Responding to Diversity

A Study of the Commissioning of Services for People of Black and Minority Ethnic Origin with Physical Disabilities and/or Sensory Impairments, Aged 18-64 Years

November 2001
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Executive Summary

Key Message

The diversity of needs of people with physical disabilities and/or sensory impairments from a wide range of black and minority ethnic communities present a significant challenge to local authorities. This study demonstrates that local authorities are starting to develop some imaginative ways of rising to that challenge. These initiatives are not confined to the conurbations with the higher concentrations of such communities but are also to be found in more rural areas where the challenge is, in some ways, greater owing to the smaller numbers and/or their wider dispersal. There is a need for authorities to learn more from one another so as to ensure that improvement is more consistent across all types and sizes of authority.

This report is aimed at promoting that process. In order to assist authorities in auditing and improving their existing services, a checklist for action has been included in the report, based on the study’s findings. A series of regional workshops were held in the autumn of 2000 to disseminate the findings.

Purpose of Study

This is the report of a study by the Social Services Inspectorate into the current state of development of services for black and minority ethnic adults with physical disabilities and/or sensory impairments. It was done by means of a postal survey of all social services authorities in England, which were asked to liaise with their partner health authorities over the completion of the survey return. This survey was undertaken in the summer of 1999 and achieved a 60% response rate. A sub-set of authorities was selected for follow-up visits in order to explore some of the identified issues in more depth.

The purpose of the study was to identify and share information with all authorities about service development initiatives for this target-group, since there is continuing low take-up of services by black and minority ethnic adults with disabilities, whose numbers are projected to grow significantly in the next few years. In particular, the requirement on social services and health authorities to produce a Joint Investment Plan under the Welfare to Work
programme offers the opportunity for a combined re-evaluation of the extent to which disabled adults from all sections of the community are being helped into employment.

**Information and Access**

The survey confirmed that most authorities are almost entirely reliant on census information for estimating the numbers of black and minority ethnic disabled adults in their areas, although some have carried out local research to update this information. Databases, such as Registers for Children with Disabilities, are not yet sufficiently developed on an inter-agency basis to provide a solid foundation for the planning of future services. The recording of the ethnicity of service recipients is slowly improving but it remains poor in a considerable number of authorities.

Some initiatives to improve the presentation and distribution of information about services to black and minority ethnic communities have been imaginative. The same applies to some efforts at making services more accessible. Interpretation services are now widespread, though not in all languages; signing skills and other forms of communication with hearing impaired black and minority ethnic adults are much less well developed. Access to advocacy support is also still patchy. Very few authorities make specialist provision for the assessment of the needs of black and minority ethnic disabled adults.

**Assessment and Care Management**

People from black and minority ethnic communities are, on the whole, less well informed than the rest of the population about their entitlements and the services available. For many reasons, they may also be more inhibited about seeking assistance.

Additionally, staff lacking in awareness of ethnic and cultural issues, can respond inappropriately, further depressing the take-up of services. The absence of a common language can also lead to an over-concentration on practical needs to the neglect of emotional and psychological needs. The needs of carers, and more especially young carers, in black and minority ethnic families are also often overlooked. Because the necessary skills are at an early stage of development, it is important that authorities have in place systems to capture the learning from growing casework experience.
Some authorities have recognised that black and minority ethnic disabled adults do not have equitable access to the same range of services as other disabled adults and are looking to develop more customised services. However, many authorities lack strategies for determining the appropriate balance between investment in ethnic specific schemes and more culturally appropriate generic or mainstream services. According to the survey returns, very few black and minority ethnic disabled adults had yet been accepted on to direct payment schemes. The study visits identified that more priority is needed for the reviewing of care plans for black and minority ethnic disabled adults in order to ensure that services are better adjusted to changing needs.

**Commissioning Services**

The positive development of joint commissioning of physical disability and sensory impairment services was occasionally hindered by the variety of organisational changes in health and social services. Inter-agency arrangements for the planning and commissioning of services are similarly in a state of flux but, in some authorities, more robust arrangements are starting to develop for the more meaningful involvement of black and minority ethnic adults and their carers in the planning and commissioning process. The uneven distribution of the black and minority ethnic population means that it would be more appropriate for some authorities with very low numbers of black and minority ethnic people to consider consortia or sub-regional arrangements for the commissioning of such specialist minority services.

There are currently few objectives in commissioning plans for this adult-group and few of those are couched in terms of measurable targets. Service providers, including not-for-profit black and minority ethnic organisations, are still at an early stage in learning how to customise services for different individuals and communities. Refugees and asylum-seekers remain severely disadvantaged in terms of access to even basic services in most areas, with some notable exceptions.

**Assuring Quality**

Many authorities are now using the standards devised by the Race Equality Commission to audit the cultural appropriateness of their services. The extent to which service specifications address ethnic and cultural dimensions shows wide variation. As for other services, contract compliance is under-resourced and the level of funding rarely permits often small not-for-profit organisations to invest in their own quality assurance systems. Quality of services is, therefore, variable but improving, particularly where disabled adults themselves and their carers are enabled to be actively involved in the planning and monitoring of services.
Best use of Resources

The great majority of the initiatives for ethnic-specific schemes are dependent on short-term-funding sources. Some authorities are more entrepreneurial than others in accessing these sources. However, very few appear to have plans for the progressive integration of these schemes into mainstream funding. The Best Value agenda will drive a re-evaluation of the inequity in the funding of not-for-profit providers, who feature prominently in meeting the needs of black and minority ethnic disabled adults. Accommodation of the necessary increases in funding is likely to require some de-commissioning of other mainstream services.

There is a dearth of staff with the requisite combination of skills to meet the needs of black and minority ethnic adults with physical disabilities and/or sensory impairments. Their skills are not currently being used to best effect in multiple short-term schemes. There is an urgent need for more strategic workforce planning, encompassing not only Health and Social Services but also the independent sector.

Conclusions

The study points to the need for both health and social services authorities:

- to improve their analysis and understanding of the diverse needs and requirements of people from the many different black and minority ethnic communities, so as to achieve equity of access to services;
- to review their workforce planning and development strategies to ensure that sufficient staff with the necessary combination of skills are trained and deployed to best effect;
- to promote the development of independent agencies able to empower and to advocate on behalf of black and minority ethnic adults with disabilities;
- to define their service development priorities in association with relevant local black and minority ethnic interests, so as to achieve equity of choice and quality of service;
- to ensure the appropriate allocation of their resources on the basis of need across all sections of the population;
- to set challenging and measurable goals and to be active in monitoring their achievement.
1.1 Introduction

The forthcoming Census in 2001 will confirm that there are rising numbers of black and minority ethnic adults with physical disabilities and/or sensory impairments. This is as a consequence of more children with disabilities surviving into adulthood and of increasing numbers of people in late middle age within black and minority ethnic communities who have developed disabilities. It is, therefore, timely for both health and local authorities to be reviewing their strategies for this user-group, so as to take advantage of this forthcoming new intelligence.

This study arose from an appreciation by the Social Services Inspectorate (SSI) in the Department of Health that services for black and minority ethnic adults with physical disabilities and/or sensory impairments are less well developed than most other services. It was, therefore, decided to undertake a study with a view to identifying and sharing good practice in this area, as a way of promoting the development of these services by facilitating communication between authorities.

1.2 Context

SSI has, in recent years, undertaken a series of inspections relating to services for people with physical disabilities and/or sensory impairments and to services for older people from black and minority ethnic communities, as well as inspecting the overall arrangements for commissioning community care services (see Appendix 1 for details). All of these exercises highlighted a degree of fragmentation in the services provided and a low take-up by people from black and minority ethnic communities.

These inspections confirmed the findings of other research into the barriers to accessing services by people from black and minority ethnic communities. These include:

- lack of appropriate service information and/or its effective distribution
- limited awareness of public services in black and minority ethnic communities
• fear of dealing with statutory authorities
• inhibition reinforced by experience of racist attitudes
• negative past experiences of services
• range of language, literacy and communication difficulties
• dearth of black and minority ethnic staff in statutory care services, especially trained bilingual support workers
• little confidence in the capacity of authorities to understand and meet their needs
• poorly developed care pathways offering co-ordinated and holistic health and social care
• non-availability of culturally appropriate services
• delay in developing advocacy support.

These difficulties are all the greater for black and minority ethnic people with limited or no sight and/or hearing and/or constraints on their mobility and/or the lack of a common language. In that sense, they are disadvantaged minorities within a minority.

As part of a range of initiatives, the Government is striving to promote:

• fairer access to health and social care services;
• an end to discrimination on grounds of race and disability;
• social inclusion, including assistance to disadvantaged individuals in gaining employment;
• more integrated health and social care services;
• better use of resources through applying the principles of Best Value to the commissioning of services.

On all of these counts, black and minority ethnic adults with physical disabilities and/or sensory impairments stand out as a target-group. The Government recently announced funding for an anti-smoking campaign, targeted on black and minority ethnic communities. This followed preliminary
results from the Health Survey which showed that Irish, African Caribbean and, more particularly, Bangladeshi men have much higher rates of smoking, contributing directly to the higher incidence of heart disease and other disabling conditions. Given this picture, the progress that local authorities, in conjunction with health authorities, are able to make in providing a more equitable, integrated and culturally appropriate range of services to this user-group will be a litmus test of the extent to which these initiatives are succeeding.

1.3 Methodology

In the summer of 1999, SSI convened a Reference Group of interested parties, drawn from:

- Association of Directors of Social Services (ADSS)
- NHS Executive (NHSE)
- Major voluntary sector organisations
- Academic institutions
- National and regional lead inspectors (SSI)

An independent consultant was commissioned to facilitate the exercise and to write up the study. The full membership is set out in Appendix 3.

A postal questionnaire was distributed to all Social Services Departments in England, with the request that it be completed in consultation with a local Health representative. Replies were received in August and September from 90 of the 150 authorities, representing a response rate of 60%. From those replies, a small sub-set of authorities was selected from across the country for follow-up visits by the regional SSI lead inspectors and members of the Reference Group. The authorities were Bradford, Harrow, Kirklees, Peterborough, Slough and Wandsworth. These authorities were chosen as they identified particularly interesting developments, which merited more detailed exploration.

The Reference Group is grateful to these authorities for arranging the schedules for those visits, involving senior corporate and departmental managers, planning and commissioning officers, operational staff responsible for relevant schemes both within the local authority and in the independent sector and groups of users and carers participating in those schemes. The visits took place in the Autumn of 1999 and the Spring of 2000.
1.4 Principles of Good Practice

The commissioning and delivery of services need to be underpinned by a guiding set of principles. The Commission for Racial Equality defined such a set of principles, with the backing of the Social Services Inspectorate, the Association of Directors of Social Services, the NHS Confederation and the Chartered Institute of Housing, in its guide, ‘Race, Culture and Community Care: an agenda for action’ (1997) which stated:

- Social inclusion requires that everyone should have equal access to community care services on the basis of need.

- All practices should aim to promote racial understanding and to eliminate any discrimination or disadvantage in the provision of services.

- Information about available services, and the procedures for obtaining and complaining about them, should be provided in ways that are accessible to black and minority ethnic patients, users and carers, with interpretation, translation and advocacy support available as necessary.

- Assessments of need and individual care plans should respect the privacy, dignity, religion, diet and cultural heritage of black and minority ethnic patients, users and carers, including any preference to deal with a practitioner of their own sex.

- Statutory authorities should work in partnership with a range of black and minority ethnic organisations to establish a mixed economy of care that provides equity of choice and outcomes for all, based upon a sound knowledge of their local black and minority ethnic populations.

- Services should be planned and provided in collaboration with black and minority ethnic interests, building on the strengths of patients, users, carers, families and communities, and enabling users to remain within their own communities, if they so wish.

- Services should be delivered in ways that are racially and culturally appropriate to those to whom they are offered.

