that:

We don't even know who it is that isn't using the health service.

We would like service information which we have almost none of because monitoring...inpatient admissions and the hospitals themselves admit its very badly done. We know very little about children's conditions and their experiences of health care.

Ethnic monitoring is something that really does need to take place and I think it is an issue of training as well, making sure that people, that staff as all levels know why ethnic monitoring is necessary and how it links into the wider policies and structures of the organisation, and that it's not a stand alone thing and it's not designed to discriminate in a positive way because that's illegal, so it's about demystifying and dispelling myths from both staff and patients through users as well so ethnic monitoring is something that I feel would eventually lead to improved access to services because then, that would enable patterns [and ] trends would be identified and gaps would be obvious

## Poverty and social exclusion

Many respondents when asked about the health needs of ethnic minority children highlighted factors of poverty and social exclusion:

If you're a person who's actually living in poverty and you actually don't feel very well most of the time because you're not eating properly, you're worn out looking after your kids etc etc you don't notice that you're ill until you...You've got much more difficulty getting appointments because you've got nobody to look after your kids and you can't pay anyone to help them. Even though you live near the hospital you've got to walk, you know, all these things actually compound against actually getting in. so you take a much longer time to get in.

Issues that were highlighted included poor housing and overcrowding. In addition to the ill-effects on physical health, many people pointed to the impact on children's emotional well-being.

Racism on council estates coupled with bullying and harassment were cited as persistent concerns with the potential to undermine the confidence of the whole family and in particular, children. It was observed that parents often feel ill equipped to challenge racism for fear of making a bad situation worse.

Some respondents highlighted the circumstances of mothers, pointing out that the health, including psychological health of mothers has an effect on children. An example given was the impact of increased male unemployment which has altered the patterns of socialising during the day. Many women, who would find company in each other's houses and use this as a forum for support and relaxation, now prefer not to visit friends/relatives where the husband or other males are present. The incidence of depression due to isolation and stress was reported to be on the increase, compounded by the stress of poverty and poor housing conditions. In general the respondents felt that women who were living in the margins of poverty suffered greater mental stress than their counterparts in the more affluent areas of the City. Some respondents pointed to the lack of facilities for "women's only" recreation in leisure centres etc.

Most professionals commented on the lack of play facilities for children and young people with fears that this may be contributing to boredom and frustration and a growth in anti-social behaviour.

# Specific health concerns

Diet in the Minority Ethnic Family was cited as a major contributing factor in the high incidence of diabetes, and coronary heart disease. Although it is difficult to generalise across different minority ethnic communities, there are problems with obesity amongst young people from Asian backgrounds, and the genetic predisposition to higher rates of diabetes and heart disease within these groups adds significance to this concern. There is an absence of effective strategies for addressing the health issues of overweight children in general and the situation of South Asian children raises a particular public health problem.

Eczema and related skin complaints were given as examples of problems among Chinese and Vietnamese children (and to a lesser extent within other minority groups). Respiratory complaints, such as asthma, appear to be broadly similar across different ethnic groups.

In terms of mental health, several respondents pointed to an apparent rise in the number of children with emotional and behavioural difficulties. Although this has not

been reflected in larger numbers of Asian children presenting to paediatric services with such issues, this may be due to under reporting, a failure to recognise behavioural difficulties as a health issue, or unwillingness by families to seek medical advice on child mental health. By contrast, the number of African-Caribbean children presenting with such difficulties remains relatively high. Apparently high rates of attention deficit diagnoses raised particular concerns in this respect. There was a suggestion that higher rates of absenteeism amongst fathers may be contributing to children's emotional difficulties within this group. Children from South Asian backgrounds appear to be considerably under represented in terms of contact with paediatric services for ADHD related problems.

## Disability

Specific attention should be paid to the situation of disabled children and young people from minority ethnic communities, where prevalence rates are often higher. For example, a current national survey of progressive neurological conditions shows that there are much higher rates of genetic impairment amongst South Asian children (as illustrated by evidence from paediatric services in Bradford). This trend continues to be attributed within the medical profession to historically restricted gene pools within the country of origin, and to consanguinous marriage. Although the number of children affected remains relatively small, in numerical terms, the intensity of service intervention and health care required makes this a significant area of concern and impacts disproportionately on service budgets.

Even where language is not a major barrier in consultation or diagnosis, due to the availability of interpreting and translation services, medical professionals from the majority community do encounter cultural tensions in working with some minority ethnic families with disabled children. There is a recognition of failure to understand fully the underlying cultural context. For example, there may be an apparent conflict between the traditional health beliefs of older generations and a simultaneously high expectation that Western medicine will provide a 'cure' for all conditions. There is also some concern that models of advocacy, based on children's rights and self-determination, generate cultural and inter-generational tensions for some disabled children within families where more restrictive traditional beliefs dominate. However, it is important not to generalise such experiences to whole communities.

From a medical perspective, children's health needs may be perceived as similar across all ethnic groups and there may be a consequent reluctance to advocate culturally or ethnically specific service responses for particular communities. However, issues of access to services are recognised and often interpreted in terms of cultural barriers. Some families, and some mothers in particular, may be considerably disempowered in relation to health services, and using link workers or key workers from hard-to-reach communities (such as the Bangladeshi community) may be one approach to bridging such gaps. Establishing culturally responsive gateways to mainstream services may find more favour with professionals than the establishment of separate culturally targeted responses. The key stages of initial diagnosis and significant childhood transitions are of particular concern.

Cultural differences in the care of disabled children were highlighted by some interviewees. Parents in certain settings have shown a tendency to treat 'mature disabled children' as 'infants', and continue to subject the child to complete control. This form of established practise in some minority ethnic homes, which reduce a

mature 'adult' into an immature child causes professional and ethical dilemma for professionals who recognise the damaging implications of such child rearing practices. One respondent pointed out how the 'dependency factor' "caused problems regarding rehabilitation and respite care and could suffocate the growth potential of the child."

It was also noted that a greater proportion of the carers were mothers, with many fathers playing little or no role in the care of the disabled child. Respondents had observed that mothers with disabled children can find strong support with their disabled child in the early days, however, this does have a tendency to diminish, and leave the parent feeling quite isolated.

Respondents felt that much more scope exists for educating parents in the minority ethnic community on the management and support of children with disabilities. It was postulated that a lot more could be done to raise awareness in schools and at GP surgeries. Parenting programs generally available for parents of disabled children were described as Eurocentric and therefore, inappropriate. This did little to inspire the engagement of minority ethnic parents, who akin to others had a lot to learn.

