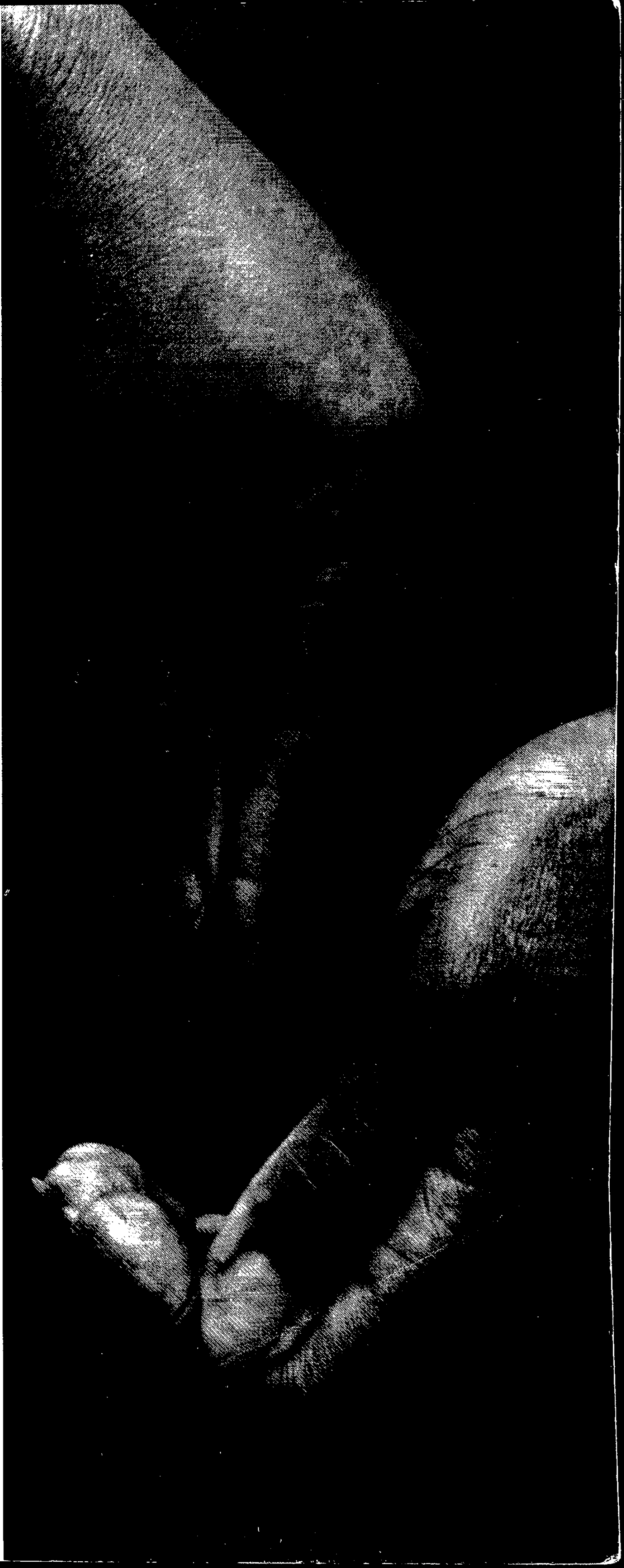
King's Fund

Purchasing for Black Populations

Laxmi Jamdagni



King's Fund
Publishing
11–13 Cavendish Square
London W1M 0AN

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This is dedicated to my mother, Murti,
who died of stroke during the course of this work

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Laxmi Jamdagni

Foreword by Robert J Maxwell

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Published by
King's Fund Publishing
11–13 Cavendish Square
London W1M 0AN

First published 1996

ISBN 1 85717 105 5

A CIP catalogue record for this book is available from the British Library

Distributed by Bournemouth English Book Centre (BEBC)
PO Box 1496
Poole
Dorset
BH12 3YD
Tel: 0800 262260
Fax: 0800 262266

Printed and bound in Great Britain by Peter Powell Origination & Print

Cover photograph by Stuart Blackwood

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Foreword

Since World War II, Britain has become a society of many races, and the process of transformation is continuing. According to census estimates, in 1951 the Black population (defined to include all non-White minority ethnic groups) was 0.2 per cent of the population of England. The percentage now is 6.3 per cent, projected to rise to 7.5 per cent in 2020, because the Black population is younger than the population at large.

So the British people are changing. But our collective behaviour is not changing nearly fast enough. Few of us have much understanding of the variety of cultures, beliefs and traditions that have shaped the new Britain. We speak few of its languages. Typically British organisations still practise, however unconsciously and unintentionally, institutional discrimination. Our institutions only too often are stuck in an outdated and inappropriate mode: a mode of Empire, class and a single language and culture as 'superior'.

We have to learn to change and change fast, for at least three reasons. First, it is totally unjust to purport to be a just society and yet to discriminate on the assumption that one colour, one culture, is 'better' and that others are not entitled to equal regard. Second, individually and collectively we are the losers if we do not rejoice in and exploit our diversity. And third, unless we can transform ourselves into a society that does have mutual trust and confidence, we will tear ourselves apart. Peace is not primarily a matter of imposed order, but of mutual tolerance. If we cannot recognise that and act on it, the future is bleak indeed.

This report is about what NHS purchasers can do to change things. I congratulate Laxmi Jamdagni on it. She describes clearly and succinctly six case studies of a range of different initiatives by health authorities. She then draws conclusions, for example about feedback to users to sustain trust, and the need for awareness (on all sides) that results take time; the need for ethnic monitoring data, distinguishing the experience of, and outcomes for, different groups; the case for investing in the development and support of the Black voluntary sector as service providers. She then makes a series of thoroughly sensible recommendations.

When the NHS was restructured in 1990 by the NHS and Community Care Act, the King's Fund formed several views about purchasing. We thought it would be weak initially, and we were right. We thought it should be strengthened to influence health services for local populations. And we hoped that it could be used to correct injustices experienced by Black communities.

With Department of Health support, we established a project to fund purchasing agencies 'to improve services to Black and ethnic populations through the contracting process'. The mode of work throughout the past five years has been a combination of local initiatives, consultation, and an attempt to learn at national level from the local experience. This report is in that tradition. I commend it to you.

Robert J Maxwell
Secretary and Chief Executive
King's Fund

Acknowledgements

I would like to thank all those who contributed to this work: the six King's Fund projects, both the project workers and managers who shared their perceptions and experiences of undertaking this work; as well as the members of the local Black communities who gave their time and trust in the sincere hope that this would help to make a difference in the future – it has begun to.

I am also grateful to those who gave comments on earlier drafts: Paula Morrison, Angela Coulter, Tahera Aanchawan and especially Christine Farrell. Finally, I would like to thank the following: Bradford Health Commission, Sandwell Health Authority, ASRA (Smethwick) and the West Bromwich Afro-Caribbean Resource Centre for supplying the photographs; the SHARE project for their assistance with references; and Giovanna Ceroni for her support with the production of this publication.

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A note on terminology

The term 'Black' is used to refer to people from racial or other minorities in Britain who may be disadvantaged because of their racial backgrounds. It is acknowledged that there is no single accepted term and that there are people who do not identify themselves as Black but who share a common experience of racism.

Executive summary

1. This report describes some of the opportunities for and barriers to improving health services to local Black populations through the commissioning and purchasing mechanisms now in place in the NHS.

2. It draws on the local and national lessons from six projects funded by the King's Fund, in conjunction with the Department of Health. These were located in the following health authorities: Bradford, Newcastle and North Tyneside, Sandwell, Camden and Islington, East London and the City and Redbridge and Waltham Forest. Their aim was to access the views and experiences of their local Black communities, and to use these to influence the health authorities' decision-making process.

3. The work took place within the context of great organisational change within the NHS, implementation of *Local Voices* and the *Patient's Charter*, and the emergence of official government policy responses to some of the perceived needs of Black communities.

4. The different areas covered were: quality standards (patient meals and communication) – Bradford; interpreting and mental health services – Newcastle and North Tyneside; stroke services and mental health advocacy – Sandwell; respite care services – Camden and Islington; mental health services – East London and the City; and quality standards (patient meals and information) – Redbridge and Waltham Forest.