- Workforces should, wherever possible, reflect the communities they serve, and be trained to respond appropriately to the varied and changing needs of communities.
Introduction

- Positive action, as allowed in race relations legislation, should be taken, where necessary, to redress any disadvantage experienced by black and minority ethnic communities.

- Ethnic record-keeping and monitoring of patients, service users and staff is necessary to measure progress in improving services and to check how effectively equal opportunity employment policies are working.

1.5 Target Audiences

This Report is directed primarily at those staff responsible for the formulation, implementation and monitoring of strategies for commissioning health and social care services for this target group of patients/users and carers. However, it may also be of benefit to those providing those services, whether in the statutory or independent sector as well as those organisations advocating on behalf of disabled black and minority ethnic patients/users and their carers.

1.6 Definitions

The term “black and minority ethnic” describes people who share certain characteristics (common history, language, religion or family or social values) which distinguish them from the majority of the population. It, therefore, covers people with a very wide range of linguistic and cultural needs. In this Report, the term refers not only to black and Asian groups, but also to Irish, Jewish, Gypsy, traveller and other white ethnic groups, any of whom may be seeking asylum. Over half of those described in these categories will have been born in this country but remain disadvantaged.

The term “commissioning” has also been given a variety of meanings. This Report adopts the definition given by the Audit Commission in its publication ‘Take Your Choice: a commissioning framework for community care’ (1997), namely, that it is “the process of specifying, securing and monitoring services to meet individuals’ needs, both in the short and long term”. Joint commissioning encompasses the provision of both health and social care services.
This chapter pulls together the issues identified in the subsequent chapters in the form of questions to assist managers in health and social services agencies to:

- evaluate their current services for black and minority ethnic adults with physical disabilities and/or sensory impairments, and
- frame a joint agenda to improve those services.

### 2.1 Information and Access

- Have Health and Social Services agreed standard categorisations of black and minority ethnic groups, liaising, as appropriate, with the Statistics Division of the Department of Health?

- Is intelligence shared between Health and Social Services in such a way as to identify medium term trends in patterns of disability amongst black and minority ethnic people, with an agreed inter-agency protocol on the exchange of information?

- Is there an inter-agency strategy to improve the accuracy of the Register of Children with Disabilities?

- Have Health and Social Services jointly prioritised their research requirements to fill in gaps in knowledge about disabled black and minority ethnic adults, where there is the greatest disparity between anticipated demand and service take-up?

- Is there an inter-agency communication strategy for conveying information to black and minority ethnic groups and facilitating their access to health and social care?

- Are interpreters and advocates for black and minority ethnic adults trained to deal with issues of culture and religion as well as of physical disability and sensory impairment, covering the full diversity of ethnic groups in the local area?
2.2 Assessment and Care Management

- Has the acceptability of the assessment arrangements been checked with a range of disabled black and minority ethnic users and their carers?

- Do operational staff have ready access to informed advice on either ethnic and cultural issues or physical disability/sensory impairment issues, depending upon their area of deficit?

- Are the assessment procedures of the various health and social care disciplines being co-ordinated in a way that offers a comprehensive, holistic approach to the needs of disabled black and minority ethnic adults and their carers?

- Do assessments ensure that not only the practical needs but also the emotional/psychological needs of black and minority ethnic disabled adults are met?

- Is the identification and assessment of the needs of carers, and especially young carers, of black and minority ethnic disabled adults being actively monitored?

- Do disabled black and minority ethnic adults and their carers have equitable access to:
  - interpreting and language support
  - advocacy support
  - assistive technology to aid communication
  - training to work with interpreters and advocates
  - choice of service, including direct payments
  - complaints procedures?

- Does the policy on adaptations take appropriate account of ethnic and cultural considerations?

- Is priority given to reviewing the care plans of disabled black and minority ethnic adults?

- Has Social Services researched the impact of its charging policy on service take-up by disabled black and minority ethnic adults?

- Are systems in place to make use of the learning from casework with disabled black and minority ethnic adults?
2.3 Commissioning of Services

- Have Social Services agreed with Health Authorities and Primary Care Groups the planning/commissioning arrangements for services to black and minority ethnic adults?

- Is there a clearly defined managerial accountability in Health and Social Services for the commissioning of these services and have those managers been equipped with the requisite training/experience?

- Does the Joint Investment Plan under the Welfare to Work programme specifically address the needs of black and minority ethnic adults with disabilities?

- Have time-scales been agreed for the development of joint commissioning of these services and for resourcing the necessary joint management posts?

- Has consideration been given to the advisability of cross-authority commissioning of these services?

- Have mechanisms been established for the meaningful involvement of disabled black and minority ethnic adults and their carers and of not-for-profit black and minority ethnic service providers in the development of services?

- Are the leaders of black and minority ethnic communities involved in the monitoring of the prevalence of disabling conditions, so that they can advise on appropriate community health measures?

- Are there clearly defined and measurable targets (expressed in terms of outcomes for users and carers) contained in the latest Community Care Plan and the Health Improvement Programme?

- Are these targets brought together in a comprehensive Race Action Plan, as recommended by the Commission for Racial Equality and endorsed by the Department of Health?

- Is there inter-agency agreement on the range of services required and the balance of investment in ethnic specific services as against the development of the cultural appropriateness of all or selected services?
• Is there sufficient investment in the capacity-building of black and minority ethnic service providers, especially if they are to carry the major responsibility for meeting the projected increase in demand?

• Is there a responsive flexibility to demographic changes e.g. the sudden advent of disabled refugees and asylum-seekers?

2.4 Assuring the Quality of Resources

• Have Health and Social Services agreed the core standards that should apply to all services for black and minority ethnic disabled adults?

• Are a range of disabled black and minority ethnic adults and their carers involved in the setting and monitoring of those standards?

• Are those standards translated into a core set of measurable performance indicators?

• Do the service specifications of contracts take full account of ethnic and cultural issues?

• Does the funding of independent sector services enable providers to develop their own quality assurance systems?

• Has provision been made for evaluating existing short-term schemes?

• Are staff being trained to meet the above standards and is the impact of race and disability awareness training on service quality being monitored?

2.5 Making Best Use of Resources

• Are Health and Social Services currently accessing all available resources for the development of these services?

• Is there an inter-agency strategy for integrating current short-term schemes, if validated by evaluation, into longer term mainstream funding?
• Are the resource allocation processes for these services appropriately integrated (e.g. grant aid, Joint Finance, Specific Grants, spot/block purchases)?

• Is costing of ethnic/cultural requirements (e.g. gender segregation/need for bilingual support workers) factored into financial estimates?

• Are resources identified against race equality targets?

• Is the contracting profile the most appropriate to the current stage of development of cross-sector services?

• Are the core competencies of staff required to deliver culturally appropriate services to black and minority ethnic disabled adults being identified within the staff training and development plan, including working with interpreters and advocates?

• Is race and disability awareness training integrated within a multi-agency programme of organisational development?

• Is the delivery of culturally appropriate services reflected in staff appraisal schemes?

• Are Health, Social Services and the independent sector providers coming together to develop medium term workforce planning for this area of service, including ‘growing’ their own staff?

• Are the needs of disabled black and minority ethnic adults being appropriately considered, through the involvement of experienced advocates, in the Best Value or other reviews of services of relevance to them?
This chapter considers what information is available on black and minority ethnic people with physical disabilities and/or sensory impairments; what information is provided to them and what steps are being taken to facilitate their access to services.

3.1 Census Information

The great majority of the 90 authorities who responded to the postal questionnaire were almost entirely reliant on the Census information from 1991. A few had undertaken forward projections, recognising that the numbers had grown by 35% between the censuses of 1981 and 1991 and that growth was anticipated to have been greater in the last ten years. Furthermore, it is known that approximately 3 million people were not included in the 1991 Census and of those, under-enumeration applied particularly to African Caribbean people and to traveller families. On the basis of this imperfect information, the size of the black and minority ethnic populations in the responding authorities is set in Figure 1.

Figure 1  Size of black and minority ethnic populations in the local authorities, responding to the Department of Health postal survey 1999

This demographic breakdown gives a slightly higher proportion of the black and minority ethnic population than the national average. This is due to the bias in the sample of responding authorities (see Figure 2).
When the responding authorities are analysed by type of authority, there is shown to be some bias towards the Metropolitan and Shire authorities.

The Census information will be updated in 2001. In order to take advantage of the next Census, a number of authorities, which are in process of upgrading their information systems, are utilising the revised black and minority ethnic categories that are to be employed in that exercise. A few authorities expressed the hope that the Government might consider a “mini-census” in 2006, precisely to assist in monitoring fast changing numbers in particular categories, including the black and minority ethnic communities.

For the time being, there is no reliable data available on the number of black and minority ethnic people living in this country, still less on the proportion of those people who have a physical disability and/or sensory impairment.

<table>
<thead>
<tr>
<th>Region</th>
<th>Number of responding authorities</th>
<th>% of authorities in Region</th>
</tr>
</thead>
<tbody>
<tr>
<td>London</td>
<td>16</td>
<td>48%</td>
</tr>
<tr>
<td>Southern</td>
<td>22</td>
<td>61%</td>
</tr>
<tr>
<td>Central</td>
<td>20</td>
<td>53%</td>
</tr>
<tr>
<td>Northern</td>
<td>32</td>
<td>74%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>90</strong></td>
<td><strong>60%</strong></td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Type of Authority</th>
<th>Number of responding authorities</th>
<th>% of authorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>London Borough</td>
<td>16</td>
<td>48%</td>
</tr>
<tr>
<td>Unitary</td>
<td>25</td>
<td>54%</td>
</tr>
<tr>
<td>Shire</td>
<td>22</td>
<td>63%</td>
</tr>
<tr>
<td>Metropolitan</td>
<td>27</td>
<td>75%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>90</strong></td>
<td><strong>60%</strong></td>
</tr>
</tbody>
</table>
However, it is known from small-scale studies that epidemiological projections of disability in black and minority ethnic groups have to include the impact of the greater poverty and poor housing to which they are exposed, as well as disabling conditions which have a genetic component, specific to certain ethnic groups. For example, it is known that there are, in African and African Caribbean communities, approximately 5,000 people affected by Sickle Cell anaemia (with a 50% increase in children affected in North London in the last five years) and another 600 with variants of thalassaemia, another blood abnormality. Kirklees completed a study in 1995 of those with this latter disorder, which continues to inform their service planning in this area.

The prevalence of these and other disabling conditions is increasing in black and minority ethnic communities. In Bradford, where Asians make up 28% of the population, Asian children with special needs comprise 38% of all children so diagnosed. These disabilities range through cerebral palsy, congenital deafness to metabolic brain conditions and blood abnormalities. Children affected by combinations of these conditions have very complex health and social care needs, but, thanks to medical advances, more are surviving into adulthood, often being cared for in the community rather than in hospital. The number of such children is increasing in Bradford by approximately 25 each year. This trend, therefore, has major resource implications for both health and social care agencies.

The prevalence of these conditions is the subject of ongoing research, but it is currently thought to be due to an interaction of genetic and social factors. One of the contributory factors may be the traditional practice of marriage between first cousins, especially in some smaller black and minority ethnic communities with a limited gene pool. In Bradford, the health and local authority have, after prolonged consultation with community leaders, introduced genetic counselling in order to help marriage partners to make informed decisions about potential risks. Other towns with the larger black and minority ethnic communities, such as Slough and Peterborough, are having a similar process of consultation, but it behoves all authorities to be mindful of this dimension.