One respondent who visited a mother of a disabled child felt that support from local family members can be welcome, but occasionally oppressive and critical. "It is unlikely" claimed one respondent that an Asian mother with a disabled child can turn to any of her in-laws and shout "help!" The need for projects or schemes that offered support and empathy to Carers of disabled children was a feature of many of the conversations.

Paradoxically, many parents from the minority ethnic community act in ways that suggest that white professionals always know what is best for their disabled child. They seldom challenge the action that these individuals wish to take.

It was argued that the existing key worker pilot scheme for children with complex impairments should be extended to include a specific focus on advocacy work with minority ethnic families, and involving key workers from those communities.

SUMMARY: Staff working across a wide range of agencies identified communication and access to services as key issues of concern. Cultural competence was also identified and there was a strong view the ethnic composition of staff in health services should more closely reflect that of the communities they serve. The importance of sharing information across agencies was highlighted. Social exclusion, particularly poor housing, poor environments and poverty in general were identified as the prime determinants of ill-health.

# 7. Views of Parents

The primary objective of the research was to determine the health needs of children from minority ethnic communities. Parents are important health advocates for their children and the primary care givers for their day-to-day health needs. They are involved in making decisions with and for children that impact on their health, and they often exercise control over children's health related choices (particularly in the case of younger children). Consequently, it was important for us to consult with parents and to listen to their views and experiences, alongside those of children themselves and health care professionals. The following summary and examples draw on group discussions and individual interviews with parents of children from a number of minority ethnic communities in Leeds. The discussion deals first with health beliefs and practices and then with the use of health services.

The sample included 28 parents, who were interviewed by an Asian researcher using a semi-structured interview schedule. All of the parents were full-time residents in Leeds and from a range of minority ethnic backgrounds including Chinese, Bangladeshi, African-Caribbean, Indian and Pakistani. The majority of the parents interviewed were mothers, although two fathers and one grandmother were included in the sample. The ages of their children ranged from 18 months to 19 years. Most of the interviews were conducted on an individual basis, either in the parent's home or place of work. Two interviews were conducted in pairs and one larger group discussion was conducted with an existing community group of mothers who met together on a regular basis. Additional informal discussions were added with two key informants in working with minority ethnic parents in the community.

The interviews focussed on health behaviours and knowledge, service needs, access to services, and specific health issues. For example, we asked parents what they did to ensure their children stayed healthy, what made them ill, and how they had learned about child health; we asked them what they did when children became ill, which services they had used, and what their experiences had been; we asked how they knew about available services and whether there were any difficulties in accessing them.

## Health beliefs and practices

In considering health beliefs and practices, we asked parents what they perceived to be the causes of good or bad health for their children, and how they responded as parents in seeking to help to keep their children healthy. Overall, parents tended to talk about child health in terms of lifestyle and environmental factors, relevant to both physical and mental health. They were however less likely to talk about health and illness in terms of biomedical aetiology. Diet, exercise, housing and racism were highlighted as commonly perceived causes of good or ill health.

Diet was the most commonly mentioned factor, and most of the parents consulted felt that the maintenance of their children's good health was largely determined by the availability of a healthy diet. They tried to control or guide their children's eating patterns, by making available what they perceived to be nutritious food (such as fruit and vegetables) and by steering them away from over-consumption of foods they considered to be damaging to health. In this sense, parents saw themselves in an educating role, in teaching children about eating for a healthy diet. As one mother put it:

My children love chocolate and sweets but I do try and educate them and tell them how damaging they can be for their teeth (Pakistani mother)

Clearly, such views would not be restricted to minority ethnic parents alone. However, culture and ethnicity did play a significant role in shaping the kind of dietary education and advice that parents sought to give their children. Where traditional diet and food preparation methods played a significant part in cultural family life, parents (mothers) often believed that their own traditional ethnic diet (South Asian, Chinese, Caribbean, etc.) offered a healthier alternative to Western foods. Several parents considered traditional diets and staple foods to provide children with the healthiest diet (e.g. because they were perceived to be more balanced, fresh, or avoiding harmful foods, etc.). For example:

Chinese diet is the most balanced of all diets. Freshly-made food is really critical in Chinese diets...We don't usually have frozen foods or ready made meals...Even if we haven't got time we try very hard to make things freshly. (Chinese mother)

A lot of Caribbean food, to keep them strong...Not just healthy body, healthy mind. I think diet comes into both of them. (Caribbean mother)

Similar comments were made by some Bangladeshi and Pakistani mothers. There was then some concern for the dietary health of older school-aged children who were seen to choose less healthy alternatives as they gained more control over their daily choice of food (e.g. in purchasing school meals, snacks or sweets). In this context, many parents were concerned about their children's preferences for Western 'junk food'. Here there was some recognition that food and eating patterns were part of the particular clash of cultures experienced by many second and third generation Asian young people born and brought up in the UK.

Conversely, there was also recognition, amongst a small minority of parents, that long held family beliefs about the virtues of traditional rural South Asian diets might be misplaced, particularly as those diets have been transposed into British contexts, and under the influence of pervasive urban poverty. Thus, for example, there were concerns that some children from poorer Bangladeshi and Pakistani families in innercity areas were exposed to daily diets that were both unvaried and unhealthy (for example, containing high fat and low nutritional values). Here, there was a perception that greater exposure to Western food alternatives (such as school meals) might provide healthier alternatives. Parental levels of education were seen to be important in respect of diet, and some parents expressed concerns about the low level of health education amongst other parents from their own communities (although not about themselves).

There was also a general consensus among the parents that regular physical exercise was important for children's good health. Parents often encouraged their children to participate in school sporting activities or dance, to play and run in the garden, to take family walks to the park, to walk or cycle to school. However, many were also conscious that their children often took less exercise than they considered would be good for them, particularly in the case of older children. Most accepted this philosophically, although some were more proactive (one mother had purchased an

exercise bike specifically to ensure that her children had sufficient exercise on a regular basis). The need to maintain regular exercise was sometimes in conflict with family perceptions of the appropriateness or accessibility of such opportunities for themselves and their children. Some parents, notably single Asian mothers of disabled children were concerned that it was difficult to get out much at all with their children (due to cost, disabling barriers and cultural pressures associated with the role of women).

Although it would be impossible to generalise from such a small sample, there was some suggestion that African-Caribbean and Chinese mothers involved in the research placed a higher emphasis on the need for children's physical exercise and sport than those from Bangladeshi or Pakistani communities. Some parents were concerned that children, especially boys, did not have enough opportunity for energetic sport and physical exercise at school (for example, where the disciplining of perceived challenging behaviours amongst Black boys in school was punished by enforced inactivity at play times). We did not encounter any specific parental comments about the cultural appropriateness of exercise activities for children at school.