5. The project authorities had different track records in work on race and health: some were 'ready to learn' by co-ordinating an action plan on race and health work in the health authority and improving relationships with their local Black communities; some showed 'some positive signs' for future strategic as well as service development; while others demonstrated that they were at the 'current cutting edge' in the field through taking risks and creating new models for others to follow.

6. The lessons from the work highlighted three significant factors for success: access to, and relationships with, local Black communities; the political will of the purchaser; and a relationship between purchaser and provider which is based on shared learning and a degree of trust.

7. Good-practice guidance is given on listening to local Black voices, including the following factors: environment, use of qualitative methods, overcoming constraints to participation, and engendering trust. Two models are presented – one employing a partnership-and-outreach approach, and the other using and developing the role of the community health council.

8. Four specific recommendations are made:

   (i) that the NHS Executive develops a *Local Voices* implementation strategy designed to ensure action planning after consultation;
   (ii) that the NHS Executive co-ordinates and assists the sharing and transfer between districts of good practice principles and service developments appropriate to the needs of Black communities;
   (iii) that the NHS Executive actively promotes the development of the Black voluntary sector as potential providers of services;
   (iv) that the NHS Executive actively promotes the development of independent advocates to ensure that Black users gain equal access to the health service.

9. A strategic framework for development in health and race for purchasing agencies is identified based on the lessons from this work and the national policy guidance available. The strategic framework is dependent for its success on the following elements: vision, political will, skills, incentive, resources, and an action plan.

Part 1

Introduction

Chapter 1

The context

- Is the NHS addressing the health care needs of Black communities better now than it was before the reforms?
- What opportunities are there to tackle racism in the NHS, and what barriers remain?

This report explores the answer to these questions by describing the local and national lessons from the work of six health authority projects funded by the King's Fund, in conjunction with the Department of Health (DoH). The health authorities involved were: Bradford, Newcastle and North Tyneside, Sandwell, Camden and Islington, East London and the City, and Redbridge and Waltham Forest. Details of their methods and findings, which will be of interest to practitioners in the field, are given in the Appendix. The aims of the projects were to access the views and experiences of their local Black populations and use these to influence the commissioning and contracting process. To date, broad commitment to equal opportunities and access to health care has been in evidence in theory more than in practice.[1,2]

The report identifies key principles and good-practice guidance on carrying out consultation and user involvement with Black communities. The individual project outcomes are then described, showing how each has influenced quality standards, service developments and/or contracts. These illustrate how different opportunities can be taken in the reorganised NHS depending on three key variables: access to, and relationships with, local Black communities; the political will of the purchaser; and the relationship between purchaser and provider.

This work has taken place within an environment framed, on the one hand, by major changes in the planning and delivery of NHS services, and on the other, by the growing official recognition for a focused race and health agenda to improve services to Black communities. The purchaser/provider split is still relatively new, and the development of the purchasing function has created diverse models of working with providers. The critical questions are: has this split improved service planning and delivery, and are providers more accountable to their local communities than they were previously? It is the race aspect of these generic questions which is considered in this report.

The six projects offer some encouraging signs: firstly, of how Black communities' and Black users' participation, both as campaigning voices and as active research subjects, acts as pressure for change; and secondly, how the results of this consultation can be channelled through the commissioning and contracting mechanisms to improve services.

The evidence also indicates that top-level awareness of, and commitment to, Black people's concerns from the new health commissioning agencies are a prerequisite for a healthy alliance between these two forces. No amount of community consultation or involvement can take the place of this commitment as a catalyst for change because priorities are not shared and because the power balance remains unaltered.

The common lessons learnt and the shifts that have taken place during the life of the projects show how much needs to be done to achieve measurable change. The commissioning agencies require foresight and political will to employ the new mechanisms and guidance available to achieve permanent progress, for while the tools may have changed, the obstacles remain the same:

- barriers to communication which prevent equal access to mainstream services;
- insufficient recognition of how the traditional way of delivering health services to Black communities has been inappropriate and insensitive, unjust and unacceptable.

Chapter 2

Background to the projects

The funding and support to these six projects follow a history of research and development work at the King's Fund which has identified different ways of tackling institutional racism in the health service. For example, in 1986 a King's Fund Task Force helped health authorities to develop equal opportunities policies.[3] In 1991, as a result of the recommendations in *Action not Words*,[4] the DoH funded the establishment of **Share**, an information exchange on health and race issues, based at the King's Fund. In 1993, a *Checklist on Health and Race*[5] was produced as a resource to both purchasing and providing managers which set out guidance on improving services to Black populations. In the same year, *Equality across the Board*[6] was published in conjunction with NAHAT, which highlighted the need to increase the number of Black non-executive members on Trust and health authority boards. These initiatives were also supported by the DoH.

Early lessons

To test the opportunities for improving services which were provided under the NHS reforms, the King's Fund awarded project grants to four health authorities in 1990.[7] This work explored ways in which local Black communities could influence service provision through the new commissioning mechanisms. These projects were located in Central Manchester, Coventry, Parkside and Ealing health authorities. They simultaneously worked on race and health issues in the early days of the reforms when the process of change was to be gradual. The new purchaser/provider management arrangements were to be put into place reflecting the existing range, level and quality of services.

The projects were successful in raising awareness of race issues in the new purchaser/provider relationship in a number of specific service areas. This work also established the need to identify and make interventions in the different dimensions of commissioning, i.e. needs assessment, quality assurance and contractual arrangements. Their main legacy, however, as shown by the evidence in this report, has proven to be the establishment of 'health and race standards' implemented and monitored across all service areas to improve the quality of and access to services.

In 1993, the King's Fund decided to continue support in this field. A tendering and selection process resulted in the following health authorities being granted £25,000 each, which was used to employ project co-ordinators to undertake the work: Bradford, Newcastle and North Tyneside, Sandwell, Camden and Islington, Redbridge and Waltham Forest, and East London and the City. This second round of projects took place at a time when the role of purchasers had become more established, and the annual contracting cycle had become the familiar framework for developing services.

Track records

All these project proposals demonstrated a commitment to developing work with local Black communities to improve jointly services so that they were appropriate and acceptable to their needs. However, the health authorities involved all had different starting points and track records, both on the level of consultation with local Black communities and on the extent to which this had resulted in action to improve services.

Some authorities had been implementing the lessons from their race-specific work over a number of years, which meant that the organisational commitment was in evidence (e.g. a senior manager having a designated lead on race issues), and that the project had a clearly defined plan, structure and service focus from the outset. They had also prepared for the commissioning and contracting frameworks to be 'on alert' for implementation of the findings of the project work. Other authorities were seeking, through this project, an opportunity to test the organisational fitness required in responding to the Black community's expressed needs through contracting.

Change models

The projects adopted three different approaches to change, according to their respective histories. The first, 'ready to learn', focused on co-ordination of an action plan on race and health work in the health authority and on improving relationships with their local Black communities. The second, 'some positive signs', highlighted agreement to strategic as well as service development. The third, 'current cutting edge', demonstrated how a history of consistent progress enabled the taking of risks and piloting of innovations which created new models for others to follow.

Part 2

The race and health picture

Chapter 3

Impact of mainstream changes

Impact of mergers

Organisational changes and restructuring caused by the NHS reforms have led to high levels of staff movement in many districts. This has included the relocation or disappearance of individuals who had taken a lead on health and race work. The merger of family health service authorities (FHSAs) with district health authorities (DHAs) in particular has resulted in gains and losses of 'cultures of commitment', depending on where most work on race issues had been undertaken, and whether the lessons from this work would inform the new environment.

These two changes have impacted negatively on race-specific work, which tends to be project-based. For example, in only three of the King's Fund project authorities did the officer who prepared and negotiated the project proposal remain in post, steering the work with a clear vision; one project had four different lead managers in succession before it got off the ground, reducing the actual work with the local Black community from two years to one.

Local Voices and the *Patient's Charter*

Introduction of the *Local Voices*[8] philosophy has given fresh legitimacy to listening to the views of local people, and their needs and experiences as patients. The *Patient's Charter*[9] has provided a framework which gives a high profile to patients' rights and their expectations of standards regarding patient care. The implementation of both of these policies can help to effect the changes required to make the NHS more responsive and accountable to the Black communities' needs.