3.2 Databases

Most authorities are ill-equipped to plan for future changes in numbers of black and minority ethnic adults with physical disabilities and/or sensory impairment, because the Registers of Children with Disabilities are incomplete. This is because such Registers are voluntary, depending on the co-operation of parents and/or the co-ordination mechanisms between agencies continue to be deficient. Most such Registers are held by Social Services Departments,
although a few, like the one in Manchester, have been set up on an inter-agency basis. Only 14 authorities (16%) responding to the survey confirmed that they had any joint databases. The sharing of information between Social Services and Education is improving but difficulties persist between Social Services and Health, not only on grounds of confidentiality but also concerns over the Data Protection Act. Agencies are still uncertain, in law, despite statements from the Data Protection Registrar, whether the transfer of information to another agency requires the formal permission of the relevant party on each occasion. As agencies are now looking to integrate their recording systems, it is to be hoped that some definitive clarification of this issue will be forthcoming after the current consultation exercise on the sharing of Social Care Information.

Turning to adult databases, all local authorities are required to maintain registers on disabled persons, with separate registers for blind and partially sighted people and for those who are deaf or hard of hearing. All accept that these registers are far from complete, with some estimates that registers account for only 70% of blind people and 40% of those with a partial visual impairment. This level of under-registration is, therefore, likely to apply to an even greater extent to black and minority ethnic representation on the registers.

The creation of unitary authorities in the recent Local Government Review, which resulted in some housing and social services departments being combined, has led to some initiatives to develop shared data-bases on black and minority ethnic residents, such as in Reading and in Windsor and Maidenhead. An increasing number of authorities are establishing Registers of Adapted Properties, but, as will be amplified in the next chapter, black and minority ethnic people with physical disabilities continue to be under-represented in applications for adaptations to their homes.

### 3.3 Ethnic Record-Keeping and Monitoring

It is a mandatory requirement for secondary health care facilities, such as hospitals, to record the ethnicity of their patients, but not yet for primary health care teams. It has long been recommended as good practice for other public services but it has not so far been given the force of law, which is what some authorities believe will be necessary for it to be implemented effectively, especially on an inter-agency basis. In fact, the Department of Health is currently considering whether, arising out of its Referrals and Assessment Packages Project (RAP), there is a “business case” for standardising information requirements in respect of gender, race and disability.
As Joint Reviews of Social Services by SSI/Audit Commission have found, the current level of ethnic monitoring in those agencies averages below 50%. However, those authorities which have given priority to this recording of ethnicity in their registers of disabled people, such as Sandwell and Wolverhampton, have greater confidence in the accuracy of their intelligence. The breakdown of registered black and minority ethnic users in Wolverhampton, categorised according to their disability, gives a reasonably representative profile of their distribution.

**Figure 4  Ethnic Analysis of Registered Disabled People in Wolverhampton**

<table>
<thead>
<tr>
<th></th>
<th>Physical Disabilities</th>
<th>Visual Impairment</th>
<th>Hearing Impairment</th>
<th>Sickle Cell</th>
<th>Multiple Disabilities</th>
<th>Totals</th>
</tr>
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<tbody>
<tr>
<td>Black Caribbean</td>
<td>155</td>
<td>21</td>
<td>15</td>
<td>7</td>
<td>4</td>
<td>202</td>
</tr>
<tr>
<td>Black African</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Black Other</td>
<td>16</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>19</td>
</tr>
<tr>
<td>Indian</td>
<td>967</td>
<td>68</td>
<td>24</td>
<td>0</td>
<td>19</td>
<td>1078</td>
</tr>
<tr>
<td>Pakistani</td>
<td>46</td>
<td>7</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>57</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Chinese</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>96</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>102</td>
</tr>
<tr>
<td>White</td>
<td>2828</td>
<td>240</td>
<td>275</td>
<td>2</td>
<td>74</td>
<td>3419</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>4116</strong></td>
<td><strong>341</strong></td>
<td><strong>321</strong></td>
<td><strong>10</strong></td>
<td><strong>98</strong></td>
<td><strong>4886</strong></td>
</tr>
</tbody>
</table>

Source: Wolverhampton Metropolitan Borough Council (1999)

High levels of recording ethnicity are not confined to urban areas with large concentrations of black and minority ethnic people. The local authority and the health authority in Norfolk have invested in a Joint Information Officer, specifically for black and minority ethnic needs. As a consequence, ethnicity is now recorded in 87% of all cases. Some authorities have introduced additional procedures in order to improve the capture of black and minority ethnic data. In Bedfordshire, a hospital checklist has been introduced, one of whose aims is to identify ethnicity because, for example, this information is not recorded on the standard BD8 diagnostic notification of visual impairment. A Primary Care Group (PCG) in Birmingham has started to pilot ethnic monitoring in its practices in advance of any statutory requirement, so other PCGs will be able to benefit from the lessons learned.
As Primary Care Groups are preparing to achieve Primary Care Trust status so they are re-examining their information systems. This is at the same time that many local authorities are seeking to upgrade their I.T. systems. It is vitally important that these agencies invest in systems that are compatible with one another, if there is ever to be a significant improvement in the quality of information held on black and minority ethnic patients/users with physical disabilities and/or sensory impairments. The use of new computerised geographical information systems (e.g. Swindon) should inform authorities more about the actual location of their black and minority ethnic service users.

The postal survey underlined the limitations of many local authority I.T. systems currently in use, more than half of which cannot readily be interrogated to identify the current number of black and minority ethnic users by their disability, still less to identify the services provided at what cost and with what outcome.

Figure 5  Local authorities reporting to know the numbers of black and minority ethnic service users by their disability (n=90)

<table>
<thead>
<tr>
<th>Category of black and minority ethnic service user</th>
<th>Number of authorities</th>
<th>% of responding authorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults with physical disabilities</td>
<td>39</td>
<td>42%</td>
</tr>
<tr>
<td>Adults with visual impairment</td>
<td>35</td>
<td>39%</td>
</tr>
<tr>
<td>Adults with hearing impairment</td>
<td>35</td>
<td>39%</td>
</tr>
<tr>
<td>Adults with blood abnormalities*</td>
<td>10</td>
<td>11%</td>
</tr>
<tr>
<td>Adults with dual or multiple disabilities</td>
<td>17</td>
<td>19%</td>
</tr>
</tbody>
</table>

* Several authorities reported that this information was held by the health authority but not shared with the local authority.

3.4 Research

A number of authorities have sought to augment their knowledge by commissioning local pieces of research. These include, amongst others:

- **Bournemouth** local authority and health authority have jointly researched the needs of refugees and asylum-seekers;
- Calderdale local authority and health authority have, under the auspices of their Better Services for Vulnerable People (BSVP) programme, jointly engaged the Policy Research Institute in Ageing and Ethnicity (PRIAE) at Bradford University to look at the needs of black and minority ethnic people with physical disabilities with particular reference to their rehabilitation requirements;
- Dudley commissioned a local black and minority ethnic voluntary organisation to undertake research into specific communities;
- Kirklees has similarly commissioned PRIAE to investigate the rehabilitation requirements of older ethnic people with physical disabilities, which may also provide insights relevant to younger members of those communities;
- Kirklees has also commissioned Leeds Metropolitan University to explore the needs of black and minority ethnic young people, aged 15-25 years, which will include those with a range of disabilities;
- Newham received some funding from the Home Office in 1995 for an extensive study into the needs of deaf and hard of hearing people from black and minority ethnic communities;
- Newham, Tower Hamlets & Hackney Health Authority has funded Deafblind UK to identify those from the black and minority ethnic communities with a dual sensory disability;
- Nottinghamshire researched the needs of black and minority ethnic people being served by the Outreach services from its Disability Living Centre;
- Oldham local authority and health authority carried out an in-depth study of a sample of individuals from their Pakistani and Bangladeshi communities in order to determine their health and social care needs;
- South Tyneside are undertaking a Health and Lifestyle survey of black and minority ethnic people in their area.

However, it is not enough to acquire this information, it has to be effectively analysed and used to inform service planning. This usually means safeguarding some resources in order to fund a programme of service change or development. Such funding has not always been available to act on the findings of research projects.
3.5 Access

Knowledge of the distribution and needs of black and minority ethnic individuals and communities is a pre-requisite of knowing how best to communicate with them about the services available. This is most challenging when such individuals are widely dispersed and/or belong to widely differing community groups. This increases the need to maximise resources across agencies and work with the voluntary sector to support access.

3.5.1 Publicity

Most authorities have translated their main service leaflets into the principal languages used in their areas but have often found that they are of limited benefit. This may be due to:

- the language used in translation being pitched at the wrong level or in the wrong dialect, especially if it has not been tested with a local readership;
- the leaflets not being systematically distributed to the most appropriate locations beyond social services offices, such as G.P. surgeries, religious or retail venues;
- low levels of literacy in target local communities and
- the cultural norm for such communication being oral.

For these reasons, some authorities have been more creative in their use of different media:

- Bradford is in process of producing a number of video tapes in the form of ‘soap opera’ styled plays;
- Kirklees issues a bi-monthly newsletter for the Asian communities, entitled Ujala; it has also created a video, in association with its local Race Equality Council, in four Asian languages.

Two authorities have run conferences targeted at black and minority ethnic communities: in 1998, Nottingham ran a conference on Race and Physical Disability and, in 1999, Rotherham arranged a conference for black and Asian carers. Rotherham has employed a black and minority ethnic link worker who disseminates information through a network of organisations, such as the All Pakistan Women’s Information Group. Birmingham Focus is one of the largest
black and minority ethnic volunteer organisations which has been effective in networking with other organisations from black and minority ethnic communities in raising awareness of visual impairment issues.

More direct communication is possible through networks of disabled people themselves. The Asian Disability Network in Bradford now numbers nearly 400 members. Leeds and Kirklees have established networks specifically for younger disabled members of black and minority ethnic communities. There are a few black and minority ethnic members of the Dorset network, which continues to operate also in the new unitary authorities within the former county boundary. The Internet offers opportunities for greatly extending the range of information made available through these networks.

### 3.5.2 Access Points

Newham, which has the highest proportionate black and minority ethnic population in the country, has an Equalities Access Charter. This sets the standard against which to measure how equitably services are being made available to the different black and minority ethnic communities. Such a benchmark exists in few other authorities. It is known from SSI inspections and Joint Reviews that public offices continue to vary considerably in their accessibility to physically disabled users and potential users. However, authorities across the country are reviewing their access arrangements. Access to community care services is being pulled in a number of different directions towards:

- more corporately integrated access either through “one stop-shops” dealing with enquiries for all council services;
- combined access to primary health and social care services, most usually based in GP surgeries;
- greater use of community-based facilities both more accessible and acceptable to larger numbers of people.

These developments may work to the advantage of black and minority ethnic disabled adults. Generic corporate access requires less detailed knowledge of council services before making contact. ‘Surgeries’ by Asian-speaking Occupational Therapists at access points in Bradford have extended their outreach into those communities. In Wandsworth, the Director chairs a Race Working Group which monitors progress in improving the accessibility and appropriateness of services to different communities, for which there are
specified targets in local action plans. The black and minority ethnic Welfare Rights Unit in Doncaster finds that it is able to facilitate access to a wide range of services. Access points combining Social Services with Health Services will diminish the stigma associated with seeking social care assistance, which remains strong in many black and minority ethnic communities. For that same reason, authorities such as Leicestershire find that access is more acceptable through voluntary organisations, especially those grounded in their local communities.

There is another trend towards call-centres for dealing with all phone enquiries, which will make access more difficult for non-English speakers, unless specific arrangements are made. Black and minority ethnic carers, with little or no English, express concern about the lack of emergency access to assistance via someone speaking their own language. North Staffordshire Health Authority is assisting the voluntary organisation DIAL to run an Asian Advice Line; Manchester has a Jewish helpline, but few other such schemes were identified in the survey. Oldham is seeking funding for an out-of-hours bi-lingual service. In preferring a separate, specialist service, black and minority ethnic disabled users and their carers may be at odds with campaigning disability groups, which are pressing for more integrated access arrangements.

It will clearly be important that any new access arrangements are introduced sensitively and that service users who have previously used specialist access routes e.g. specific to their sensory impairment or to their black and minority ethnic group are helped to adapt to the revised systems. This is particularly relevant to those with any hearing impairment who may lack the confidence to transfer to alternative systems, owing to their communication difficulties.