Additional factors associated with healthy behaviours included concerns about tobacco and alcohol usage, especially by parents of Asian young people. Ensuring that children got enough sleep, and establishing regular sleeping patterns at an early age, was seen as important, along with the need to brush teeth and maintain adequate levels of personal hygiene.

I try to make my children wash their hands before they eat, after going to the toilet etc, and keep reminding them why it is important. Teenagers tend not to think much about health and rarely seek medical help unless they are quite ill. (Bengali mother)

Although parents tended to focus first on the importance of keeping children's bodies healthy through diet, exercise and rest, they also identified mental and emotional health as a key concern in overall child health. The parents we consulted believed that positive mental health in children could be achieved primarily through caring love and emotional support within the family. There was concern that family break-up and paternal absenteeism could impact very negatively on child mental health (particularly in the absence of positive male role models for boys within the family). A few parents considered the stress caused by differential treatment and race discrimination in the classroom to be a negative influence on their children's health. Experiences of personal and institutional racism were also seen by some parents to contribute to long-lasting emotional upset for their children, particularly older children. The support of a close and loving family network was considered to be critical in those cases where children had been victims of racial discrimination or abuse.

There's a lot of discrimination for Black people...but I personally believe that Black males have it harder than Black females...Now my son's almost 16 and he's quite tall and when I walk with him in town the looks you will get...are just unbelievable...and he'll just say it always happens. (Caribbean mother)

Things like that affects my eldest son who's now left home. He gets very depressed, very stressed out, very unhappy... The services available to him, as a young man, are not very good at all... There are services there but they are geared to the mainstream...If it's a mental health problem they go down the mainstream road, they don't think it's about stress or depression. (Caribbean mother)

While parents believed that they tried their utmost to keep their children in the best of health, sometimes the causes of illness were perceived to be beyond their control. In addition to viruses and infections (generally thought to be acquired in the school classroom), parents pointed to a range of environmental factors affecting child health over which they had little if any control. For example, a number of parents attributed childhood illnesses to the inhospitable British climate, such as damp and cold (making comparisons with the perceived healthier climates of the Caribbean or the Indian sub-continent). For example:

They've both got hay fever, and it's strange when they go away to (the Caribbean) ...and he's needed no medication and he's come back and he's had to take it. (Caribbean mother)

However, the most obvious environmental factors mentioned in parental accounts were related directly to urban poverty. For example, parents pointed to pollution and damp housing in causing respiratory conditions, to inadequate diet, clothing, and the quality of neighbourhood environments (such as vandalism and rubbish in the streets) in influencing both physical and mental child health. It was noted that minority ethnic children in Leeds often living in old and inadequately heated housing:

Many of the houses in those areas are over a hundred years old and this has a serious effect. (Indian father)

In addition, there was recognition that family income is a direct factor in keeping children healthy – this was a particular issue for poor single mothers of disabled children, due to the extra costs of living with impairment, and compounded by lack of knowledge about the benefits system.

In addition to the general discussion of health beliefs, we also asked parents about their immediate responses to episodes of children's ill health. On the whole, in the case of minor illness or injury, parents were ready and willing to treat and care for their children at home in the first instance. There was some evidence of ethnic and cultural dimensions to health care and treatment at home, with a number of parents (mothers) emphasising the efficacy of treatments they had learned from their own parents or grandparents. These included both traditional remedies (such as the use of culinary herbs and spices) and informal treatment regimes (such as traditionally influenced beliefs about appropriate bed rest).

In view of such responses, we also asked parents to identify the sources of their own knowledge about child health (and in particular the sources of knowledge that mothers felt they had drawn upon in learning to care for children). There was little confidence in the utility of health promotion leaflets as a means of learning about child health, due in part to an apparently widespread difficulty in reading English amongst South Asian mothers. There was greater confidence in the advice and support provided to new mothers by health visitors and midwives, although there

were again some doubts about the degree to which such information was really absorbed:

There are scattered leaflets now and then about particular issues...but these are not enough...especially for the (Bangladeshi) mother who is visited by the health visitor...She is not taking five per cent of what she is saying. (Pakistani father)

While, parents identified the potential or actual contribution of health visitors, health promotion leaflets and books from the library, the overwhelming feeling was that effective lay knowledge about child health and health care was transmitted directly between successive generations within the family (and almost exclusively between women). There was thus a sense in which child health care was seen to 'come naturally' to mothers:

Every woman knows about her children's health because she's a mother...it comes naturally. (Bangladeshi mother)

My mum, learning the way she looked after me and my sisters. You always remember that...Not really the doctors...because they just give you books, packs...I did a lot of reading because I was quite young...I was quite interested in what was going to happen...A lot of it was common sense. (Caribbean mother)

There are a lot of theories on what is good and what isn't but at the end of the day what suits you most is the best. (Bengali mother)

Overall, minority ethnic parents felt comfortable and confident that mothers possessed the appropriate knowledge and skills to deal with minor instances of ill health within the home and this was regarded as the most appropriate response to such episodes (fathers were seen as largely irrelevant or uninterested in this context). Although there was resilience, resourcefulness and self-sufficiency amongst mothers in caring for children's health, it is worth noting that we found no evidence of any real reluctance to use existing health services when children became more ill, or of any generalised mistrust of those services. However, parents did have concerns about some aspects of services and about some of their personal experiences. The following section examines minority ethnic parents' views on health services in more detail.

## Health services and practitioners

We asked parents about the circumstances in which they used child health services, about their recent use of such services and their reasons for doing so. We asked about their encounters with health practitioners and about the appropriateness of the treatments their children had received.

Where parents were unable to diagnose or treat their child's illness at home, they were most likely to visit their family doctor in the first instance. Regular check-ups with the doctor or dentist were seen as a responsible way to keep children healthy and almost all of the parents we met claimed that their children had routine dental check-ups. Parental choice of GP or dentist was based largely on geographical convenience (close to home) and, to a lesser extent, on preferences for minority

ethnic practitioners. However there was a marked tendency for parents to note that many members and generations of their extended family visited the same practice, especially where the doctor was perceived as having a good knowledge of the ethnic community concerned.