Equality policies and the internal market

However, a clear vision and commitment are required simultaneously to boost purchaser confidence in commissioning and buying appropriate services. Formally adopted equalities policies are just as essential tools now to guide action, as they were before the reforms. An exercise to collect the equal access (services) and equal opportunity (employment) policies of the six health authorities, revealed how little, collectively, was up to date, readily available and in current use. The various organisational mergers and the division into separate commissioning and providing bodies had caused delays in redrafting and gaining approval of revised policy documents. Yet, effective consultation strategies and purchasing plans representing the health needs of all sections of the local community need to be informed by such appropriate guidance.

This is all the more pertinent as the internal market in the NHS is forcing hard choices and decisions about priorities. The concepts of cost-effectiveness and rationing were introduced at about the same time as official signs of recognition for a 'race' agenda became evident. There is a parallel here also with the introduction of charges for some formerly free social services, as part of the community care reforms: unequal access had prevented many Black people from benefiting from their entitlements in the first place.

Penalties and incentives

In the meantime, the use of penalty clauses in contracts has generally not been considered to be a viable option or lever to enforce good practice in implementing equal access to services. Four out of the six project authorities did not use penalties in contracts for *any* reason. One project authority invoked penalties if providers did not record the postcode of clients receiving a service, or if providers did not give the required information on time.

Only Sandwell health authority had experience of using penalties to effect change in race and health work. Penalties were introduced in the 1994/95 contracts for non-production of translated materials. This resulted in one local provider being fined and adopting good practice in this work in conjunction with the Sandwell Joint Translation Unit.[10] However, since then, further changes have been made in the way contracts are negotiated, and a more collaborative approach with providers is to be adopted.

Need for ringfencing

Examples of short- and long-term financial incentives are given in this report as evidence from the project work. They show how innovation and relative risk-taking can be stimulated to improve services under specific conditions. It looks, therefore, as though race work will need to be supported with incentive funding which is ringfenced for the foreseeable future – otherwise it will not be able to 'compete in the market'. Resources are required for both the mainstream and the Black voluntary sector: for the continued development of statutory services to enable Black communities to access their rights to acceptable health provision; and for financial support to enable Black community organisations to compete equally for contracts as providers themselves.

Chapter 4

Policy milestones

The early 1990s saw the emergence of official government policy responses to some of the perceived needs of Black communities. These cover the areas of research and information; racial equality in the employment and training of Black staff in the NHS; racial equality in the planning of services; ethnic monitoring of service use; and the setting-up of a unit of staff to help ensure that these and other mainstream health policies are implemented for the benefit of Black communities. These responses are described below.

Ethnic Minority Staff in the NHS: A programme of action, 1993[11]

The aim of this programme is 'To achieve the equitable representation of minority ethnic groups at all levels in the NHS (including professional staff groups), reflecting the ethnic composition of the local population'. Eight goals are identified where action is required by NHS employers. These are related to: recruitment and promotion; staff development; racial harassment; appointments to NHS boards; service delivery; doctors; nurses; and fast-track career training schemes.

Ethnicity and Health: A guide for the NHS, 1993[12]

Where the *Health of the Nation*[13] strategy set the priorities for the population as a whole in five key areas of health (coronary heart disease and stroke; cancer; mental illness; HIV/AIDS and sexual health; and accidents), this guide provides information which is essential for achieving those targets among different ethnic groups. It sets out the known and substantial differences in health between different groups and stresses the importance of providing health promotion services relevant to specific lifestyles. Guidance is included on diabetes, infant health and sickle-cell anaemia and thalassaemia as well as on the five key areas.

Maternity Services for Asian Women and *Sickle-Cell Anaemia*, 1993[14, 15]

These publications were included in a series of 'Patient Perception' booklets. They describe clinical services from the experience of the patient. Critical patients' views are expressed, and each booklet ends with a set of challenges for commissioning authorities.

Collection of Ethnic Group Data for Admitted Patients, 1994[16]

The introduction of ethnic monitoring systems in hospitals became mandatory from April 1995. The 'ethnic group' field was added to the contract minimum data set for admitted patient care in England, which covers in-patients and day cases. This has been implemented to provide the NHS with a tool to enable the provision of services without racial discrimination. The recording of the self-defined ethnicity of each patient should identify current service use and possible gaps in services, and allow the monitoring of service response to identified gaps. It should also highlight under-use of services by specific groups when compared to the local population profile, and initiate appropriate action to both improve access to existing services and develop services to meet needs.

Priority F included in the *Planning and Priorities Guidance,* 1994/95[17]

The official list of ten NHS priorities included, for the first time, reference to meeting the needs of Black communities. Priority F states:

> *'Improve the performance of the NHS for the specific client groups of minority ethnic people, elderly people, children, people with physical disabilities and people with severe mental illness.'*

The NHS Ethnic Health Unit, 1994[18]

The unit has been funded for three years by the DoH to implement the NHS Executive's objective for ethnic health which is: 'Ensuring health services of the highest quality are effectively targeted to the needs and wishes of ethnic communities within available resources.' It encourages partnership working between health authorities and the community; identifies and disseminates good practice nationally; supports health authorities to adopt principles of good practice in the delivery of sensitive and appropriate services to Black communities when implementing key policies such as *Health of the Nation* and the *Patient's Charter*; and it operates a grants programme designed to enable development work in these areas. It also works in collaboration with other health agencies such as the King's Fund and the Health Education Authority.

Chapter 5

Regional influences

While districts will have been preparing for the implementation of these national policies, employing the official guidance variably according to their perception of local priorities, other activity at the regional level has also influenced purchaser behaviour across the six projects, which were located in the following regions: West Midlands, Northern and Yorkshire, and London.

West Midlands Region

In November 1994, West Midlands Regional Health Authority (WMRHA) organised a conference to focus and clarify thinking in the race and health purchasing and commissioning arena.[19] This succeeded in setting an agenda for change, to move from the existing ad hoc pattern of commitment to a more strategic level. The corporate contract agreements with the 15 district health authorities in the region now require that each district develops a commissioning action plan to meet the health needs of their Black communities. Districts have also been asked to nominate a person at board level to be responsible for ensuring this action is taken forward. WMRHA has appointed consultants to support the plans with advice and purchasing guidance.

Northern and Yorkshire Region

In March 1995, Northern and Yorkshire Regional Health Authority, working with Bradford Health Commission, organised a conference to bring together recent local work in the race and health purchasing arena. This resulted in the sharing of good practice from both purchasers and providers in the region, and identification of different points of influence in the commissioning process. Two regional factors have supported work in this field: the appointment of a commissioning manager with a brief in equal opportunities; and implementation of Priority F beginning with a survey of both purchasers and providers to produce evidence of work being undertaken to implement anti-discriminatory practice.

London

The Health and Ethnicity Programme was set up by the former North West and North East Thames RHAs in 1989.[20] In its five years of existence, it raised the profile of race and health issues broadly in policy and planning work across the district. It took a lead in the issue of ethnic monitoring, undertaking three pilot studies and publishing the *Guidelines for the Implementation of Ethnic Monitoring in Health Service Provision*.[21]

The London Health and Race Purchasers Forum was set up in March 1993 to facilitate networking for the growing number of race and health workers appointed to health authorities in the capital.[22] Two King's Fund projects based in the former Parkside and Ealing health authorities had simultaneously piloted work on race, identifying the key challenges for the purchasing agenda. Their networking helped to highlight a cross-London need to share local information and ideas on good practice. The Forum has served a number of functions: it has supported race workers who often struggle alone against the pressures of trying to influence change with peers and managers, as well as in agencies and with local communities; it has developed London-wide critical debate on major issues such as the best method of meeting the language and communication needs of London's Black communities; and it has been able to offer strategic support to work at the local level through its publications.[23, 24, 25]

Part 3

The evidence

Chapter 6

Working with local Black communities

Political context

Black people have forged their own history of making their voices heard about public services in Britain, whether as users, non-users, families, community groups or professional advocates or representing social services clients, parents of school children, council housing tenants, or NHS patients. This has been necessary for three reasons:

- the need to be able to log their claim to equal access to services available to the rest of the population;
- the need to protest about individual and institutional racism from which the Race Relations Act 1976 had failed to protect them, when trying to access services;
- the need to place on policy makers' agendas their specific requirements according to their race, language, culture or religion.