Authorities, such as Calderdale and Kirklees, are experimenting with video-links, text phones and e-mail to assist those with hearing impairments, linking social services offices with hospitals. Some black and minority ethnic disabled users are able to benefit from the Rothercare intercom system in council housing in Rotherham and the similar Carelink scheme in Bury.

3.5.3 Language and Interpretation Services

This study has confirmed that interpretation is one of the most problematic areas for black and minority ethnic disabled adults and their carers. Studies in Oldham and elsewhere have shown that as few as 10 per cent of black and minority ethnic users and carers (including younger adults) are comfortable communicating in English. A linguistic inequality reinforces a sense of powerlessness, particularly for disabled users. Birmingham Health Authority is seeking to address these issues through the development of an Integrated Language and Communication Strategy.
Some authorities have been notably more successful than others in recruiting or developing reception staff able to speak Asian languages. For example, Kirklees has, at its Social Services Information Points, 26 per cent black and minority ethnic staff, of whom 18 per cent are bi-lingual. Newham has a Language Shop where staff have a command of some 17 languages. Warrington and Harrow have a comprehensive programme to ensure that all field staff are trained in working with interpreters. Worcestershire has a long-established Ethnic Advisory Link Scheme (EALS) of volunteer interpreters, who give assistance to both health and social services staff. In common with other such schemes, it has struggled for funding, but now has secured a three-year contract from health and social services, boosted by some Charity and Lottery grants.

Most health authorities and trusts, where there is a significant black and minority ethnic population, have opted for appointing link or access workers with the necessary linguistic skills, plus access to an interpretation service, such as Language Line, rather than seeking specialist staff with those skills. The advantage of these staff is that they have both the linguistic skill and the requisite health/social services knowledge, although this may not extend to specialist knowledge of physical disability or sensory impairment. The majority of interpreting services lack this dimension of understanding.

Interpreters in Asian languages are, more usually, male, which can place female users or carers at a disadvantage. If a male user or carer is more proficient in English, communication may be directed towards him to the exclusion of the female partner, as the user/carer may choose not to pass on that communication. In such circumstances, the presence of a female advocate may serve to ensure that nobody is disadvantaged. Users and carers alike stressed the importance not only of the interpreters being appropriately trained but they themselves as well as staff needed training in how to work with interpreters. There continue to be instances where English-speaking children or relatives are asked inappropriately to translate for their disabled parents or other relatives.

### 3.5.4 Signing

Newham and a few other authorities have supported white and black and minority ethnic staff to acquire British Sign Language (BSL) skills, Levels 1 and 2. Barnet used some of its Partnership Grant to develop signing skills. Kirklees has built up these skills to the point that 18 per cent of reception staff are able to sign and, in common with an increasing number of other authorities, all of its reception facilities are fitted with a loop system to assist those who are hard of hearing. Wandsworth has a black sign interpreter, who is a member of the Sensory and Physical Disability Team. The interpreter assists individual...
users and also other local agencies, as well as supporting the Registration and Inspection Unit on statutory visits to residential homes where there are black and minority ethnic residents with a hearing impairment.

In recognition of the isolating impact of hearing impairment, Bradford has provided joint finance to a voluntary organisation (ABDA) to set up a support group for young deaf people and their parents from the black and minority ethnic communities. Such specific initiatives may be required because, as was found in the Newham and Nottinghamshire studies (see above), many black and minority ethnic adults with a hearing impairment do not use British Sign Language or any other recognised sign language, opting instead for lip-reading or, more often, their own home generated signs, which are only comprehensible to other family members. In such circumstances, other strategies of communication have to be developed, which may include training paid staff in the particular form of communication favoured by that individual. Time has, therefore, to be allowed to staff to equip themselves with the necessary communication skills in these situations.

3.5.5 Advocacy Services

The number of advocacy support services continues to grow but they are unevenly distributed across the country, according to the postal survey.

**Figure 6** Advocacy support schemes available to black and minority ethnic adults with physical disabilities and/or sensory impairment by SSI Region

<table>
<thead>
<tr>
<th>Region</th>
<th>Number of responding authorities</th>
<th>% of responding authorities by region</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central</td>
<td>16</td>
<td>80%</td>
</tr>
<tr>
<td>London</td>
<td>10</td>
<td>63%</td>
</tr>
<tr>
<td>North</td>
<td>12</td>
<td>38%</td>
</tr>
<tr>
<td>South</td>
<td>6</td>
<td>27%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>44</strong></td>
<td><strong>49%</strong></td>
</tr>
</tbody>
</table>
It was unclear from the survey the extent to which black and minority ethnic users and carers were accessing schemes specifically designed for those with physical disabilities and/or sensory impairment. This was certainly the case with Harrow Association of Disabled People. It was more self-evident where there were ethnic-specific schemes, such as the Organisation for Sickle Cell Anaemia Research (O.S.C.A.R.), the self-help scheme for those with Sickle Cell disorders, and specific organisations such as the Black Sisters Collective in Walsall or the Asian Stroke Association in Birmingham.

As with interpreters, there is a need for staff to be trained to work with advocates, rather than viewing them as being in opposition. It is also the case that with black and minority ethnic people with physical disabilities and/or sensory impairment, staff need to have a better understanding of when both an interpreter and an advocate are required. This would also help to counter the tendency to use the interpreter as a surrogate advocate. Kirklees has developed four videos for different black and minority ethnic communities to promote access to services as well as a self-advocacy booklet ‘Thinking Aloud’.

Because advocacy services are often developed opportunistically with short term funding, they can be very fragmented, even between health and social services. For that reason, Luton has created a Joint Commissioning Advocacy Manager to co-ordinate and consolidate these support services. In Wandsworth, the Health Authority has developed a project to enable community organisations to improve their own advocacy potential and effectiveness.
This chapter reviews the range of organisational arrangements and procedures for assessing and reviewing the needs of black and minority ethnic adults with disabilities.

4.1 Assessment

4.1.2 Organisational Arrangements

From the perspective of many disabled black and minority ethnic adults, the organisational arrangements for assessing and meeting their needs in both health and social services are fragmented and confusing, to an even greater extent than to the majority population. Some authorities, such as Harrow, have set up joint health and social services disabilities teams; others are in process of at least bringing occupational therapists, employed by health and social services, under unified management. It is the aspiration of many to co-locate such personnel in multi-purpose Disability Living Centres. The Royal Oldham Hospital has an Ethnic Health Team; Newcastle has joint-funded two part-time black and minority ethnic liaison officers, one based in the hospital and the other in the community. A number of authorities continue to contract out their services for visual and hearing impairment to major voluntary organisations. Access to those services is largely separated from that to other social services.

As was found in a survey in 1999 by the Tavistock Institute on behalf of the Royal National Institute for the Blind (RNIB), few authorities make special arrangements for visually impaired users from black and minority ethnic communities. 102 out of the 199 authorities in England, Wales and Northern Ireland responded to the survey (see Figure 7).
Figure 7  Special arrangements for visually impaired users from black and minority ethnic communities

<table>
<thead>
<tr>
<th>Percentage of local authorities with special arrangements</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist worker with black and minority ethnic</td>
<td>5.9%</td>
</tr>
<tr>
<td>and visual impairment brief</td>
<td></td>
</tr>
<tr>
<td>Specialist worker with black and minority ethnic</td>
<td>2%</td>
</tr>
<tr>
<td>but not visual impairment brief</td>
<td></td>
</tr>
<tr>
<td>A voluntary organisation provides services</td>
<td>2%</td>
</tr>
<tr>
<td>Ad hoc arrangements</td>
<td>3%</td>
</tr>
</tbody>
</table>

From this survey, there is little evidence of special arrangements for those with a hearing impairment. **Merton** has a **Hard of Hearing Resource Centre** which includes provision for people from black and minority ethnic communities. **Stockport** has a specific scheme catering for profoundly deaf people from the Asian communities.

### 4.1.3  Assessment Process

The assessment process itself can be daunting to many from black and minority ethnic communities. **Leeds** has produced a leaflet specifically for potential users from black and minority ethnic communities. **Wiltshire Health Authority** has issued a well-regarded leaflet, used by both health and social services personnel, entitled ‘Respect for Privacy, Dignity, Religious and Cultural Beliefs’.

**Sandwell** has gone further in commissioning an independent consultancy firm to produce a **Resource Pack for staff**, explaining key features of the main religions and cultural beliefs, bearing on the provision of health and social care. This includes a list of aids and equipment relevant to black and minority ethnic users (e.g. the lota, the watering jug used for ablutions). This list should assist with a general awareness but it is important that staff do not stereotype users and carers, concentrating instead on what matters to the individual in terms of his or her quality of life.

There is a gradually increasing understanding of the importance of the religious and cultural dimensions of caring but there is still a long way to go. It is of concern to black and minority ethnic organisations that many of the values and processes of health and social care remain essentially Euro-centric. In particular, the interpretation of privacy, dignity and independence can have
connotations that are alien to cultures that adhere to concepts of familial interdependence. Some authorities also reported that charging policies appeared to have a disproportionately deterrent effect on black and minority ethnic users accepting services. This may, in some cases, be due to a lack of understanding of the charging system and/or a failure to claim the benefits to which they are entitled.

Some staff can be dismissive of stances taken by black and minority ethnic users and carers because they do not appreciate their religious and/or cultural significance (e.g. an antipathy towards commodes). At a deeper level, some staff can betray impatience at the apparent passivity of service users, who see themselves as submitting to 'God's will', and need reassurance that services need in no way interfere with their faith.

It is repeated examples of insensitivity which deter many people in black and minority ethnic communities from ever seeking assistance. Advances in understanding need to be reflected through ongoing amendments to procedures but, in this survey, only 16 authorities (18 per cent of respondents) reported that they had revised any of their procedures in the last three years. This may, in part, be due to the fact that black and minority ethnic users and carers are significantly under-represented in the making of complaints.

On the other hand, anxiety or uncertainty about how to engage with black and minority ethnic users and carers can lead to an over-concentration on practical matters of personal care to the exclusion of offering emotional support to individuals who are struggling to come to terms with their disabilities. It was telling that, in the Nottinghamshire study (see above), 60 per cent of Asian female users gave as their highest priority emotional and social support. It is unsurprising that many black and minority ethnic users simply do not believe that non-black and minority ethnic staff can empathise with the sometimes overwhelming impact not only of racism within the host community but also of the strong prejudices against disability which may be still prevalent within some of their own black and minority ethnic communities.

Wiltshire funds an arrangement with its local Race Equality Council to assist in the assessment of the needs of the widely dispersed black and minority ethnic residents in the county. However, it is wrong to assume that the involvement of black and minority ethnic staff will of itself provide the bridge of understanding to all of the many and diverse black and minority ethnic groups. There is, ultimately, no substitute for the professional skills of active listening, informed by cultural understanding, in order to arrive at a full appreciation of an individual's needs and circumstances. Often it needs only a degree of imagination and flexibility, (e.g. as in the case of the stroke victim isolated at home, who declined the all-white day centre but pined to return to his old social club, without being offered the necessary transport assistance).
Precisely because authorities are still in the early stages of developing these combinations of skills, it is important that they have in place mechanisms to learn from casework experience and to revise their systems accordingly. It is, therefore, disappointing that only 16 authorities (18 per cent of respondents) reported that they had revised their procedures in the last three years, half of those authorities being located in Central Region.

4.1.4 Occupational Therapy

By far the greatest practical help that black and minority ethnic adults with disabilities seek is from the occupational therapy services. Authorities are beginning to address the unacceptably long delays for these services, particularly for adaptations. These delays can be compounded for black and minority ethnic adults where interpreters are needed for completing forms and translating the complexities associated with building work. The number of qualified occupational therapists from black and minority ethnic communities is slowly increasing, as is the number of occupational therapy aides from that background, but these services remain amongst the most difficult for black and minority ethnic people to access.