I've been with that particular practice since I was a baby, because of that, a lot of our family when they came over from (the Caribbean) most of my family are with that GP. I've got older and I've just taken my children to that doctor. (Caribbean mother)

Only a minority of parents interviewed said that their GP was from a similar minority ethnic community. Those that did identify ethnic similarity believed this to be a positive factor in reducing cultural barriers between family and practitioner, such as conflicting religious practices and language.

I think having a doctor from an ethnic minority, who happens to be Asian, he understands...our skins are similar...Some (skincare) products, he'll say to me he thinks are more similar for white people...I like that because he can understand... (Caribbean mother)

I'm lucky I've got a good GP, one in particular...They're both ethnic, both Asian...you know, because we are of similar backgrounds...He always takes time out and explains it. You always come out laughing no matter how ill you might have felt going in...But I've had doctors in the past that haven't done that. (Indian mother)

In one of our discussions, there was concern that more minority ethnic doctors were required in some parts of the city to adequately respond to the needs of local communities (particularly Bangladeshi doctors). However, it was suggested that there would be problems of recruitment and that young British Asian doctors might be choosing not to go into general practice (favouring hospital specialisms instead). At the same time overseas recruitment for NHS staff was seen to have shifted to newer migrant communities. As one Bangladeshi father put it:

In the sixties we were invited but now we are outdated. We are importing doctors from Eastern Europe...There are hundreds and hundreds of doctors in India and Bangladesh...They can import doctors...We are only asking for five or ten doctors (in this area of Leeds). (Indian father)

Where parents spoke a language other than English, having a GP who spoke the same language was a major advantage in gaining parental confidence for the service provided to their child or family (in their discussions with us, it was often difficult for parents to distinguish between consultations on their own account and those involving their children). There was a lot of discussion about language, translation and interpretation in relation to minority ethnic patients accessing mainstream health services. Language barriers were a particular issue for the Chinese and Bangladeshi mothers that we met, and few (none of the Bangladeshi mothers) were aware of the availability of interpreters.

Because of the language barrier some parents have to go again and again and again. (Bangladeshi mother)

Although the majority of parents we talked to spoke some English, almost all mentioned friends or family who did not. In cases where parents and doctors had no common language, parents were generally advised to bring a friend or relative to interpret. In several cases this involved the child as interpreter, including some cases where the child's health or illness was under discussion. Although accepted by most parents, family interpreting was seen as less than ideal (and might be considered to raise tensions of privacy and confidentiality).

Issues of misinterpretation of need or perceived misdiagnosis were also mentioned by some parents in terms of culture, especially in instances where the doctor and patient were from different ethnic backgrounds - for example, in the case of a young Chinese boy who was misdiagnosed with jaundice because the doctor was unfamiliar the range of natural skin tones.

The way Chinese people express their illness is different from the way it's accepted by Western doctors...Sometimes this can cause confusion, misinterpretation or misdiagnosis of the illness...If doctors/hospitals are aware of this it would help them to conduct a correct diagnosis (Chinese mother)

Another parent, whose child had a violent reactive allergy, related an experience with a GP, in which she claimed:

He said, "Once you're back into your own country, the water change, your child will be fine". (Chinese mother)

Misinterpretation worked both ways and there were also some examples where parents had misunderstood a diagnosis or treatment instructions for their child (for example, because of language barriers, the use of medical jargon, or cultural context).

Talking to parents about their encounters with health services and practitioners, it was evident that parents favoured GP visits over hospital visits as far as their children were concerned. Explanations for this preference included shorter waiting times and less busy environments. As one mother put it:

Hospital environment is not very comfortable, are not able to discuss things extensively because quite rapid procedure – go in, get treated, come out, left waiting for a long time...Not culturally appropriate because clinic is unlikely to have nurse from different minorities (Pakistani motehr)

When you go in there you feel there is no one on your side... My sister, who's a nurse, said that the nurses behave very differently towards patients. They behave according to the patient's culture (Caribbean mother)

Most of the parents talked of at least one occasion where they had taken their children to hospital. However, there was little evidence that parents considered this option as a routine response, except in the case of traumatic injury, when referred for specialist outpatient appointments, or occasionally when local GP surgeries were closed:

Sometimes the doctor's not open every day and I've had to go to casualty...They're ill that morning so I've rung up and I can't get an appointment...Sometimes with the little one especially I'll say I'm bringing him anyway because he's ill...But as they get older they're not as compassionate, because they're adults, and I'll take him to the hospital. (Pakistani mother)

In addition to family doctors, dentists and hospitals, several mothers mentioned their encounters with health visitors, especially after the birth of their first child. These accounts were, on the whole, very positive and were not characterised by the same sorts of cultural or language concerns often expressed in relation to doctors. Since there was no evidence that health visitors were any more likely than doctors to come from similar ethnic backgrounds to the parents, it seems that the character of the service provided (or perhaps the fact that children were not necessarily ill at the time) reduced the perceived tensions and cultural barriers.

Few of the parents talked about using specialist child health services, although those who did often had real concerns that these operated in a culturally insensitive and predominantly white environment. Where inner city general practices, dealing with large numbers of minority ethnic children, were likely to have some experience and sensitivity to the community concerned, specialist services were seen as less sensitive and less experienced in this respect. In one such case, a mother (Caribbean) talked about her son who felt uncomfortable about attending speech therapy group sessions due to the fact he was the only non-white person there. She felt that his withdrawal had subsequent negative repercussions in terms of his mental and personal development, self-confidence and ability to cope with everyday life.

In this context, several of the parents that we met had disabled children, or children with long-term health conditions, for which they visited hospital outpatient clinics on a regular basis (usually once every six months or annually). Parents talked about their encounters with child health practitioners and related both positive and negative experiences. The greatest area of concern appeared to be the small amount of time available for consultations with family doctors and with hospital specialists. Location and transport were also factors in accessing more specialist children's services, often removed from the neighbourhoods where parents lived:

There are a lot of services out there, but there is not a lot of services directly in the community I come from, an ethnic minority community. A lot of them are dotted on the outskirts...Things that may be of benefit to me and my family is unreachable. (Pakistani mother)

The interviews raised some concerns about parents' knowledge of existing services and suggested that word of mouth and outreach work were considerably more effective in reaching parents than health promotion initiatives based on literature, posters and leaflets. Parents wanted services to be more multicultural, to have a more ethnically diverse workforce, and to be locally accessible within minority ethnic communities. They were keen to express their views and hoped that positive change might come about from their participation in the research. As one parent concluded:

Again and again we have this research, but it is a wasted exercise if there is no follow-ups, no recommendations, no steps are taken. It's a wasted exercise both money-wise and time-wise. (Indian father) SUMMARY: Minority ethnic parents had a range of service experiences in relation to their children's health, focussed largely on encounters with family doctors, dentists and health visitors. A significant number also used more specialist services, such as speech and language therapy, child development centres, allergy clinics, opticians, physiotherapy and so on. On the whole, their experiences were positive and they felt able to make appropriate choices for their children from the available supports. However, a considerable number experienced difficulties with language barriers, perceptions of cultural incompetence and occasionally actual racism.