The Black community agenda

The Black community's agenda at consultation meetings tends to reflect this history. Nor is its voice necessarily a respecter of boundaries – whether between housing or social services, health or social care, primary or secondary care, purchaser or provider, or between the 'given' priorities for one contract planning cycle and the next. The organised framework for local consultation introduced by the NHS reforms has not succeeded in changing this agenda, as witnessed in these projects.

The projects were collectively 'nervous' at the outset about attempts to focus attention on health – consultation meetings in the past had highlighted that poverty and the ability to pay the next bill were at the forefront, rather than any perception of specific ill health.

> *'In general, Black, minority ethnic and refugee users and carers placed the current problems they faced, e.g. housing, legal issues, welfare rights issues and accessing advocacy and interpreting services as their priority concern. Considerable effort was required to raise awareness of caring issues in order to help them to focus on the subject of discussion.'* [26]

This nervousness also applied to the possibility of coming up against a lack of faith or trust as a result of either no feedback from the last consultation conducted by the health authority, or no real progress on previous complaints or recommendations made; or the 'broken promises' syndrome.

In **Sandwell,** the urgent need for an Arabic interpreter and linkworker for the relatively small Yemeni community was publicly expressed by a member of that community at the high-profile 'open agenda' consultation conference. This need had been expressed in previous consultation, but no action had resulted. This illustrates how such communities sometimes have to struggle additionally against marginalisation.

In **Tower Hamlets**, by contrast, where the service focus was on mental health, representatives of the sizeable Bangladeshi community stressed again the urgency of appointing a Bengali consultant psychiatrist – none has ever been recruited despite the now long-standing need.

In **Waltham Forest,** the Asian community voted with its feet by not attending the Asian consultation meeting (only a few community workers turned up). It transpired that they would have attended had they received feedback from previous consultation. There was a good turnout for the African Caribbean consultation meeting because people felt they had not been consulted before, but only two were recent users of hospital services (the focus of the research), the rest gave their experience of GP services.

In **Bradford**, the focus group work with recently discharged Asian hospital patients raised again the regular complaint about the poor quality of Asian food, especially chapattis. This was a relatively minor thing to put right and which would have improved patient satisfaction overnight, but for the authorities it was something that their various efforts had not yet successfully tackled.

In **Newcastle**, three leading figures in the Asian community suffered heart attacks in the initial phase of the work. As well as alerting the community to the need for health promotion, this also facilitated their direct support for the overall project, which may not have otherwise happened.

These examples demonstrate that the Black community's 'bottom line' messages, in whichever form they appear, cannot be ignored, whatever the current health authority agenda. Conversely, it may be argued that the health authority agenda will prevail unless or until the community is enabled, or obliged, to articulate its views.

Local Black voices strategies

Consultation work has made demands on community organisations' time in an unprecedented way – firstly, by social services on their community care plans, and secondly, by health authorities on their commissioning and purchasing plans. The evidence from these projects highlighted community claims of:

- consultation 'fatigue';
- the need for payment for 'services' (i.e. users giving their views, experiences and suggestions to these agencies).

Considering the demand for Black community representatives to attend a schedule of meetings for different sets of managers and client groups, as well as for different ethnic communities, all within a tight timetable, both claims would appear to be legitimate and need to be addressed.

Consultation with Black communities needs to be an integral part of an overall planned *Local Voices* strategy covering all local communities. Generic and specific work should be co-ordinated within this framework, avoiding duplication and consultation 'fatigue'. Otherwise there is a risk that race issues are deferred to the margins after an initial high profile through project work.

There is a danger that the Black community's campaigning voice and power are 'contained' by the consultation process. The evidence from these projects shows that the Black community's agenda is determined by historical as well as current disadvantage. The consultation process needs to *acknowledge* this through action.

Methods

Within the six health authorities a range of factors were used to identify the projects' service focus, and the communities to work with. These were:

- the outcomes of recent consultation or initiatives;
- the outcomes of fresh consultation;
- existing health strategies or scheduled service reviews;
- the focus of current community development work;
- the relationship between specific local Black communities and the health authority;
- the need to be seen to treat all Black communities equally, with respect to support and resources.

A variety of consultation methods were employed which were appropriate to the local context. Interviews, questionnaires, focus groups and open consultation meetings were all used to gather the views of past, present and potential users and carers, and community organisations. Different methods were being tested to develop Black user involvement in the planning and purchasing of health services. While some projects favoured a particular method, others used a combination of approaches. Open meetings served the additional purpose of launching and publicising the project.

The chosen methods were normally designed in consultation with the public health directorates. In two cases, additional advice was gained through local universities. One project submitted its proposal to, and was approved by, the Local Medical Ethics Committee. Collectively, all the projects felt that these actions were useful in enhancing the credibility of this type of qualitative research, which is the norm for work with Black communities.

The projects involved a range of patient groups, including people who had recently been discharged from hospital, those suffering from strokes and mental health problems, and primary health care users.

Two projects also sought the views of Black voluntary sector organisations, as general advocates for their communities. This was done by questionnaires and interviews. Potential users of specific services were also targeted by some projects to identify reasons for their non-take-up of existing services, and factors which would facilitate take-up.

Good practice in listening to local Black voices

Although many lessons were learnt from the consultation process, there are no blueprints for certain success. What works well in one area or with one community might not work as well in another. Flexibility, in terms of both time and money, is needed to implement any changes required. This is particularly important to bear in mind in the planning stages. Furthermore, a good local knowledge base and good relationships with local Black communities are vital if long-term consultation frameworks are to be sustained.

The following factors were found to be significant by the six projects:

- environment
- consensus on qualitative methods
- constraints to participation

- engendering trust
- partnership and outreach
- the role of the Community Health Council (CHC).

Environment

The different environments in which views were sought were important. An Asian focus group run by an Asian facilitator in a local Asian community centre provided a safe space to exchange individual experiences openly, as well as to gather specific ideas for improving services. Whereas an open consultation meeting where users, non-users and voluntary sector members had access to a 'top table' of senior service managers, provided a forum where the broader context of a user's experience could be better understood by all. Either one or a combination of these methods may be appropriate according to local circumstances.

Consensus on qualitative methods

Small-scale, qualitative work may be judged, by a provider, to be inferior to large-scale studies, despite the method being approved by the purchaser. Such a negative response was met by one project after the research findings were shared. This suggests that a mechanism needs to be set up between purchaser and provider to secure agreement, before such research is undertaken, that the findings will be given serious attention. The other project authorities, however, accepted the evidence obtained in their districts as being reliable and of good quality. In fact, the application of larger-scale studies would probably have prevented access to the level of detail which was obtained.

Constraints to participation

Some users may be prevented from taking part in needs assessment work if the chosen method prevents participation, or if specific support needs which would enable participation are not addressed. For example, people with strokes may not be able to take part in focus group discussions because of their speech limitations. To enable equal access to user involvement, therefore, adequate time and resources are required to identify and implement the most appropriate method, as well as to ensure the provision of relevant support needs where applicable.

Many users are unable to comment about the suitability of services and processes because they are unaware of or have not used some of the available services. Many also do not understand how services are organised or delivered. The situation is worse for non-users who have no expectations or vision of different service options. These issues have to be addressed when designing the methods of consultation, and by allocating enough time and resources to give adequate information to potential users. Otherwise a low response rate will provide poor overall quality results.

Black voluntary organisations normally have just a few workers and therefore cannot always give commitment to attend meetings, as this would result in withdrawing a service to their clients. Resources to meet staff replacement costs should be provided to prevent this.

Engendering trust

A common lesson to emerge is that an identifiable network of Black health workers is required for the community to relate to in a working partnership. This helps to create a wedge in the otherwise anonymous white bureaucracy of the NHS. Moreover, the Black community will not automatically have faith that a lone Black project worker can trigger major change.