Delays can have a disproportionate impact on black and minority ethnic families with disabled members because, for cultural reasons, many are unwilling to accept paid domestic or personal care in the home. Examples were given to the study team of parents and partners who have injured themselves carrying adult family members up and down the stairs in the absence of the necessary adaptations. The range of acceptable service options may also be more limited for black and minority ethnic adults.

An increasing number of authorities are declining to provide adaptations, if there is an already adapted property within a reasonable distance, often provided by a Housing Association. For a variety of reasons, this may not be acceptable to any family, but there are additional social and cultural impediments for many black and minority ethnic families:

- the head of the house-hold may be reluctant to relinquish his hard-won owner-occupier status or fear loss of statutory benefits as a result;
- the move may distance the family from the support available from the wider family network;
- the family may fear racial harassment away from their local area.
The situation is further complicated where families occupy terraced inner-city housing, sometimes in hilly locations, which do not lend themselves to adaptation. This dilemma is particularly acute for families who have more than one disabled child approaching adulthood. Bradford is actively considering how it may equitably address the needs of such exceptional families. One option is whether projected revenue expenditure on personal care which is not acceptable, could be appropriately converted into capital funding for a suitable home environment for life-long family care. A partnership approach with a local housing association is another option, creating bespoke housing solutions for identified families, which is being actively pursued. An increasing number of authorities will need to confront this issue.

Where adaptations are agreed, black and minority ethnic families can be disadvantaged by the way that adaptations are designed and built. Stipulations that lifts should not interfere with gender segregation within the household or that toilets should not be installed facing towards Mecca may not always be accommodated or can become the focus of stressful disagreements. Kirklees has developed an Adaptations Consultations Forum, which means that all prospective recipients of adaptations become involved at the planning stage. It is also regrettable that some building contractors do not treat black and minority ethnic families with respect and sensitivity, sometimes for want of the appropriate advocacy support to the family. It is, therefore, incumbent on authorities to ensure that such contractors are appropriately vetted.

4.1.5 Carers

Most authorities are still in process of ensuring that they are in full compliance with the Carers (Recognition) Act. It is only the minority that have in place systems for monitoring whether carers have routinely been offered a separate assessment, so the practice is still patchy. Staff need training in how to apply the Act in culturally sensitive ways to black and minority ethnic communities. They need to have an appreciation of cultural norms operating in different communities (e.g. the acceptability of women going out to work). These norms are, of course, undergoing generational change at different rates in different families and communities.

Because there remains a heavy expectation in some ethnic families that its own members, usually the female ones, assume the total caring responsibility for any disabled member, carers may be seriously inhibited about articulating their own needs. It is, therefore, often necessary for the assessor to spend time explaining the purpose of any support or advice that is on offer in a way that reassures such carers that their role is not being undermined or that they are in any way failing in their ‘duty’ but rather ensuring that they will be enabled to go on caring by not placing their own health at risk.
In Slough and elsewhere, the Princess Royal Carers' Trust is sponsoring a number of carers' support groups, specifically for black and minority ethnic communities, because it recognises the degree of isolation suffered by many of these carers. Young Carers' Project workers are also beginning to uncover a growing number of black and minority ethnic youngsters who are being asked to shoulder unacceptable levels of responsibility for disabled adult family members. Their needs are likely to remain hidden without positive steps being taken to identify them, involving collaboration between social services, education and health service personnel.

4.1.6 Direct Payments Schemes

Direct payments schemes have not yet been established in all authorities and are still only small in scale, except where they have built on prior Independent Living Schemes. They offer the opportunity to service users to purchase directly services more customised to their individual needs and, as such, are of particular relevance to black and minority ethnic disabled adults. However, this is an opportunity that has only so far been extended to very small numbers of black and minority ethnic users, more especially in the London area. Overall, in the survey, only a third of the 90 responding authorities reported that they had black and minority ethnic users participating in their schemes.

A few authorities have specifically sought to involve black and minority ethnic adults in these schemes. Hackney has black and minority ethnic representatives on its direct payments planning group and the Bradford scheme is run by a blind Asian man. Organisations in other areas see the potential of direct payments schemes for black and minority ethnic adults. The Race Equality Council in Kirklees and the Birmingham Institute for the Deaf are actively researching possible beneficiaries. Luton translated the guidance material on its direct payments scheme into Urdu for one Asian service user. Other authorities commented that direct payments would need to be opened up more widely to carers before it would reach significant numbers of black and minority ethnic adults.

Authorities did seem to vary in the extent to which they used their discretion in permitting such arrangements. As yet, the services spot-purchased under direct payments by black and minority ethnic users themselves have not been significantly different from those offered to non-participating users, but their experience has usually underlined the lack of choice in available services that take due account of their cultural and religious needs.
This finding has been reinforced recently by a study commissioned by the Joseph Rowntree Foundation into the needs of young disabled people of Asian, African and Caribbean origin as they make the transition to independence and their current experience of education and social care agencies. This study goes on to make a number of suggestions on how these services might be improved (see details of the publication in the Bibliography).

4.2 Care Management

4.2.1 Care Planning and Reviewing

Although the proportion of users who receive a care plan setting out the services arranged for them is gradually increasing, it is still not standard practice for significant numbers of users. It is the exceptional authority that offers to translate the care plan into the language of the user’s choice or ensures that the plan is appropriately communicated through British Sign Language (BSL) in the case of deaf BSL users. Those who use speech amplification or lip-reading can be even more disadvantaged. It is interesting to note that because the National Mental Health Deaf Unit is located in Wandsworth, a number of people with this combination of disabilities have been attracted to live in the area.

Because of the difficulty that most black and minority ethnic disabled adults experience in accessing the care system in the first place, it is important that they have the continuity of a known care manager or key worker with whom to discuss their changing needs and requirements. Users and carers confirmed that having to re-engage with the system through an unknown duty worker was a major deterrent. Parents interviewed in the course of this study complained, as do many white parents, but with possibly greater bewilderment, about the difficulties in negotiating the transition between child and adult disability services. With the increasing numbers of black and minority ethnic disabled youngsters in some authorities, this is such a significant problem that it may justify the appointment of a specialist transitions worker.

An increasing number of authorities are implementing a differentiated approach to the reviewing of care plans, prioritising cases according to the risks involved and/or the volatility of the needs. In such circumstances, black and minority ethnic users may miss out because of a general reluctance to press their demands. In other words, there is a case for affording a priority to black and minority ethnic users on the grounds that it is necessary for the authority to be pro-active in its reviewing in order to ensure an equity of service. The need for such a priority is highlighted by the instances of services never being re-instated after a user has visited relatives abroad, for example.
This chapter reviews the progress that local authorities and health authorities are making to improve the range of culturally appropriate services for black and minority ethnic adults with disabilities.

### 5.1 Joint Planning Structures

In the postal survey, authorities were asked to confirm whether they had joint planning mechanisms in place for addressing the needs of those with physical disabilities and/or sensory impairments. Approximately two thirds of responding authorities answered in the affirmative (see Figure 8).

**Figure 8  Number of authorities with joint planning mechanisms in place for those with physical disabilities and sensory impairments**

<table>
<thead>
<tr>
<th>User-Group</th>
<th>Number of authorities</th>
<th>% of responding authorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical disabilities</td>
<td>61</td>
<td>68%</td>
</tr>
<tr>
<td>Sensory impairments</td>
<td>52</td>
<td>58%</td>
</tr>
</tbody>
</table>

n = 90

However, this response is more than halved when authorities were asked to state whether they had joint planning mechanisms in place either for black and minority ethnic people in general or for those with physical disabilities and/or sensory impairments (see Figure 9).

**Figure 9  Number of authorities with joint planning mechanisms in place for black and minority ethnic people in general and for those with physical disabilities and/or sensory impairments in particular**

<table>
<thead>
<tr>
<th>User-Group</th>
<th>Number of authorities</th>
<th>% of responding authorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black and minority ethnic people in general</td>
<td>32</td>
<td>36%</td>
</tr>
<tr>
<td>Black and minority ethnic people with physical disabilities and/or sensory impairments</td>
<td>23</td>
<td>26%</td>
</tr>
</tbody>
</table>

n = 90
There has been considerable organisational turbulence in both local authorities and health authorities in the last few years. Indeed, that change is continuing in Health as Primary Care Groups are accelerating their progress towards Trust status and the provider Trusts are being re-configured. At the same time, the long-established joint planning arrangements between health and local authorities are giving way to new structures in which the focus of joint planning and commissioning is shifting to the more local level of the Primary Care Trust on which there is social services representation. In many authorities there has, therefore, been some degree of hiatus or confusion as new and old arrangements have continued in parallel existence.

These changes are bringing to the fore some of the differences in approach towards the involvement of wider stakeholders in the planning and commissioning process as between local authorities and health authorities. Many of the former have been progressively extending the involvement of users and carers and/or their representatives into all levels of service planning and commissioning, whereas health authorities and trusts have tended to concentrate on the appointment of link workers to improve their outreach to black and minority ethnic communities. Both approaches have been subject to criticism from both the black and minority ethnic and the disability lobbies: local authorities for not enabling genuine involvement by black and minority ethnic representatives beyond mere tokenism and health authorities for not paying sufficient heed to the user and carer voice.

As with the services themselves, progress in the joint commissioning of better services for black and minority ethnic people has been hampered by a continuing ambivalence/division of opinion both within and between the black and white communities about the relative merits of integrated mainstream or separate specialist provision. This has been reflected in the range of joint planning arrangements in the past. The majority of authorities have sought to address black and minority ethnic needs in an integrated way through their planning and development groups for each user-group. In only a few authorities, like Leicestershire, is there a specific planning sub-group for dual sensory disability. Black and minority ethnic representation tends to be very limited in such generic forums so communities, especially those where there are larger numbers of ethnic minority people, have increasingly opted to create their own planning groups to press for service improvements. This may take a variety of forms, for example:

- an umbrella forum of black and minority ethnic groups in Sandwell;
- a Black and Racial Minority Interest Group which feeds into the Community Care Alliance in Wandsworth;
- Black Community Care Forums in Reading and Waltham Forest;
• black and minority ethnic advisory groups contributing to both health and social care planning have been set up in **Stoke-on-Trent** and **Oldham**;

• a local authority group focusing specifically on services to black and minority ethnic people in **Sunderland**;

• ethnic advisory groups shadow all of the joint commissioning groups in **Luton**, with separate Reference Groups for hearing and visual impairment and dual sensory disability;

• a black and minority ethnic Health Forum in **Bolton**;

• specific Disability Alliances have been formed for the Black and Asian communities in **Newham, Swindon** and **Bradford**.

Some of these groups tend to feel that they are marginalized from the mainstream of service commissioning. **Nottingham** was among the first authorities in 1998 to ensure that there were black and minority ethnic representatives on both the Joint Commissioning Group and the Primary Care Group Panel.

Some black and minority ethnic representatives express concern that black and minority ethnic disabled adults may be disadvantaged by the ongoing changes in organisational arrangements and planning procedures. The first of their concerns is that minority group needs will suffer from more localised commissioning at Primary Care Group (PCG) level, since commissioning for their needs may still more appropriately be done on a pan-PCG basis and such collaboration will take time to develop. Secondly, they voice fears that the centrality of Primary Care Groups in the new planning firmament could mean either that:

• services become increasingly ‘medicalised’ to the detriment of the widely preferred social care model of disability; and/or

• that these smaller units of commissioning increase the current inequity of provision.

There is already some evidence that some Primary Care Groups are giving very different levels of priority to this area of work. This usually accords, as in **Peterborough**, with where there are the higher concentrations of black and minority ethnic patients, but this is not always the case; **Wirral PCG**, for example, is funding a project for black and minority ethnic men.