# 8. Views of young people.

In order to address the main aims of this health needs assessment, it was particularly important to obtain the views and experiences of young people themselves. This was carried out via group interviews with a range of young people to explore their concerns and ideas about health and health services within the Leeds. The interviews were conducted by two female researchers, both with experience of research with children and young people. In some of the settings, staff known to the young people were also involved in facilitating the discussions.

A total of 58 young people were consulted in a range of settings: at resource centres, in a school and at a youth club. The age range was 11 to 25 (22 were aged 10 to 15; 28 were aged 16 to 20 and 8 were aged 21 to 25) with a 60/40 ratio of male and female respondents.

What follows is an analysis of the main themes emerging from these interviews.

### Experiences of health services and practitioners

Although some young people had experience of hospital are, the majority of contact that they had with health services and practitioners was with GP surgeries.

Young people had a number of concerns about their contact with GP's, the first of which was not being listened to. Many gave accounts of being dealt with too rapidly, or of having their own sense of what's wrong with them dismissed. They saw the GP as being in a position of power:

My doctor's already got the prescription half written down before you've even told him what's wrong with you. (Male Black Caribbean 16 +)

If you know it's a certain thing they are not going to agree with you but they are going to use their power to determine it's something else (Male Asian16 +)

Although none of the young people we spoke to expressed concern over communication barriers due to a different language (they all felt confident in using English), a different kind of communication barrier was identified in the form of medical terminology. Many felt alienated by the medical language used and in turn, were not confident to ask for clearer explanations.

I'll break it down to you what's wrong.... you don't know what they are talking about with all their medical terms... they are not taking it upon themselves to break it down to the people and so you just get handed a prescription. (Male Black Caribbean 16 +)

Although young people recognised that doctors are in high demand, being rushed through appointments was a concern to young people. Some felt that they were not given enough time for a proper diagnosis and treatment to be made.

My brother, when he first went in to hospital they said he had big depression...two weeks later he was in a worse state than when he

went in there...afterwards they said that they were giving him the wrong medication. (Male Black Caribbean 16 +)

Medication itself was seen by some young people as a 'quick fix' approach, and the view was expressed that there should be more choice in treatment. It was suggested that medication sometimes only provided a short-term solution and that longer-term problems needed a more individualised approach. Linked to this was the concern that young people rarely saw the same GP and that familiarity between doctor and patient was missing. Often, young people felt they had to constantly explain their medical history. This led to different diagnosis and confusion for the patient.

You keep being taken from one doctor to the next and no-one knows you. (Female Asian under 16)

We are now called clients... and its very impersonal term and I think they should change that because they are not looking at us like people, they are looking at us like a commodity... (Male Black Caribbean 16 +)

One outcome of the above concerns is young people express a lack of trust for GP's. The majority seem to feel that health professionals do not have time for them and believe that medication is used as rapid way of getting them out of the surgery. Individual needs and concerns are apparently not dealt with. Young people also feel alienated by the power GP's seem to have and the medical language they use.

Young people also expressed concerns over receptionist staff. It was felt that they can put people off seeking help because of their unfriendly manner. Young people also shared experiences where reception staff tried to decide whether they were eligible to see the doctor. Many found this frustrating and felt that it was their right to express their concerns to the GP, not the reception staff.

...they say you are not allowed to speak to the doctor and you have to go through reception. They don't know what they are talking about and they still won't bring the doctor through. (Male Asian 16 +)

It's all about customer services and I don't think it's good when someone greets you badly because it could put people off going to get help and it has (Male Asian 16 +)

The waiting areas of GP surgeries was also identified by young people as not being geared to their needs. For example, young people, especially those in their early teens complained that there was nothing to keep them occupied whilst waiting. Magazines and books appeared to be targeted at adults or young children.

The waiting times were also a common cause of complaint. There was particular frustration when people arrived early for appointments but were not seen until after the scheduled time. Young people felt this was unacceptable, particularly if time had to be taken off work. Many also explained that waiting for a long time made them feel more anxious. It was felt that this can put people off.

You could walk in bent over in pain and they will just say, take a seat it's going to be about 3 hours. (Female Black Caribbean 16 +)

...the person on reception is also answering the phone so every time she goes to the desk the phone rings so she has to go and answer the phone...and you stand there...then you are told you are going to have to wait even longer. (Male Black Caribbean 16 +)

The opening times of services was also raised as an issue. Many young people felt that services should be extended in to the evening because of the difficulties in accessing them during the day.

like sexual health clinics, I've just noticed that they have weird opening times. It seems a bit inaccessible... so that could be a knock back and people could not want to go. (Male Black Caribbean 16 +)

There was complaint that there is not enough flexibility with services, not just due to opening times but altering appointments and seeking help from surgeries that young people tended not to use frequently. There were examples where young people have needed an emergency appointment and were refused appointments at alternative surgeries.

I had an incident with my son...so I took him to the doctors and went to fill in a form for temporary residency and I was told... if I wanted to have my child seen I would have to take him to [his own surgery] freezing. (Male Black Caribbean 16 +)

### Access to health information and education

The majority of young people felt that there needed to be better access to health information. Ideas included more leaflets available in surgeries, schools and community centres. The problem with leaflets is they frequently don't get read and this was acknowledged but it was agreed that there should be the opportunity to be able to access this information. Some people said that it would enable them to make more choices about how they were treated, or would give them information to seek alternative therapies. Direct contact between health professionals and young people in schools was seen to be a positive method of informing young people.

It's all about education and some people may not know how to help themselves or stay healthy. (Male Asian under 16)

I've got a thyroid disorder....in four of five years of medical help I haven't been advised on anything nutritional at all...by skimming through a magazine... there are all these vitamins and minerals that can assist. (Female White 16 +)

Some young people felt that there was a gender imbalance in the health issues that are highlighted. For example, one group of young people discussed testicular cancer and it was felt that leaflets are often targeted at health issues for women, whereas men's issues were ignored. It was suggested that this was an area which needed to be looked at.