The **Waltham Forest** project worker met with some cynicism: *'I am glad that you've got a job, brother, but you know and I know that nothing is going to change.'*[27] This worker's main network was the community outreach team in social services, as there was no equivalent in the health authority.

The **Camden and Islington** project recruited sessional workers covering 19 different language communities to undertake face-to-face work in the language of the interviewee (see Fig. 2 on p. 37).

The **Sandwell** project used a team of Black staff drawn from health promotion and the FHSA who were already known in the community through their ongoing work on race issues.

The **Newcastle** project worker, being the only Black worker in the health authority, was able to seize the opportunity to create eight permanent new posts for Black staff to work on diverse race and health service areas.

Bradford, by contrast, could afford to employ just one worker to undertake this project work, as the Black community were generally aware of the health authority's track record to improve their health. An example of this is the commissioning of the Ethnic Minority Community Development Service in 1993, consisting of a team of Asian workers carrying out health promotion work in the context of Asian lifestyles.

Partnership and outreach

'Working in partnership' has become a commonly used concept in health and social care, attempting to describe the ideal relationship between the statutory and voluntary sectors. The Camden and Islington project offered a concrete model based on outreach work.

While most projects focused their work with one or two communities, Camden and Islington decided to work with a range of long-established communities as well as a number of more recently arrived refugee communities (see Fig. 2, on p. 37). This approach worked mainly because the health authority had invested time and resources, in recent years, to developing its relationships with the Black voluntary sector.[28]

The history of this project has included the following stages of work between the community and the health authority:

- community representation on needs assessment work to identify specific communities and service focus areas;
- project co-ordinator employed by the health authority and located in the voluntary sector;
- a model of partnership working agreed, regarding the management of the project: a Black community representative from Islington Voluntary Action Council and the Camden Health and Race Project (affiliated to Camden Voluntary Action), the project co-ordinator, and the health care standards and equal access officer of the health authority formed the project management group;
- targeted recruitment and training of sessional outreach workers covering all the relevant cultures and language communities involved;
- detailed consultation by interviews with community organisations and past, present and potential users and carers;
- short- and medium-term solutions and actions identified jointly by commissioners and voluntary sector;
- long-term solutions planned in partnership through a follow-on 12-month project funded by the NHS Ethnic Health Unit, to develop a tailored service within the Black voluntary sector.

The successful outcomes from using this approach were dependent upon commitment from all parties involved. As a potential working model for others, two key lessons should be borne in mind. Firstly, extra time is required to fit in meetings of the project management group, on top of the overall project steering group meetings. Secondly, while the project worker is able to tap into the existing voluntary sector networks with ease by being located in offices of the voluntary sector, support is also required to facilitate networking inside the health authority.

The strategy also demonstrated that work with refugee communities can be integrated with, rather than being marginal to, mainstream work with Black communities. The problems for refugees in accessing services are compounded because of their previous experience of war, loss of family, home and/or status. This often leads to a general mistrust of authorities on the one hand, and emotional upset and mental illness, on the other. As the initial contact with refugees was with workers from their own communities, the first major barrier was removed. Meanwhile, the identification of appropriate services may highlight differences between communities for a range of reasons, all of which will need to be taken into account.

The role of the CHC

CHCs were set up in 1974 to give users a voice in health services and have developed primarily as white middle-class bodies.[29] They rarely have race issues on their agenda, nor have Black communities any great expectations of them as their potential advocates. Their statutory right to consultation has also tended to dominate their work programmes, trapping them in the bureaucracy of formal responses.

While CHCs have a responsibility to represent the health concerns of the Black as well as the white community, there is clearly some way to go in achieving this. The Greater London Association of Community Health Councils (GLACHC) report, *From Here to Equality*,[30] provides recommendations on the range of positive action required of CHCs in the Greater London area in order for them to meet this responsibility.

It is therefore of little surprise that Black people remain largely unattracted to forego their own self-help traditions and to join their local CHC to attempt to change it from within. However, in Sandwell the CHC played a key role in supporting the work of the project. The project proposal was submitted jointly between the health authority and the CHC. The CHC had learnt that its general approach to working with users through the user participation project had failed to engage Black users in the setting up of this new mechanism covering all services.

> *'I'm not sure how effectively the CHC has addressed this. We have not been successful in the first phase, many of the forums do not have Black users and there has been racism in some groups which have now become resistant to taking on board issues. In these groups*

bringing Black people in has been a repeatedly difficult process.' Chief Officer, Sandwell CHC[31]

Sandwell CHC therefore identified a number of ways to offer a service to their local Black community, and provide strategic support in the future development of appropriate services. In particular, it is now proposing to utilise the learning from this experience to set up a longer-term consultation mechanism involving Black communities.

As a result of Sandwell CHC's involvement in the King's Fund project, Black users and voluntary organisations have become clearer about its role in monitoring and improving health services through representing users. The project's exit strategy includes a funding proposal to the health authority for future development work to be carried out through the CHC. This combines the traditional monitoring function of the CHC with the need to ensure that the project findings are followed through.[32]

The proposal seeks to capitalise on the CHC's mainstream professional role and responsibilities; its established and respected profile; and the learning through the King's Fund project.

This experience provides a possible model for other CHCs and local Black communities to work together, especially where there is a gap between the work of Black voluntary sector groups and their channels of communication to decision making. This approach also helps co-ordination of consultation and service development work with the Black community.

Feedback

Feedback on the outcomes of any consultation is critical to both engage the trust of the community in a two-way process, and ensure the accountability of the health agency. Honesty is of critical importance; feedback should state clearly: what *cannot* be done; what can be done *now;* and what *can* be done, but will take some time.

Three of the projects produced and disseminated newsletters as an interim vehicle through which to feed back decisions and actions taken by the health authority. This was in addition to face-to-face feedback. Translated summary versions of the projects' work and outcomes are also being planned by some of the projects.

Chapter 7

Impact on commissioning

Quality standards and the *Patient's Charter*

Race and health quality standards had developed out of the work undertaken in London by two earlier King's Fund projects based in the former Parkside and Ealing health authorities. This early work highlighted several broad areas where action was required to improve the quality and accessibility of services to Black communities. Addressing the need to both develop culturally appropriate services and tackle aspects of racism in service delivery, they covered:

- religion
- diet
- information
- communication
- staff training
- choice of female clinician
- ethnic monitoring of staff, patients and patient complaints.

This is significant because the reforms highlighted as a major NHS goal the provision of good-quality services for all. This work identified *additional* quality standards which are necessary to apply to the delivery of services to Black communities.[33]

Despite so much structural change and revised priority setting in the NHS, this good-practice model, with local modification, has now become accepted orthodoxy nationally as one method of addressing different forms of institutional racism.

Further testament to the validity of this approach to quality, is the fact that all six projects channelled their findings either partially or wholly through improved quality-standard setting and monitoring, whatever their service focus. This was because:

- patients interviewed were better able and qualified to provide feedback on the *environment* in which their treatment and care were given than on the clinical aspects of their treatment;

- communication is a key barrier to equal access of services, and this issue usually rests with those responsible for quality issues;
- quality-standard setting and monitoring have become an acceptable service development framework within which lies the potential to make progress without taking obvious political risks;
- the lessons of piloting this work with one main provider demonstrated that similar quality standards were equally applicable to all (see Bradford and Redbridge and Waltham Forest).

The introduction of the *Patient's Charter* has underlined the importance of some of the above core standard areas for the whole population. This has usefully achieved two things:

- it has helped to legitimate the core health and race standards;
- it has encouraged generic support for issues which have a special significance for different Black communities.

For example, the provision of single-sex wards and choice of female clinician are likely to improve the maintenance of dignity and respect in hospital for white women. For many Black women, however, this is also crucial for the observance of religious and cultural traditions.

Quality standards work was the main focus of three of the projects: Bradford, Newcastle and North Tyneside, and Redbridge and Waltham Forest. These are presented as case studies below.

BRADFORD

Background and purpose

The Asian community of Bradford Metropolitan District represents 15 per cent of the total population. This is by far the largest of the Black communities and is predominantly Pakistani.[34]

The project focused on acute services as a result of previous consultation with the community. This had identified particular concerns regarding access to, and facilities in, hospital services. The research was carried out with Asian patients who had recently been discharged from the Bradford Hospitals NHS Trust, one of the main local acute providers. Interviews were conducted with patients in their own homes. This was followed by focus group discussions held in community centres. (See the Appendix, p. 61.)