Another **NHS** development proving beneficial for black and minority ethnic communities, particularly for those in major conurbations, such as in **Rotherham, Doncaster** and **Bradford**, is the innovation of **Health Action**...
Zones. Many of these have given express priority to the social integration of black and minority ethnic adults into their local communities. The concern relating to Health Action Zones is that their short term remit will come to an end before they have been able to make a permanent and substantive improvement in services to black and minority ethnic disabled adults. More forward planning is needed to ensure that successful short-term funded projects are progressively integrated into mainstream funding.

In order to make lasting changes, it is essential that the black and minority ethnic dimension, in all of its local manifestations, is given access to the planning and commissioning process. The complexity of the resultant arrangements can be seen from the map of the multifarious participants to the process in Kirklees (Figure 10).

These arrangements will necessarily grow as new initiatives are introduced. The most recent such development is the creation of some 50 multi-agency Low Vision Committees across the country. These have a particular relevance to black and minority ethnic people because of their greater predisposition to visual impairment.

**Figure 10 Map of joint planning arrangements in Kirklees for Black and minority ethnic services**

ADSS = Association of Directors of Social Services  
BIG = Black Issues Group  
HACCCA = Huddersfield African Caribbean Council of Churches and Associates  
KREC = Kirklees Race Equality Council  
REU = Race Equality Unit  
Source: Kirklees Metropolitan Borough Council 1999
5.2 Organisational Arrangements

It is essential that all agencies take stock of their organisational arrangements, in the light of the Macpherson Report on Stephen Lawrence, to ensure that they are not, wittingly or unwittingly, institutionally racist in the way that they commission and/or directly provide services. Some authorities have recognised that they have to adopt a comprehensive organisational development approach to instil the appropriate values and revise the associated processes. Bedfordshire Health Authority and Huddersfield NHS Trust are two examples of where such an approach is being implemented. Following a recent survey of all Health Authorities and NHS Trusts in London, the NHS Executive has identified the stages in the progress of an organisation towards being ‘culturally competent’ and produced recommendations to help authorities with that process, including the introduction of black health advocates (‘Sick of being Excluded’ see Bibliography).

Increasing numbers of authorities are establishing Joint Commissioning Units with their health authority counterparts, but the majority of these are focused on mental health and learning disability services. Some of these Units, such as the one in Suffolk, have forged links with their local Race Equality Council, as a way of addressing the black and minority ethnic dimension. Other authorities, such as Trafford, have created a Race Equality Commissioning Officer; Rotherham, too has a specialist Joint Commissioning Development Officer.

In many cases, these Units pre-dated the requirements to produce Joint Investment Plans (JIPs) for these user-groups. There is no such general requirement to produce a Joint Investment Plan for those people with physical disabilities and/or sensory impairments. However, there is the more specific requirement to prepare a Joint Investment Plan under the Welfare to Work programme, which necessarily includes how Health and Social Services are collaborating with education and employment agencies to improve the chances of disabled adults to secure employment. It remains regrettably the case that black and minority ethnic adults continue to face discrimination in the labour market, which means that pro-active measures are required to assist black and minority ethnic adults with disabilities into employment.

Health and Social Services can assist in this regard by setting an example with their own employment policies and practices. Luton has an Equalities Unit in Race and Disability which includes a joint planning post to ensure a black and minority ethnic input to the work of Voluntary Action, Luton; Stoke-on-Trent has used Joint Finance to fund a similar development worker. Bradford has created a number of Positive Action traineeships for black and minority ethnic...
staff, including two posts supporting the Community Development Officer working with voluntary black and minority ethnic organisations in the District. Authorities, such as Wandsworth and Cambridgeshire, have taken steps to ensure that small black and minority ethnic organisations are helped to submit tenders for services. As a result, Wandsworth now has a number of ‘Care Provider Projects’ offering a range of specialist services to the local black and minority ethnic communities.

Harrow stands out as a local authority which has elevated the capacity-building of black and minority ethnic organisations to a central role in its drive to improve black and minority ethnic services. This authority has decisively resolved its integration/segregation dilemma by recognising that black voluntary organisations are more readily accepted as service providers by most people in the black and minority ethnic communities, but that they currently lack the infra-structure to provide services of either sufficient volume or quality. Kirklees has adopted a similar approach but both authorities have been careful to ensure that the commissioning of these services has not become marginalized but is fully integrated within mainstream commissioning strategies. This is in contrast to many authorities which adopt a twin-track approach of trying to make all of their services more culturally appropriate, at the same time as grant-aiding voluntary sector organisations to provide specialist or ethnic-specific services. The dangers of this approach are that:

- neither aspect of the policy is adequately resourced nor pursued with sufficient managerial vigour;
- a two tier service delivery model develops which detracts from the policy of seeking to ensure equity of access to a range of quality services.

5.3 Commissioning Plans

There is an increasing expectation upon all statutory service-commissioning bodies that they will, at the very least, co-ordinate their commissioning strategies, if not formally combine them. This partnership working is meant to find expression in the commissioning plans of these bodies, whether that be the Community Care Plans and Housing Strategies of local authorities, the Health Improvement Plans of health authorities or, where so far required, in the Joint Investment Plans of health and local authorities.

Unfortunately, historically, black and minority ethnic and/or physical
disability/sensory impairment issues have not figured prominently in these documents. In 1998, the Royal National Institute for the Blind (RNIB) published an analysis of Community Care Plans from 80 per cent of all authorities in England and Wales for 1995 and 1996. This revealed that in the first year only three Plans made reference to visual impairment in connection with black and minority ethnic communities, despite the higher incidence of glaucoma in African Caribbean communities and diabetes-related visual impairment in the Asian communities. The number of Plans with specific references doubled in the second year but only one of those Plans set a measurable target.

Successive guidance to both local authorities and health authorities has exhorted them to develop race equality or race action plans. Ideally, in local authorities, these plans should have a corporate, cross-departmental dimension. Bury, for example, has an equal opportunities housing strategy. A number of authorities, like Sandwell, have given priority to working with black housing associations, such as ASRA, which have schemes combining general and special needs housing. Under the Scheme families can live adjacent to their disabled relatives whilst the Scheme still provides the latter with a measure of independence if that is their preference. Wandsworth reported having a scheme of five one-bedroom flats with floating support, specifically for young adults with Sickle Cell anaemia.

Some authorities are striving to engage all of their service departments in this agenda; Sutton, for example, has an Ethnic Well-Being Strategy, whereas a significant number of other authorities, including Sefton, Wirral, Wakefield and Warrington report that they are continuing to research the needs of black and minority ethnic communities before finalising their strategies. Leicestershire is using the services of the Ethnic Research Centre at Leicester University to investigate need to specified parts of the county. In Hammersmith and Fulham, the Health Authority is reviewing all of the services outlined in its Health Improvement Programmes for their cultural appropriateness.

It is the dearth of intelligence about the extent and nature of the disabilities amongst black and minority ethnic people that has meant that the majority of authorities are predominantly reactive in spot purchasing services for individuals, rather than in seeking to promote service developments through cost and volume contracting to meet anticipated demand. The current position in most authorities is as a result of largely opportunistic piecemeal development.
That is why the Policy Institute in Ageing and Ethnicity at Bradford University now advocates the “pomegranate” model of service provision for black and minority ethnic users, that is to say, the integration of the often disparate small-scale schemes for different groups. This is the approach being adopted in Hammersmith and Fulham.

Bringing such schemes together in multi-purpose resource centres provides not only powerful symbols of multiculturalism but also maximises the scope for cross-referral and interdependent support. This is important for a significant number of black and minority ethnic adults with disabilities, who fall prey to depression and/or other mental illness as a result of their social isolation or lack of life-chances. Resource centres, such as those in Birmingham, offer support to such individuals in a non-stigmatising setting. The local authority in Harrow and the Brent and Harrow Health Authority have developed this approach into a comprehensive strategy for community involvement with designated staff to implement the approach.

Some authorities, which have experimented with small block contracts, have sometimes been unable to fulfil them. This is because either they have miscalculated the numbers or, more usually, they have failed to research the views of the potential users and carers (without raising their expectations inappropriately) or to market the services to the target communities, when the services have been established. Meals on Wheels services for elderly and disabled black and minority ethnic service users are a case in point because they have been under-subscribed in some areas, especially when provided from a non-black and minority ethnic source. This might be because, for example, potential recipients are not convinced that Halal meat has been appropriately certified by an Imam.

It is a continuous learning curve, even for black and minority ethnic organisations, to understand what services are acceptable to local communities. So, for example, in Slough, the PARVAAZ organisation learned early on not to refer to its activity evening for disabled young people as a ‘youth club’ because of the unhelpful Western connotations of that term. As well as introducing a session for young women only, to cater to the concerns of parents unhappy for their daughters to attend mixed groups, the organisers have also added the opportunity for educational assistance as another selling point to parents. By expanding festive celebrations to involve the wider community, with the aid of sponsorship from local black and minority ethnic restaurants, this organisation is helping to break down prejudices against disability within that community. The development of a Bangra group of disabled young people giving paid public performances, has done wonders for the self-esteem of those young people and their families, but this organisation has had to divert much of its energies to securing a succession of short-term funds in order to keep going.
This example bears out the findings of recent research in Warwickshire by Coventry University and by Black Disability Action. These showed that neither statutory or voluntary organisations were effectively meeting the needs of black and minority ethnic disabled people and that it is a fallacy to assume that black organisations are necessarily in tune with the needs of multifarious black and minority ethnic groups.

The difficulties that some of the pioneer black and minority ethnic participants in direct payments schemes have experienced in accessing or creating services of choice are beginning to influence wider commissioning practice. In that sense, they are acting as self-selected focus groups, whose views may provide a helpful guide to service development priorities. Leicestershire is examining the possibilities of using its Adult Placement Scheme to provide short-term breaks that cater for needs in a more individualised way. Dudley is looking to expand the range of its day-care opportunities for young black and minority ethnic adults with disabilities. The feedback to this study from several such adults and their parents was that they would welcome more educational and employment opportunities. Bradford College, for example, had established access courses for more disabled students but a number of young people from the black and minority ethnic communities had been unable to take up these courses for want of the necessary health support.

In a number of authorities, sheltered workshops for disabled adults have either been closed in the recent past or they have been transferred into the independent sector. Where such sheltered employment has been preserved, as in Peterborough, it is valued by its black and minority ethnic employees, because it is regrettably still the case that, in most areas, black and minority ethnic people have even less prospect of securing employment in the open market than their white counterparts. The exclusion from employment is the greatest disadvantage experienced by many black and minority ethnic disabled adults, undermining their self-esteem and making them feel valueless within their own communities, often to the point of inducing depression.

A number of authorities, such as Newham have tried to take full advantage of recent employment initiatives, like the New Deal for Disabled People, to benefit black and minority ethnic disabled adults. Kirklees has a targeted Worklink scheme which is closely co-ordinated with the Careers and Employment Services. Luton provides Personal Advisers for black and minority ethnic disabled adults seeking to move on from Supported Employment into open employment and has commissioned the voluntary organisation Outset to research the employment needs of black and minority ethnic disabled adults in the area.
The growing numbers of black and minority ethnic adults with physical disabilities and/or sensory impairments will require both health and local authorities to be more pro-active in their commissioning strategies for all services. Although the age profile of most black and minority ethnic communities is still younger than that of the majority population, it has been evident for some time that some disabling conditions, such as arthritis, strokes and heart disease, are more prevalent in some black and minority ethnic people at a younger age, thus calling in to question some age-related eligibility criteria for receiving day care for example. Rotherham has introduced day care for Asian women aged over 55 years and Wolverhampton has adopted a similar policy for men.