...when I go to the doctors, the leaflets...there's nothing for men's health or anything about testicular cancer, its all around babies...and women really. (Male Black Caribbean 16 +)

Young people showed a good awareness of the importance of sexual health issues but felt that more information needed to be available, as well as free condoms. It was emphasised that children should be educated from a very early age, so that they could make informed choices about sex.

There can't be a barrier when it comes to your health especially when it comes to sexual diseases. We need condoms, leaflets, everything. (Female Black Caribbean 16 +)

Very few young people we spoke to were aware of services apart from GP's and A and E services. Many felt if they knew of other services they could seek alternative therapies rather than rely on the medication that GP's prescribed them.

That's all people know, the doctor of if the worst, go to the hospital. (Female Asian under 16)

Some young people identified areas where they felt there were insufficient health services. Drug services was one that was particularly highlighted with many young people expressing the view that there was a lack of support for minority ethnic young people with drug related problems.

It's bad because there is not drug advisory agency that works within this community specifically aimed at minority ethnic groups and we need one... (Male Black Caribbean 16 +)

When asked about the importance of having health staff who were of a similar ethnic background, the majoity of young people we interviewed did not see this as an important issue. For young people, gender seems to be more important:

Men's health workers are women. I don't know that there are any funded male health workers...I don't understand why there are not men to represent them. (Male Black Caribbean 16 +)

### Poverty, social exclusion and health

Many young people saw lack of money as a reason for being unable to stay healthy. Some felt that they couldn't go to the doctors because they could not afford to take the time off work and others wanted to have health checks but felt unable to because of the cost.

I went to the doctors and he wouldn't give me a medical... I just wanted a health check to see if I was alright but he wanted to charge me for it and I couldn't afford it. (Male Asian 16 +)

Some respondents pointed out that as young people they did not necessarily have control over their own health. The views and behaviour of parents and other family members have a major influence on the choices young people make. For example, several young people pointed out that they had limited control over what they ate in the home:

My mum cooks a lot of fried food so that is what I eat, but I know it's not good for me but mum likes it. (Female Asian under 16)

Older young people also commented on the effect of the family on health, particularly in relation to drugs. Young people felt that there should be more work done with whole families, educating them and supporting them. There was an emphasis on prevention so that young children could make informed choices about drugs, rather than doing them because it was a common practice within the family/ community. It was also emphasised that non-users need to be supported when a member of the family is a user.

Drugs aren't just the effects on the person but on four or five family members who feel it for them. (Male Black Caribbean 16 +)

a lot of people are influenced by their family. Like a lot of people I know do crack, its like their parents did and so did their parents. (Female Black Caribbean 16 +)

Factors in the wider community were also seen as impacting on health. Used syringes, abandoned cars, pollution and lack of places to play were all cited as things that affected health. Younger children placed an emphasis on needing more open spaces and parks to play in. Older ones similarly felt that there should be more community spaces for young people to meet up in.

## The relevance of ethnicity, culture and religion

In general, the young people taking part in the consultation groups did not see ethnicity as a major factor in health or health services.

It doesn't matter. We're not racists here. I'm not bothered about what colour they are just as long as they can do their job. (Female Black Caribbean 16 +)

Most of the young people we spoke to live in areas with large minority ethnic populations and on the whole, they did not feel that local health services discriminated against them. Some young people expressed the view that this might be different if they lived in predominately white areas.

Two specific areas were raised where young people felt that more culturally sensitive provision should be available: mental health services and sickle cell anaemia. Many involved in the discussion felt that the mental health needs of young black men are not addressed. Young people also expressed frustration at the lack of awareness and understanding of sickle cell anaemia.

SUMMARY: The issues concerning young people from minority ethnic groups were similar to those concerning young people generally. If they perceived discrimination it was just as likely to be on the grounds of them being young than of them being from an ethnic minority group. It is important to point out that it is impossible to draw more than tentative conclusions from such a small sample and that different compositions of groups may have generated different findings e.g. young people who are less confident in the use of English or young people who are regular users of health services. Nevertheless, it is an interesting (and possibly quite heartening) observation that racism is not widely perceived by young people to be a major issue in health services.

# 9. Report summary

#### Health needs assessment

This health needs assessment should be considered as the starting point for an ongoing process of information gathering and analysis, in order to target future interventions and investments to improve the health of minority ethnic children in Leeds.

Health needs assessment demands a broad definition of health and its determinants that includes individual, social, economic, cultural, environmental, and service factors.

For minority ethnic children in Leeds, a health needs assessment should be set in the context of a wider knowledge and appreciation of national health inequalities and should acknowledge the potential impact of personal or institutional racism on health and health care experiences.

#### The nature of the population

The number of minority ethnic children is increasing nationally and there are more children from ethnic minorities in younger age groups. Pakistani and Indian children form the largest sub-groups, while children of 'mixed' or 'other' parentage are the fastest growing groups.

The overall population of minority ethnic children in Leeds mirrors some of the national trends. The largest minority group of school-age children is of Pakistani origin with significant numbers of children from Black and minority White groups. Bangladeshi and Pakistani children show the lowest age profile, with an apparent decline in younger children of Indian origin (although there may be an error of recording here).

There is considerable ethnic diversity within and between the various wards, with larger concentrations of minority ethnic children in Chapel Allerton, Harehills and University wards. The availability of 2001 Census data will confirm the current picture in much more detail. However, liaison with Education Leeds over the collection and analysis of pupil ethnicity data would also provide a useful source of dynamic data.

#### Specific health issues

Household income, unemployment and poverty are key issues in those areas of the city where most minority ethnic children live. They are also identified as key factors in the ill-health of minority ethnic children nationally. Action to tackle poverty and poor family housing in inner city wards such as Harehills, University and Headingley would have a positive impact on the health of minority ethnic children

Existing survey and research data provides some useful indications of significant health differences between children of different ethnic groups. These may be associated with environmental factors, reporting, cultural behaviours, and sometimes genetic factors. These differences suggest that there may be a need for greater monitoring, and possibly targeted intervention, in key areas of the city. Such interventions might be targeted at children's knowledge and reporting of their own health, at psychological and emotional health, at promoting healthy lifestyles, the

reporting of accidents involving children, and at recording the incidence of chronic conditions and impairments.

There is a considerable amount of existing knowledge on the health and illness patterns of different minority ethnic groups, including indicators of children's health. However, there are also some significant gaps in this knowledge. It is important to recognise the diversity of ethnic groups in Leeds, the range of issues that affect young people generally and those that are specific to minority ethnic young people. Existing literature points to determinants of health and health inequalities that suggest that minority children are often disadvantaged. There is currently an absence of specific local data that would confirm or challenge the ethnic variations apparent nationally.