Service outcomes

❑ The key improvement was the incorporation of health and race standards in the 1995/96 quality schedule issued to providers as part of the contract.

The first attempt by the health authority to make progress in this area had been the introduction, in the 1993/94 contracting round, of a service equity statement (see Fig. 1) issued to all providers as part of the standard contract document. This, however, was not sufficiently detailed or specific and thus proved difficult to monitor in a meaningful way.

> **The provider has a responsibility under the *Patient's Charter* initiative to deliver the highest quality of service to its customers whatever their race, creed, culture or religion.**
>
> **The purchaser expects that all services will be provided taking into account the cultural and ethnic needs of their patients and that the provider demonstrates compliance with its service equity strategy.**
>
> **Where the provider does not have an existing service equity strategy, this must be developed and agreed with the purchaser during the contract period.**
>
> **The provider must evidence compliance with its own equity strategy to the purchaser at quarterly contract review meetings.**[35]

Figure 1 Service Equity Statement 1993/94

❑ The findings from this study provided detailed evidence from which quality standards were identified. These are now integrated into the quality schedule issued to all providers. The areas covered are: communication, information, religious and spiritual needs, choice of female professional, diet, bereavement, privacy and name policy. (See the Appendix, p. 61.)

❑ Standards were identified for the liaison officer service with which over 60 per cent of respondents were dissatisfied. Many patients were unaware of it or it had not been available when they needed it. Patients specified the times when they needed the service.

☐ Bradford health authority awarded £35,000 of Quality Incentive Scheme monies to the Trust to carry out service improvements as identified in these findings.

☐ One specific proposal to improve the Asian catering service was successfully carried out and received national publicity. Asian women caterers were employed in the Bradford Royal Infirmary to make fresh chapattis in house on a daily basis, instead of reconstituting frozen chapattis bought from outside. This innovation stemmed the history of patient complaints about chapattis that were too hard to eat.[36]

☐ Work on monitoring will aim to ensure that agreement is reached between all key players, the Hospitals Trust, the CHC, the Bradford Ethnic Minority Health of Bradford Group and the health authority, as to:

- how the Hospitals Trust's performance will be measured against service equity standards;
- how monitoring is carried out;
- who will be involved in monitoring;
- frequency and timing of monitoring.

Discussion

'Rights' or 'expectations'?

The above quality standards contain elements of both rights and expectations as defined in the *Patient's Charter*. However, an important point of distinction needs to be made here, as some of the rights which Black people have historically not had access to may be demoted to expectations. Compare rights 'which all patients will receive all the time' with expectations 'which are standards of service which the NHS is aiming to achieve. Exceptional circumstances may sometimes prevent these standards being met.'[37] Rights therefore are immediately available, or steps will be taken to ensure that they will be available as a matter of some priority, whereas expectations are rolled into the medium- and long-term, and may even not be met. Health authorities and Trusts are still 'aiming to become' equal opportunities employers and providers of services, and Black people are still waiting...

The function of quality standards in contracts may be viewed in two ways:

- minimum standards as baselines which *must* be met;
- targets for quality standards for providers *to work towards*.

Many quality standards are geared to specific improvements over time, negotiated with the provider, as opposed to basic minimum standards which should be accessible *now*.

Thus, while the health and race standards are gaining credibility as a legitimate route for securing improvements to services to Black communities, the process is likely to be a slow one, given the catch-all 'get out clause'. The key lesson, for Bradford and others, lies in the negotiation and agreement between purchaser and provider of appropriate targets and a planned monitoring programme. This was one of the findings from the first round of King's Fund purchasing projects, and is worth restating here.

The Patient's Charter – *integration or separation?*

Further analysis of how different purchasers are employing the framework of the *Patient's Charter*/health and race standards reveals four models for implementing race equality work:

- *only* the standards made explicit in the national *Patient's Charter* are employed ('respect for privacy, dignity and religious and cultural beliefs' and choice of menu depending on religion/culture)
- a range of race-specific standards are developed and *all* are under one section called 'health and race' or 'service equity'
- only *some* race-specific standards are kept separate, leaving others in the generic framework of the national *Patient's Charter* standards
- the national *Charter* standard of a 'named nurse' to be responsible for each patient during their stay in hospital has been picked up by Bradford as a concept having equal value with respect to continuity of communication/advocacy support. A named liaison officer is being recommended to extend this service to patients whose first language is not English.

These examples suggest that health and race standards are integrated into or separated from the *Patient's Charter*.

Quality improvements as new services

Quality improvements are sometimes simple in concept but complex in reality. An example of this is the history of attempts at improving the Asian meals service in Bradford hospitals.[38] Over the years, the challenge had been to provide food which was not merely culturally appropriate in terms of form and content, but culturally acceptable in terms of quality. The Trust had made various efforts to address patient complaints about the poor quality of chapattis. However, neither the in-house catering service nor an Asian community provider could adequately manage this task: the first resulted in English-style Indian cooking, despite training, while the second, delivered from outside and under contract, resulted in the provision of chapattis which had become hard on reheating to the regulation standard.

A solution was eventually identified through the focus group work and discussions with the Trust: to purchase (employ) a chapatti maker in the hospital kitchen itself. This would ensure that the traditional quality indicator could be met, i.e. that the chapattis served would be *thaza* (fresh). The irony of this history is that while in current NHS thinking this constitutes a 'purchasing innovation' (chapatti makers are only employed in Asian luncheon clubs or restaurants), to the patients it is a simple and obvious answer which may well have emerged much sooner had they been consulted previously.

So the implementation of this quality standard entailed more than just target setting and monitoring:

- it constituted a service development which improved access to the catering service;
- it improved the quality of the Asian meals service;
- it changed the way the service was delivered.

This successful innovation was funded through Quality Incentive Scheme monies allocated by the health authority. The cost of introducing this development was £2,500, and the Trust will continue to provide this service from its own budget from this year.

NEWCASTLE and NORTH TYNESIDE

Background and purpose

Newcastle has a Black population of 4.1 per cent, and the figure for North Tyneside is 1.6 per cent. This population is predominantly from India, Pakistan and Bangladesh, and also includes a significant Chinese community.[39]

Provider units in the region had only recently begun to address the issue of improving services to Black communities when the King's Fund project commenced. There was a low level of awareness of relevant issues among staff, particularly managers. There was no strategic overview, and any work had developed in an ad hoc manner. This led to duplication of services, and services being developed without community consultation. Recent consultation, however, had identified a range of quality issues to improve services, but these had not been actioned. It was therefore decided to set up a health and race providers' forum, which had at the core of its remit the setting and implementation of improved quality standards in hospital services.

The forum began by sharing local information and the different policies and practices currently in place across the region. This highlighted a spectrum of standards. The development of the forum resulted in provider units working collaboratively with purchasers to:

- implement the same policies;
- take a collective approach to consulting with the community;
- develop consistent standards for use across the two districts.

Service outcomes

☐ **Diet**. Traditional Asian food is to be purchased from one local provider, while in the past, all hospitals were purchasing food from different providers around the country – London, Bradford and Leicester. In addition, a pilot project to translate menus has commenced at the Royal Victoria Infirmary.

☐ **Religious representation**. Consultation was undertaken with leaders from all religious denominations. This resulted in all departments and wards across Trusts having a list of contact numbers and addresses for religious representatives. One unit has also developed an information pack for staff reference. In addition, a statement on the need to respect religious and cultural beliefs has been incorporated in service specifications.

☐ **Information to patients.** Provider units are working collectively to translate information where appropriate. However, alternative methods of presenting information are also being pursued. A video on coronary heart disease has been produced, and the health authorities are currently preparing a video on 'Changing Childbirth' initiatives in Newcastle and North Tyneside.

☐ **Practice charters**. In line with national guidance, GPs are being encouraged to develop practice charters. These charters provide a statement about the service that is offered and the standards of care that a patient should receive. While there has been a limited response to this voluntary initiative across the district, three single-handed Asian GPs in Newcastle have implemented this to improve access to primary health care services. The charters have been translated into the four main Asian community languages and displayed in surgeries. The expected outcome is an increase in the communities' awareness of the services offered, and their more effective use of services.