The groups of black and minority ethnic disabled adults for whom little or no commissioning of services is yet taking place are those who are refugees or seeking asylum, not least because knowledge of their needs and whereabouts is so scant. Uncertainties and changes in relation to the respective responsibilities of local and central government and the progressive dispersal of these individuals around the country have also fed into the difficulties. It is, nevertheless, of concern that some black and minority ethnic disabled refugees and asylum seekers have experienced difficulties in accessing the most basic of care, such as registration with a GP. Harrow is one of the few authorities in this study which reported using Joint Finance to assist refugees through a Small Initiatives Fund; Merton has an Asylum Welcome scheme. As organisational arrangements become more settled, it will be important that those authorities which have rapidly gained experience in this area share their learning with others which are only just beginning to confront the challenges posed by these individuals.
This chapter reviews the approaches that authorities are taking towards ensuring the quality of services provided to black and minority ethnic adults with disabilities.

6.1 Standards

A growing number of authorities are undertaking baseline audits of the cultural appropriateness of their services, often using the standards promulgated for local authorities by the Commission for Racial Equality in “Racial Equality means Quality”, first published in 1995. Some authorities recognise that they are still at Level 1 or 2 in terms of their current performance, whereas others, such as Portsmouth, lay claim to Level 3. Stoke-on-Trent has used these standards to produce a service monitoring form. Kingston-upon-Hull has developed Access Standards based upon Part 3 of the Disability Discrimination Act 1995, which form part of more comprehensive guidance on equality standards. Leicestershire Health Authority has a feedback project with its own 12-point checklist for evaluating health equality.

In the postal survey, 49 authorities or 54 per cent of the sample reported that they had service specifications that ensure relevance to both disability and cultural appropriateness. The proportion rose to 75 per cent of the London Borough responses. This indicates that just under half of authorities country-wide have yet to integrate these dimensions into their standards. Many of these authorities have very low proportions of black and minority ethnic residents in their populations but it could be argued that this makes the articulation of standards for that small minority all the more important.

Standards are more powerful where they are related to performance indicators, so that their translation into practice can be more readily monitored. Only 16 authorities, (or 18 per cent of the survey sample), reported that they had developed such indicators. They included such disparate authorities as Brent, Kingston, Wandsworth, Bath and North East Somerset, Luton, Coventry, Trafford and Cumbria. The next challenge facing authorities is to come up with outcome measures which are able to demonstrate in what ways services are having a beneficial effect on the lives of black and minority ethnic users and carers.
While there is a need for specific service standards relating to black and minority ethnic services, it is also necessary for those standards to be integrated within an overall performance management framework. The local authority and the NHS Trusts in Oxfordshire devised a comprehensive set of Race Equality Standards to apply in evaluating their three-year service development programme, covering the four areas of policy and planning, communication, service delivery and employment. Newham has adopted a Total Quality Management approach, which incorporates an evaluation of cultural appropriateness. A significant number of authorities are turning to the Business Excellence Model as their overarching framework, but none of the authorities responding to the survey reported that they had so far applied this model to their black and minority ethnic services.

Most authorities are now well advanced in converting their grant aid arrangements with service-providers to black and minority ethnic users into Service Level Agreements. These include each authority's interpretation of the standards of care to be maintained. In some authorities, like Walsall, the local authority and health authority have agreed common standards. Some of the authorities responding to the survey helpfully enclosed copies of their specifications. Typically, they include specifications in relation to mobility and sensory loss and the cultural dimensions of personal care, diet, religion and death. However, they vary considerably in their scope and detail. Harrow, for example, has a Code of Practice for service providers on the use of interpreters of spoken languages and British Sign Language. Birmingham has published Lifetime Home Standards, including black and minority ethnic dimensions, with which all providers contracting with the authority are expected to comply. Several of the responding authorities commented that they would welcome some national guidance on such standards to ensure a greater consistency of service. With the advent in the near future of independent Care Commissions, regulating not only residential and nursing care but also domiciliary care for the first time, there may be a better prospect of such standardisation.

A number of local authorities contended that it would significantly benefit the priority given to all black and minority ethnic user-groups, if specific indicators related to those services were added in to the Performance Assessment Framework (possibly a sub-indicator to the analysis of the ethnicity of people receiving an assessment and of those receiving a service following assessment (Indicators E47 and E48)). This would mirror the expectation set out in ‘The NHS Plan: a plan for investment, a plan for reform’ which envisages that local action on tackling health inequalities and ensuring equitable access to health care will be measured and managed through the NHS Performance Assessment Framework.
One authority went so far as to suggest that there should be more active enforcement of Section 71 of the Race Relations Act 1976, under which local authorities and the Housing Corporation have a general duty to promote equality of opportunity and good race relations and to eliminate unlawful racial discrimination when carrying out their work. If the current Race Relations (Amendment) Bill passes into law, this will strengthen the existing Race Relations Act by introducing a statutory duty to promote race equality and by outlawing indirect discrimination.

6.2 Monitoring Systems

Standards are, of course, only meaningful if the systems are in place to monitor compliance. As the Joint Reviews of Social Services Authorities by the Department of Health/Audit Commission continue to find, performance management both in relation to directly provided services and those provided in the independent sector is generally under-resourced. Contract compliance officers are usually too few in number to be anything other than very selective in the monitoring that they undertake. The Audit Commission has urged authorities to develop a mix of contracting approaches, depending on the local market in such services, recognising that block contracts give providers a greater security of funding on the basis of which to develop their performance management infra-structures.

The majority of service providers to black and minority ethnic adults with physical disabilities and/or sensory impairments are small, not-for-profit organisations, whose level of funding rarely permits investment in formal performance management systems. The same applies to most small-scale providers from whom service packages are individually spot-purchased. As authorities are looking to bear down on their contracting on-costs by moving towards more preferred providers, who are expected to ensure their own performance management, so these predominantly small providers become more vulnerable under this contracting regime.

For this reason, some authorities have created designated posts not only to develop services to black and minority ethnic service users but also to monitor their quality. Bath and North-East Somerset, for example, has a Race Equality Project Manager who reports to a Race Equality Development Group; Bournemouth too, has an ethnic monitoring group. Other authorities have involved their local Race Equality Council in service reviews, not believing that they have the necessary expertise within their own staff and/or wanting a degree of external independence. A few, such as Newham, have opted for
external consultants, some of whom are disabled themselves. **Blackburn with Darwen** are using their Partnership Grant for an extended three-year “whole systems” review of all physical disability and sensory impairment services across all agencies.

### 6.3 Quality of Service

Feedback to this study suggests that the quality of some services targeted to black and minority ethnic users and carers continues to be of variable quality. The most frequent complaints related to the lack of punctuality of transport and the poor quality and lack of choice in some specialist meals services. However, the most concerning issue is the reported variability in the quality of care managers, because it is the quality of the care manager which is the major determinant of the quality of the service. This concern of black and minority ethnic users and carers echoes that of many white disabled users and carers.

In a significant number of authorities, the care management of physical disability services is combined with that for older people, the volume of which far outweighs that for physical disability. As a consequence, care managers have limited opportunity to develop the necessary specialist knowledge of disabilities, which would enable them to give authoritative advice and assistance. The move towards integrating such care managers into primary health care teams is likely to increase the generic demands upon them, reinforcing the need for multi-disciplinary teams in physical disability and sensory impairment to give specialist support. Still further specialist knowledge is needed to deal appropriately with the racial and cultural dimensions of disability, thus further reducing the prospects of providing a quality service, unless active measures are taken to recruit and train staff in the required numbers with these combinations of skill and experience. Most authorities acknowledge that they currently fall a long way short of that goal.

### 6.4 User/Carer Involvement

In recent years, local authorities have been involving users and carers more and more, either in feedback questionnaires or in service review exercises directly in advance of the requirement to do so as an integral part of their Best Value reviews of all services on a five-year cycle. There is less history of black and minority ethnic users and carers being involved in the original framing of the standards of service to be expected. In the postal survey, 32 authorities (or 36 per cent of the sample) reported that service specifications had been improved by user/carer input.
• **Kingston** carried out a survey of their black and minority ethnic users in 1997;

• **Harrow** selected 50 black and minority ethnic users to participate in their Best Value review of home care;

• **Sandwell** has ensured the participation of black and minority ethnic users in its reviews of its Occupational Therapy and Joint Equipment Store, as well as its day care services; **Nottinghamshire** did likewise when reviewing the services delivered from its Disability Living Centre;

• **Newham** invited 250 black and minority ethnic disabled users to contribute to the Best Value review of their services.

Health authorities have historically been less inclined to involve patients and their carers in their reviews of services but some lay involvement is increasingly seen as essential in order to have public credibility. Users and carers are able to have more of an impact when they have an informed and continuing role in service development. It is, therefore, encouraging to see the growth of patient reference groups being set up to advise Primary Care Groups. For example, the Ladywood Primary Care Group in **Birmingham** has established a Reference Group on diabetes in which black and minority ethnic patients are evaluating new models of care on an ongoing basis.
This chapter reviews the ways that authorities finance services to black and minority ethnic users with disabilities and how effectively those resources are used.

### 7.1 Sources of Funding

This study has again confirmed that the majority of recent initiatives for black and minority ethnic adults in both social and health care have been financed from short-term funding sources, whether they be time-limited specific grants from central government or finite amounts from voluntary Trust Funds, such as the Joseph Rowntree Foundation.

Some authorities are imaginative in the diverse sources of funding that they use. Single Regeneration Budget (SRB) funds, Partnership and Challenge Funds are being used in authorities, such as Calderdale and Kirklees, to finance health promotion schemes, aimed at reducing the incidence of heart, anaemic and diabetic conditions in black and minority ethnic communities. SRB funds have been used to train up access workers in Harrow and in Oldham to recruit interpreting link workers for GPs. The latter authority has also accessed European Social Fund monies to fund race awareness training and to set up co-operatives, which include black and minority ethnic adults with disabilities, under the Pathways to Employment initiative. Other authorities have had recourse to Joint Finance; Bedfordshire, for example, funded the development of its interpreting service in that way. The same authority secured funding from the Innovation and Good Practice Grant, provided by the Housing Corporation to research ethnic housing needs, including that for mobility housing.

However, the longer-term survival of these schemes can be problematic. It is the exceptional authority that thinks ahead to the longer-term integration of these initiatives into their mainstream funding and ways of working. Nottinghamshire, for example, is already planning on integrating the pilot outreach services to black and minority ethnic communities from its Disability Living Centre into its mainstream provision. Sandwell local authority and health authority have combined to fund a joint Project Change Manager for a three-year period to ensure that its black and minority ethnic initiatives are
impacting on mainstream provision in a permanent way. In its consultancy work, the Policy Research Institute in Ageing and Ethnicity (PRIAE) at Bradford University is very clear about the need to project manage change over a number of years and to devote dedicated management time to that process.

Many authorities now divide their grant-aiding of voluntary sector organisations according to purpose. If it concerns community development, this funding is handled through the Chief Executive’s Department (or Community Development Department), whereas the Social Services Department deals with more targeted social care provision. Many of the short-term schemes mentioned above, funded from external sources, fall on the cusp of these two purposes, so may not be picked up by either for longer-term funding. This division of funding responsibility has a particular resonance for many black and minority ethnic organisations which operate an open access policy encompassing both disabled and non-disabled people, so they have difficulty in qualifying for either stream of funding. It is the perennial complaint of these organisations that they are asked to provide mainstream services on marginal, often insecure funding, plagued by the loss of key staff, amidst the constant changes in funding and having to re-train their replacements.

7.2 Best Value

The Best Value regime by which local authorities, but not as yet health authorities, are required to abide, offers the best prospect of progressively absorbing the costs of short-term black and minority ethnic initiatives into mainstream budgets. It is already evident from some of the Best Value Performance Plans local authorities are now required to produce, that this discipline is driving managers to relate resource allocation much more closely to the achievement of measurable objectives.