#### Service usage

There is clear evidence of national differences between children of different ethnic groups in attendance at GP and dental services, in the incidence of dental problems and in the prescription of medicines. This merits further investigation locally, through increased ethnic monitoring, and suggests in particular that Bangladeshi and Pakistani communities in Harehills, Chapel Allerton, City and Beeston should be targeted for health promotion work relating to the take-up of dental care. There is also a case for targeting refugee and asylum seekers to increase attendance. In addition, concerns about the apparently high rates of prescription to African-Caribbean boys should be further investigated in the local context.

Existing national data on children's patterns of hospital attendance shows variation between different ethnic groups, including significant gender differences. South and South East Asian children appear less likely than the general population to have visited a hospital as outpatients but there are fewer differences in inpatient admissions. The biggest gender differences are in day patient attendance, where there is a striking under-attendance (or under-reporting) in the case of Indian and other South Asian girls. A more detailed investigation of ethnicity data for Leeds hospital admissions is required to investigate the local implications of these trends

It is important to look at the qualitative experience of service use in order to appreciate many of the specific health needs of minority ethnic children. There has been an increasing amount of work in this area. The examples of recent work in the area of haemoglobin disorders and learning difficulties suggest some key areas of concern. These include the assumptions of service providers, the cultural competence of services, the significance of services outside the traditional realms of 'health' care, and the role of community based self-help groups.

### Ethnic monitoring

The task of local health needs assessment for minority ethnic children in Leeds is considerably hampered by a lack of reliable ethnic monitoring data on the usage of relevant services. However, the development of new systems for monitoring in both primary care and hospital admissions offer the potential for further more detailed investigation. This should be considered as a next step in the needs assessment process.
#### Views of key informants

A central component of this health needs assessment has been gathering the views and experiences of key informants. These have been professionals from a range of services providing agencies across Leeds including representatives of statutory organisations, voluntary organisations and community groups; parents of children from ethnic minority groups and young people themselves.

## Professionals

Staff working across a wide range of agencies identified communication and access to services as key issues of concern. Cultural competence was also identified and there was a strong view the ethnic composition of staff in health services should more closely reflect that of the communities they serve. The importance of sharing information across agencies was highlighted. Social exclusion, particularly poor housing, poor environments and poverty in general were identified as the prime determinants of ill-health.

Language and communication issues were universally identified as being of critical importance. There were communication problems identified at all stages in the chain of service delivery from accessing information about services (and health promotion) in the first place to the first point of enquiry (e.g. reception) and at every subsequent stage of service provision by health care practitioners. However, there was some confidence that recent service developments (such as the advocacy and interpretation service) were steps in the right direction.

There was a general view that many services have improved their quality of care towards minority ethnic communities and that there was now a wider recognition that health services need to meet the needs of all diverse users. There was however, still a widely held view that members of the minority ethnic communities continue to receive a 'poorer' service from statutory agencies than their white counterparts.

Many staff are unaware of what services are available to users across Leeds. Several highlighted the need for better information sharing between agencies through, perhaps, a directory of services.

Staff highlighted the general 'run-down' nature of housing in which some minority ethnic communities live and the subsequent ill-effects on health. There were numerous reports of overcrowding and properties being in a bad state of repair. This has an impact on both physical health and emotional well-being.

### Parents

Minority ethnic parents had a range of service experiences in relation to their children's health, focussed largely on encounters with family doctors, dentists and health visitors. A significant number also used more specialist services, such as speech and language therapy, child development centres, allergy clinics, opticians, physiotherapy and so on. On the whole, their experiences were positive and they felt able to make appropriate choices for their children from the available supports. However, a considerable number experienced difficulties with language barriers, perceptions of cultural incompetence and occasionally actual racism.

#### Young people

The issues concerning young people from minority ethnic groups were similar to those concerning young people generally. If they perceived discrimination it was just as likely to be on the grounds of them being young than of them being from an ethnic minority group. The young people we spoke to had mixed experiences of health services. They identified the importance of information about health and better access to services. The impact of poverty and the lack of control many young people feel they have over their own health (through diet, in particular) were raised as issues.

#### HAZ Workstream Priorities

The initial findings from this needs assessment should be considered in the context of existing Health Action Zone priorities. In particular, the findings support future action on: translating and interpreting services, cultural awareness training within existing services, the need to mainstream existing innovative pilot projects, the greater involvement of minority ethnic communities in service planning and delivery, and the need to move beyond short-term funding for high quality targeted projects.

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# APPENDIX A: Numbers of Children in Leeds Primary Schools by reported ethnicity and location of school Ward (source: Education Leeds, 2000-2001)

Ward	Total	Bangladeshi	Black African	Black Caribbean	Black other	Chinese	Greek/ Greek Cypriot	Indian	Not recorded	Other	akistani	Traveller	Unclassified	Vietnamese	White other	White UK
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Aireborough	2199			1	3	8		5	6	12	7		5		29	2123
Armley	2692	1	1	25	31	4	1	51	12	30	139		14	1	36	2346
Barwick/Kippax	1613				6	1		5	9	10			4		4	1574
Beeston	1854	92	3	7	10	3	1	23	19	20	309	1	27		28	1311
Bramley	2258		2	7	11	5		6	23	25	10		12		19	2138
Burmantofts	1761	2	19	18	37	3	1	3	10	30	11		3	1	19	1604
Chapel Allerton	2266	34	32	273	238	4		139	15	69	245		13	13	96	1095
City And Holbeck	1793	64	3	7	14	7	1	28	28	26	93		10		6	1506
Cookridge	1736	1	8	10	12	12	1	29	1	67	17		4		30	1544
Garforth/Swillington	2545		2		1	9		7	20	16			11		21	2458
Halton	2350		3	3	1	5		5	28	22	5		6		28	2244
Harehills	2807	305	17	80	85	15		76	20	91	928		10	4	20	1156
Headingley	1048	1	13	35	33	21	1	40	3	31	340		3	1	50	476
Horsforth	2071		1	7	7	9	1	7	6	30	2		9		29	1963
Hunslet	1417		2	4	15	2		1	26	5	6		1	1	2	1352