Discussion

High profile

The success of this work would appear to relate to the fact that the project worker provided a dedicated and ready resource for the four local providers who recognised the need for action. In addition, strong links were made with the university's public health department, which was simultaneously conducting clinical research on different aspects of Black people's health. These factors gave the overall work of the project a high profile in the district, which is especially significant considering the relatively small size of the Black population. It is estimated that as few as three Black patients are admitted into hospital in Newcastle and North Tyneside every week.

Primary health care services

The GP practice charters initiative is an important device for improving access to primary health care services. The majority of the local Black population has most contact with health services through GPs and community nursing services. Research[40] has shown that Asian people have less satisfactory consultations with their GPs and fewer referrals to other agencies than their white counterparts. They also make less use of the other members of the primary health care teams, thus increasing the burden on GPs.

Commissioning action plan

The work of the project was a catalyst for the health authority's approval of a three-year action plan on commissioning better services for the Black communities.[41] The action plan is based on both national priorities identified in the *Health of the Nation* strategy, and local priorities identified through local needs assessment and community consultation. The action plan covers: circulatory disorders (particularly coronary heart disease), diabetes, mental health, maternal and child health and accidents.

REDBRIDGE and WALTHAM FOREST

Background and purpose

Waltham Forest has a Black population of 22 per cent, while the figure for Redbridge is 18 per cent.[42] This was a joint project between the health authority and the main local provider in Waltham Forest, the Forest Healthcare Trust. It was recognised that Black users might be disadvantaged in terms of their health needs and their ability to access services. There was particular concern to plan improvements to services for older Black people, as their numbers were increasing. The project's aim was to identify improvements required in hospital services to Black patients. This was achieved by interviewing Asian and African Caribbean users aged 50 years and over, after recent discharge from hospital. Two consultation meetings were also held, one with each community. (See the Appendix, p. 64.)

Service outcomes

☐ Two service improvement commitments were agreed for implementation in 1995/96, by not only the Forest Healthcare Trust, but also Redbridge Healthcare Trust. These were with regards to patient meals and information.

☐ **Patient meals.** The research identified that 35 per cent of patients felt that the food was unsatisfactory in terms of both quality and choice. Many arranged for relatives to bring them food from home during the course of their stay.[43] Traditional African Caribbean and Asian meals are now to be provided to patients, which are of good quality and which offer a choice of menus on a daily basis. There are plans to involve users in the process of determining the acceptability and quality of the meals provided.

☐ **Information.** The research identified that no patients had been given any form of written information about their care, treatment or discharge plan.[44] The Elderly Care Directorate of Forest Healthcare Trust and the Medical Directorate of the Redbridge Healthcare Trust will now provide information to users on the following issues:
- hospital and community services on offer and how to access them;
- how to make a complaint;
- discharge planning procedures.

Such information will be provided in the four main community languages of the local community, i.e. English, Bengali, Hindi and Urdu. The appropriateness of the information will be tested with a sample of different community groups before it is mass-produced and circulated.

Discussion

Impact of mergers

The experience of this project shows how the decision-making process and possible strategic outcomes were affected by the latest impending merger on the purchasing side. However, this did not prevent the provider, as a separate organisation, from implementing the relevant findings with respect to improvements in service delivery.

A range of organisational and service development proposals had been made by the director of commissioning as a result of the project's overall work and findings. These included improvements to hospital, community and primary care services, as well as the creation of a new post in the health authority to advise and support managers on future policy and practice on health and race issues. However, the end of the project coincided with the merger between the DHA and the FHSA. This prevented the outgoing board from considering these recommendations. The new combined health authority, wishing to maintain some momentum, took the decision to set up a health and race strategy group of senior managers, to draw up an action plan based on all the issues identified.

In the meantime, the Forest Healthcare Trust was able to accept and implement those recommendations applicable to its service delivery *without* the need for the purchaser to take the lead. This is because the provider was a joint sponsor of the project. The improvements identified to the hospital and district nursing services will be addressed in the Trust's business plans for 1996/97. These include the provision of improved interpreter and advocacy services, and training for staff on race issues to challenge prejudices and provide more sensitive services.

Transfer of good practice

This project also demonstrated how both purchasers and providers can apply more generally the lessons learnt from consultation within *one* care group (elderly) and within *one* district: the Trust applied all the findings to *four* different care groups, and the health authority negotiated the findings on patient meals and information with both of the main Trusts that served the *two* districts of the new health authority. While this may not always be possible, it is a cost-effective way, in terms of both cash investment and community time, of implementing good-practice lessons wherever feasible without recourse to yet more consultation.

Service developments and contracts

Service development work during the annual contract cycle can take a variety of forms. The following case studies illustrate the approaches taken by Camden and Islington, Sandwell, and Newcastle and North Tyneside.

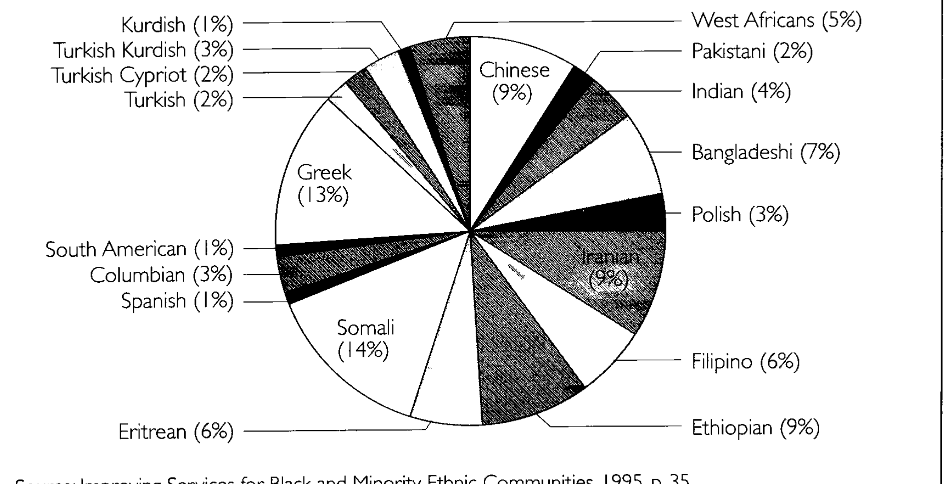
CAMDEN and ISLINGTON

Background and purpose

Camden has a Black population of 17.8 per cent, while the figure for Islington is 18.9 per cent. It is estimated that the Camden and Islington health district has the largest number of refugees (22,000) in the North Thames health region.[45]

This was the first study into the respite care needs of the Black communities living in Camden and Islington. In 1992 a report on existing respite care provision was produced by the previous health authority, but this was based on feedback from current and past users which represented few Black users. Needs assessment work carried out in 1993 in conjunction with the Black community identified the need to develop appropriate respite care services.

The purpose of the study was to identify the most appropriate ways of meeting the respite care needs of older people, adults and children with disabilities, and their carers. Users and carers from 19 different ethnic communities were the subject of the study (see Fig. 2). Refugee communities



Source: Improving Services for Black and Minority Ethnic Communities. 1995, p. 35

Figure 2 Users & carers survey – ethnic origin of respondents were the focus of the research on children, while more established communities were the focus of the research on older people.

The project conducted two surveys: one with community workers from the network of local were the focus of the research on children, while more established communities were the focus of the research on older people. Black community organisations who acted as a gateway to a range of information on service provision; and the other with users and carers. (See the Appendix, p. 66.)

The project found that the majority of the community worker respondents were aware of only three or less of the 11 listed services for carers. These services were 'patchy and difficult to access'. Many of the carers themselves were found to be suffering from a variety of conditions. These ranged from stress and depression, to back pain, heart disease and diabetes. The following case studies highlight some of the ways in which the users and carers suffered additional stress and ill health due to lack of access to suitable services.[46]

CASE STUDY 1

EXPERIENCE OF CARING

A West African mother has two daughters with disabilities. She rarely has a good night's sleep as the condition of one of her daughters demands 24-hour supervision. She had had a bad experience at a local youth centre when her daughter was suddenly taken ill and the centre did not know how to cope.