The Best Value agenda also requires local authorities to contrast and compare both the cost and quality of the services provided by local authorities themselves with those provided by the independent sector. In many cases, this is likely to show that the latter are comparatively under-funded, leading to some reappraisal of the appropriate level of funding. A recent report by the Association of London Government (see Bibliography for details) called for increased investment in the black and minority ethnic voluntary sector, with the emphasis very much on services specifically designed for black and minority ethnic user-groups. That same report also calls on NHS Trusts to be much more pro-active in countering the health inequalities experienced by black and minority ethnic communities.
It is to be hoped that Best Value will challenge the fragmentation of funding and accountability, helping to bring about more coherent and integrated commissioning of services for black and minority ethnic disabled adults. The Association of London Government contends that this would be greatly assisted by better co-ordination at the level of government departments. Authorities are encouraged to undertake service reviews that cut across departments, as one way of promoting co-ordination at the local level. In order to undertake these reviews effectively authorities will need to identify and to commission advocates with an understanding of the needs of disabled black and minority ethnic adults to assist in this auditing.

Best Value is likely to identify that a plethora of short-term schemes is not the most-effective way of achieving results, not least given all the recurrent on-costs of recruitment alone. More developed analyses of supply and demand should also lead to more sophisticated contracting and more partnership working with preferred providers to develop new or different services in advance of anticipated demand, both of which will produce some efficiency savings.

However, it must also be recognised that there are some additional costs associated with the provision of culturally appropriate services. Commissioning authorities have tended to underestimate these costs, which have often been borne by black and minority ethnic not-for-profit organisations out of their own resources. There are commissioning on-costs for researching new areas of need, in providing the necessary communication supports but, more particularly, on the provider side incurring the costs of gender segregation or separate equipment for Halal cooking. Enquiries made on study visits indicated that commissioning authorities have yet to develop any meaningful costing of black and minority ethnic services, so that these figures can be factored into their commissioning strategies.

As Best Value drives authorities to make more cost-effective use of resources and to re-evaluate the equity of resource allocation on the basis of need, so it is likely that authorities will need to consider the de-commissioning of some existing services for the white majority of patients/users in order to fund services for black and minority ethnic disabled adults at a more equitable level.

7.3 Employment and Workforce Planning

Most authorities now subscribe to the policy that their workforce should be broadly representative of the populations they serve. Authorities are, however, also anxious not to end up with a policy in which black and minority ethnic people are only served by other black and minority ethnic people. This leads to ambivalent situations in which black and minority ethnic staff are employed
both in general roles and on ethnic-specific projects. The former are often subject to considerable pressure to advise and support white colleagues in dealing with black and minority ethnic users and carers without themselves seeking similar assistance in reverse. The latter can find themselves trapped in specialist roles, unable to progress on to more general roles if that is their wish.

With a few exceptions, most authorities fall short of recruiting the proportion of black and minority ethnic staff required by their policy. Some are pro-active in setting recruitment targets, developing management training and investigating any loss of black and minority ethnic staff, whereas others eschew target-setting and the like. It is clearly helpful if there is a corporate drive behind this employment policy, as in Harrow. With similar backing, Wandsworth now has a Sensory and Physical Disability Team able to offer services to people of diverse ethnic origin across the whole spectrum of physical disability and sensory impairment.

In some areas, authorities have made more use of the legal provision to recruit black and minority ethnic staff for specific posts (section 5(2)(d) of the Race Relations Act 1976). Bradford has recruited and sponsored the training of two Asian Occupational Therapists, as well as continuing its other Positive Action traineeships. Leeds has actively sought to promote the recruitment and training of black and minority ethnic disabled staff. As necessary, Rotherham has employed individual Pakistani home carers, where this has been the specified preference of the Pakistani user.

Because black and minority ethnic staff remain few in number in most authorities, they value the opportunity to come together in support groups. This has a spin-off benefit for black and minority ethnic users and carers, where these groups are enabled to exercise a sensitising influence on service planning and development. It is, nevertheless, the case that some black and minority ethnic staff leave in frustration at not being able to make sufficient impact, opting instead for the comparative insecurity of working in the black and minority ethnic voluntary sector. Yet others remain dissatisfied within the statutory sector, feeling ‘trapped’ in designated link worker roles and thwarted in their attempts to progress to higher levels.

As both health and social services authorities confront increasing recruitment difficulties across the board, there is some urgency in prioritising the workforce planning of black and minority ethnic staff and facilitating their career planning not only between health and social care but also across the statutory and non-statutory boundary of service provision. It is certainly wasteful for them to be graduating through a succession of short-term schemes and that very insecurity is likely to deter more able applicants. In the short term, unqualified bilingual co-workers can be introduced to achieve a more
appropriate skill-mix in multi-disciplinary teams, as, for example in the Rehabilitation Team in the Nottingham Community NHS Trust. However, such developments need to be backed by longer-term investment in training and access to further education, as well as targeted community education programmes that help black and minority ethnic communities to be more aware of the career opportunities in health and social care.

The majority of authorities now have mandatory race awareness training for all their staff, such as the Working with Diversity training in Stockport. It is less frequent that authorities have in place on-going systems for monitoring the impact of that training on operational practice or have provision to involve disabled black and minority ethnic users and carers in staff training. There is scope for both health and local authorities to co-operate more in the commissioning of this training and to incorporate it into more comprehensive multi-agency, multi-disciplinary organisational development programmes.

The Trent Region of the NHS, for example, is to be commended for the cultural training that it has organised for Occupational Therapists in its region. Some authorities are also able to respond flexibly to individual training requests, such as in Kent, the sponsoring of a member of the physical disability team to learn Punjabi. In many ways, however, it is training in the early identification of physical disabilities and sensory impairments that relevant operational staff require, because, otherwise, there is the danger that symptoms will be missed as part of a wider cultural misunderstanding.

If health and local authorities are to achieve the shifts in attitudes and skills required in their organisations in order to be able to offer an appropriate range of culturally appropriate services to disabled black and minority ethnic adults in the context of an increasingly competitive labour market, then workforce planning and development will have to assume a significantly higher priority.


Commission for Racial Equality (1997) Race, Culture and Community Care: an agenda for action


Coventry University/Black Disability Action (2000) Double Invisibility; report on services to black and minority ethnic disabled people

Department of Health Social Services Inspectorate (1997) A Service on the Edge: Inspection of Services for Deaf and Hard of Hearing People

Department of Health Social Services Inspectorate (1998) A Sharper Focus: Inspection of Services for Adults who are Visually Impaired or Blind

Department of Health Social Services Inspectorate (1999) They Look After Their Own, Don't They? Inspection of Services for Black and Minority Ethnic Elders

Department of Health Social Services Inspectorate (1999) That's the Way the Money Goes: Inspection of Commissioning Arrangements for Community Care Services
Department of Health (1997) Think Dual Sensory: good practice guidelines for older people with sensory loss


Department of Health Survey of Joint Initiatives by Social Services and Health to Commission Services for People of Black and Minority Ethnic Origin (Aged 18-64 Years) with Physical Disabilities and/or Sensory Impairments

Introduction

The purpose of this questionnaire is to identify leading-edge service developments for this user-group, especially at the interface between Social Services and Health over the last three years. Short study visits to selected authorities will be undertaken subsequently by the relevant SSI and NHSE Regional Offices, before issuing a report, sharing best practice with all authorities.

If possible, please complete this questionnaire with a local Health representative. Please attach any relevant documents or extracts that describe any of the cited initiatives.

DEFINITION: The recommended ethnic monitoring categories are:
Irish, Indian, Pakistani, Bangladeshi, Chinese, Black African, Black Caribbean, Black Other (specify), Other (specify).

1. Name of Authority __________________________________________
2. Name of Social Services Officer completing the survey: ______________
3. Telephone Number of SSD Officer: ____________________________
4. Name of contributing NHS Officer (if any): ______________________
5. Telephone Number of NHS Officer: ____________________________
6. Date:_____________________________________________________

Appendix 2
Questionnaire

Responding to Diversity
SECTION 1: Context

1. What proportion of the population in your area is of minority ethnic origin?

2. Do you know the ethnicity of current adult service users with physical disabilities?
   - YES □  NO □
   - With visual impairment? YES □  NO □
   - With hearing impairment? YES □  NO □
   - With haemoglobinopathies (Sickle Cell, Thalassaemia etc.) YES □  NO □
   - With dual and/or multiple disabilities? YES □  NO □

3. If YES to any of the above, please specify the number, ethnicity and disability below:

   __________________________________________________________
   __________________________________________________________

4. Do you have any joint data-bases for this user-group with Health, Housing or Education e.g. Register for Children with Disabilities, Disabled Persons' Register, Blind and Partially Sighted Registers with robust data on ethnicity?
   - YES □  NO □

5. If YES, please specify below:

   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
SECTION 2: Joint Commissioning Arrangements

1. Do you have any formal joint mechanism with Health for considering the planning/commissioning of services to:
   - Those of minority ethnic origin? YES □ □ NO □ □
   - And/or those with physical disabilities? YES □ □ NO □ □
   - And/or those with sensory impairments? YES □ □ NO □ □
   - And/or those of minority ethnic origin with physical disabilities and/or sensory impairments? YES □ □ NO □ □
   - or any other arrangements? Please specify. YES □ □ NO □ □

2. If YES, please specify any relevant initiatives over the last three years for disabled adults of black and minority ethnic origin with disabilities in any of the following areas:
   - consulting with minority ethnic users/carers/communities □
   - estimating/researching needs □
   - drafting information, raising awareness □
   - commissioning translation/interpretation services □
   - commissioning any new services □
   - recruiting or training staff □
   - evaluating cultural appropriateness of services for disabled adults □
   - other - please specify: □

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3. If no formal joint planning/joint commissioning arrangements, please specify any other relevant partnership arrangements with Health and/or other agencies.

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4. Are the objectives/priorities for this user-group set out in any jointly agreed document e.g. Community Care Plan, Race Action Plan, Health Improvement Plan, Housing Strategy, Partnership bid etc.?

If YES, please summarise or attach relevant extracts:

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SECTION 3: Service Arrangements

1. Have you revised/improved either internal policies and procedures or protocols with Health for this user-group over the last three years?  
   • YES □  NO □

2. If YES, please attach copies of relevant documents

3. Do you have service specifications/standards that ensure both relevance to disability and cultural appropriateness?  
   • YES □  NO □

4. If YES, please attach

5. Have these specifications been improved by user/carer input/feed-back?  
   • YES □  NO □

6. Have you identified any performance indicators or outcome measures?  
   • YES □  NO □

7. If YES, please attach

8. Are there any users of minority ethnic origin participating in your direct payments scheme?  
   • YES □  NO □

9. If YES, have any new or improved services been commissioned as a result?  
   • YES □  NO □

10. If YES, please specify

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   ---------------------------------------------------------------------------------------------------
   ---------------------------------------------------------------------------------------------------

11. Is there any advocacy group, representing the interests of this user-group?  
    • YES □  NO □

12. If YES, please specify

   ---------------------------------------------------------------------------------------------------
   ---------------------------------------------------------------------------------------------------
13. What are the main obstacles to improving services in this area?

________________________________________________________
________________________________________________________
________________________________________________________
________________________________________________________

14. Do you think that there are any measures that central Government could take to facilitate progress in this area?

YES ☐ NO ☐

15. If YES, please specify

________________________________________________________
________________________________________________________

16. Any other comments

________________________________________________________
________________________________________________________
________________________________________________________
________________________________________________________
________________________________________________________
________________________________________________________
Appendix 3

Membership of Reference Group

Joy Wilson  SSI, Central Region  (Chair)
Jonathan Phillips  SSI, Northern Region
Helen Davies  SSI, London Region
Chris Johns  SSI, Southern Region
Jeff Bashton  SSI, Headquarters
Ray Warburton  SSI, Headquarters
David Behan  ADSS representative
Pauline Fox  NHSSE representative
Carl Freeman  Royal National Institute for the Blind
Jon Dunicliff  West of England Centre for Independent Living
Surendra Shroff  EMERGE
Lesley Jones  Centre for Research in Primary Care,
Nuffield Institute for Health, University of Leeds
Bob Welch  Independent Community Care Consultant

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