Kirkstall	1489	2	11	21	26	8		52	5	27	65		4		35	1233
Middleton	2714		2	2	12	5	1	5	7	8	4		11		12	2645
Moortown	2214	2	23	115	93	17	2	179	6	70	283		36	4	62	1322
Morley North	2250		2	9	4	6		35	13	26	5		2		19	2129
Morley South	3176	3	5	3	9	8	1	22	10	45	5	1	9		25	3030
North	2305	3	16	66	39	34	8	120	3	69	79		10		104	1754
Otley	1860	2	1	1	11	5	1	14	4	15	7		7		38	1754
Pudsey North	2301	1	2	7	4	10	1	162	41	13	158				14	1888
Pudsey South	2154			17	4	4		45	4	22	30		2		13	2013
Richmond Hill	1876	1	12	5	17	4		11	182	13	5		15		45	1566
Rothwell	2218			7	7	3	1	11	8	18	6		12		11	2134
Roundhay	1620	11	5	27	31	13	5	141	1	57	165		17	2	35	1110
Seacroft	1827		1	31	6	1		7	12	10	7		1	2	11	1738
University	1713	25	44	190	107	34		41	25	121	218		15	6	38	849
Weetwood	1275		7	20	32	8	2	28	30	34	30		11	2	11	1060
Wetherby	2182				12	2		6	25	14	7		5		79	2032
Whinmoor	1932		4	5	25	1	1	27	15	11	16		2		23	1802
Wortley	2020		3	9	1	3		25	4	13	17		2		11	1932
TOTALS	67556	550	244	1012	944	274	30	1356	621	1070	3219	2	293	37	1003	56881

# **APPENDIX B: Topic Guide for Parent Interviews**

# CHILDREN

How many, ages...?

# HEALTHY BEHAVIOURS AND KNOWLEDGE

- What are the most important things to keep your children healthy?
- What do you do to make sure your children stay healthy?
- How do you know what is good for your children's health?
- What do you think are the main things that can make your children ill?
- When children are ill, what do you do?
- Is there anything beyond your control that is likely to make your children ill?

# SERVICE NEEDS

- Which services have your child(ren) used in the past 6 months? Why?
- What are your main reasons for using these particular services?
- Is there anything about these services you did not like/feel comfortable with?

# ACCESS TO SERVICES

- How did you hear about the health services that you use?
- How did you get to use these services?
- Have you had any problems using these services?

# SOCIAL EXCLUSION

- Has anything prevented your children from using certain services? What?
- Has this affected your children's health?
- What would make it easier for you to use these services?

# SPECIFIC HEALTH NEEDS

- Do your children have a health problem that needs regular attention?
- How did you find out what was wrong?
- Have you been given the support you need?
- Is there anything else you would like to tell us about your children's health which you think is important?

# **APPENDIX C: Topic Guide For Children**

# INTRODUCTION.

Introduce yourself. Provide information about research aims. Explain structure of interview. Gain consent for tape recorder and establish ground rules.

# HEALTHY BEHAVIOURS/KNOWLEDGE

First we will look at health and how you keep healthy.

What is health?

Prompt: physical, mental, sexual. Factors such as food, exercise, disease, medicines

What is good health? What would you do to make sure you stay healthy?

Prompt: diet, exercise, environment.

Why are these things important?

What is poor health? What makes you unhealthy/ill?

Prompt: poor diet, no exercise, smoking, drinking, drugs, environment, stress, disease

Why do these things have an effect?

Is there anything beyond your control that is likely to make you ill?

Prompt: poor housing, damp, stress, depression

We've spoken about things that can make us healthy or unhealthy but do you actually think its important to stay healthy?

Where could you go / who could you first ask if you were worried about your health?

Prompt: doctor, hospital, health clinic, pharmacist, school nurse, friends, family

How do you know these things work?

Why these particular people?

When you are ill, what do you do?

When would you go to see the doctor? (or hospital) (how ill would you have to get)

Why would you go to the doctor and not the hospital?

When would you go to the dentist? (regular check ups, only when problem with teeth/gums)

Are you registered with a dentist local to you or do you take your children to hospital?

### SERVICE NEEDS AND ACCESS TO SERVICES

Now we will look at which health services you use and what you think about those services.

Health Services include things like, doctors, nurses (school nurse), dentists, hospitals, pharmacists, health visitors, family planning clinics.

Which services have you visited recently (past 6 months)? Why?

Did they help? If yes, how? If not, why not?

What are your main reasons for using these particular services?

Prompt: is it location? costs? specialist? Culturally appropriate?

Tell us about your experiences of accessing health services in Leeds

How did you hear about the health services that you use?

Prompt: through relatives, friends, social groups, GP and other health professionals, leaflets

How did you get to us these services?

Were you referred or self referred? How long did you have to wait? Were you on a waiting list?

Have you had any problems using these services?

Communication barriers? Interpreters?

Access barriers? Problems because of where you live etc?

# \*EXERCISE TO EXPLORE VIEWS ON EXISTING SERVICE PROVISION/ACCESS TO SERVICES

# AGREE DISAGREE

This is a game about whether you agree or disagree with the statements that are read out. Ask the group to put their hand up if they AGREE and then if they DISAGREE. Following on from this, ask each member of the group about the reasons for their decision.

### STATEMENTS:

- I can easily make an appointment to see my doctor
- If you're black it is nice to see a black doctor
- Health services treat all users equally
- It is difficult to get to my doctor's surgery/health centre
- Children and young people from Black and ethnic minority groups often encounter racism when they go for health care
- My doctor explains things in a way in which I understand
- Children and young people from Black and ethnic minority groups have just the same health needs as white children and young people
- Different ethnic minority groups have different health needs
- Most health care workers have a good understanding of other cultures
- If I or any of my family needed an interpreter I would know how to go about it

- It is more embarrassing to seek help on certain health issuse than others
- My doctor's surgery/health centre is a welcoming place for children and young people from Black and ethnic minority groups
- There are certain health problems that are more common amongst ethnic minority groups

# SOCIAL EXCLUSION

Now we want to find out about things that might stop children using services.

Has anything stopped you from using certain services? What?

Prompt: your parents, money, too far to travel, male/female staff?

Has this effected your health?

How? Do you feel that your health has got worse?

What would make it easier for you to use these services?

Prompt: services nearer/ within community, more staff from your cultural /ethnic background?

# SPECIFIC HEALTH NEEDS

Next we are trying to find out about health problems which affect a lot of children from ethnic minority groups.

Do you or any of your friends/family have an illness?

Prompt: asthma, diabetes,

How did you find out what was wrong?

Did you seek professional advice? Knew from family history? Did you worry about getting help? Did you know where to go?

Have you/they been given the help they need?

If yes, what? If not, why not?

Is there anything else you would like to tell us about your health, which you think is important?

Get biographical information and thank them for their time.