EXPERIENCE OF BEING CARED FOR

The 12-year-old girl suffers from sickle-cell anaemia. She is epileptic and has severe learning difficulties. She feels more comfortable staying at home and would be keen to have a respite carer who knows how to handle emergency situations.

CASE STUDY 2

EXPERIENCE OF CARING

A 35-year-old man, who came from Vietnam ten years ago, works full time in the catering industry. He is worried about leaving his mother on her own during the day time but he cannot afford not to work. He still remembers the days when she had just been discharged from the hospital, and he

cont'd

CASE STUDY 2 *cont'd*

needed to stay in to care for her. He nearly lost his job and did not realise that he could have requested help. Even now he is very stressed with the extra household and caring duties that he has to take on after his 14-hour shift.

EXPERIENCE OF BEING CARED FOR

Mrs L is over 70 years old, had a stroke two years ago, and is now relying on walking aids and a wheelchair. She is left on her own during the daytime and is very much confined to the ground floor part of her two-floor flat. She has once turned down an offer for respite care by Camden social services because she did not understand what it was about.

CASE STUDY 3

EXPERIENCE OF CARING

A Somali woman looks after her mother who is 64 years old and has arthritis. She also has five children. The flat is not adapted to ease her tasks. She is finding the tasks of personal caring, including bathing, increasingly difficult and stressful.

EXPERIENCE OF BEING CARED FOR

The elderly woman is experiencing constant pain and stiffness in her joints. She feels that the current respite services are not suitable for her needs. She would like to go out to day centre types of services organised by members of her own community.

Service outcomes

☐ The outreach approach led to direct referrals of hidden needs being made to Islington Crossroads – the national voluntary sector respite care agency. This had the effect of adding to their waiting list by 62 per cent.

☐ The health authority allocated new development monies, in anticipation of the level of hidden and unmet needs identified by the project. A total package of service developments worth approximately £43,000 is being considered for implementation of the findings. This includes: production of publicity; spot purchase of respite care places at Black community centres; recruitment of bi-lingual respite carers to provide services through existing voluntary sector initiatives and the Black voluntary sector; and the recruitment of interpreter/advocates to enable assessment of potential users. This last point is critical because unless this item is funded, the additional clients to the Crossroads waiting list may be subject to continued lack of access to services, even though their needs are no longer hidden.

❑ The principles for a respite care service specification for local Black communities were identified by the project. These include:

- information disseminated in relevant languages and media, on services available, eligibility and access criteria, and rights and options;
- provision of day care placements at Black community centres;
- provision of trained staff from the same language and cultural communities as the user for the in-home respite care service;
- the attitudes of staff and their ability to adapt to users' daily routines and needs to be subject to a trial period;
- provision of appropriate holiday options, for either carer or user.

❑ Based on the early findings, the health authority bid for and was successful in receiving £30,000 for a one-year follow-on project funded by the NHS Ethnic Health Unit. This will build on the work, in partnership with the Black community, and support the development of the required service in the Black voluntary sector. The aim is for the service to become an approved provider on the health authority standing list.

❑ The project findings will feed into the health authorities' submission to the DoH of definitions of respite care (1995), to influence long-term planning locally and nationally.

Discussion

The existing statutory and white voluntary sector is not currently meeting the respite care needs of the Black communities. However, there is some considerable way to go before the Black communities are in a position to offer the required services themselves, as providers. This is because of historic underfunding.

Black voluntary sector provider development therefore needs to be resourced and supported to ensure that services are provided which are acceptable and appropriate in both form and quality. Consultation with Black users is likely to continue to highlight this as a priority need, and in the meantime, mainstream services are changing very slowly to meet the needs.

The community care reforms stipulated that 85 per cent of the community care Special Transitional Grant should be spent on the purchase of services from the independent/voluntary sector.[47] Evidence shows, however, that this has not served to stimulate the Black voluntary sector.[48] A recent study found that only one out of 31 respondent social services departments in the north of England had taken any steps to advise Black groups about the tendering process.[49]

The NHS Executive should consider appropriate guidance to health agencies for them to enable and equip Black organisations with the necessary technical skills and resources to bid successfully for contracts as approved providers of such services. This should be undertaken as part of the mainstream work of health agencies.

SANDWELL

Background and purpose

Sandwell has a Black population of 14.7 per cent. The two largest ethnic groups are Indian (7.9 per cent) and African Caribbean (2.7 per cent).[50]

A consultation conference for Black users was held, and interviews with Black voluntary sector organisations were undertaken, to identify the expressed needs of the Black community and thereby direct the work of the project. Black elders with strokes and a mental health advocacy service emerged as the key areas for detailed research.[51]

Stroke services

The health authority's aim was to feed the results of this research into the work on the implementation of the agreed stroke strategy. This would also impact on the 1995/96 contracts for all elderly care services, and decisions on services jointly commissioned with the local authority.

Stroke is one of the *Health of the Nation* target areas, and is known to cause significantly higher mortality in African, Caribbean and Indian communities. It is the third most common cause of death in Sandwell, resulting in about 400 deaths per year. As there has been no ethnic monitoring for stroke patients, Black people's death rates in Sandwell from stroke are unknown. This research would also build on the work of the Smethwick Heart Action Research Project (1993) which investigated factors which can influence the incidence of coronary heart disease and stroke in Black communities.

The purpose of the research on strokes was to find out what constituted effective hospital and community services for Black elderly people.

Interviews were conducted with current and previous users of a range of stroke services. (See the Appendix, p. 69.)

Experience of services

A range of needs and service gaps was identified by the work with local communities which require firstly that existing services are improved, and secondly that new services are developed to meet specific needs. These were:

- gaps in information provision, especially on assessment and discharge procedures, rights and entitlements to services (e.g. transport facilities);
- poor use of, and access to, community support services;
- lack of involvement in assessment and hospital discharge;
- lack of specific and appropriate mainstream service provision, i.e. day care/hospital services and respite care services.

Seventy per cent of the sample felt they had been discharged too early, without proper after care arranged. Forty-one per cent had no social services follow-up, and fifty-two per cent had no assessments for aids and adaptations. This put a great strain on carers: *'I was discharged without any community services being in place ... I had to rely on my daughter coming and washing me every day'.*[52]

Some users felt grateful for whatever services they received, as their expectations were low in the first place.

About a quarter of the sample wanted information on the complaints system. However, 27 per cent expressed concerns about using the system for fear of reprisals. *'I will not complain because I need help. If I complain they will not like me any more ... better to keep my mouth shut.'* [53]

Direct communication with professionals was a key obstacle in accessing services. Information on treatment and care was given to the carers of 72 per cent of the sample. This caused tensions in some user/carer relationships. *'We had a few arguments and misunderstandings because I didn't know what they said.'* [54]

The majority of users wanted equal access to traditional Asian or Caribbean food, as well as social activities run by people from their own community, during their hospital stay.

Employment of bi-lingual advocates as opposed to simply interpreters was preferred by some users to *'... make me aware of my rights and choices'.* [55]

There was a need for health promotion programmes about stroke prevention and healthy lifestyles.

Many users found the services provided by the Asian Sheltered Residential Accommodation and the African-Caribbean Resource Centre most sensitive to their needs. This was because there were no language or cultural barriers; their lifestyles, religion and culture were understood and respected; and their social and emotional needs were cared for.

Service outcomes

☐ The feedback on assessment and hospital discharge informed the revised assessment and discharge policy of Sandwell Healthcare Trust, the main provider of stroke services.

☐ Follow-up work was undertaken with the relevant service managers to respond to users' specific information needs.

☐ A sum of £15,000 was allocated for the development of respite care at home for Black elderly people, which will be provided by a voluntary sector agency in partnership with a number of Black voluntary organisations. This service was funded through Joint Finance which had set aside £30,000 to implement proposals from the respite care strategy produced by the joint planning group for older people.

☐ The immediate outcomes of this work are few, but the seeds have been sown for long-term service developments through a chain of decision-making forums in the commissioning process. The findings and recommendations from this research will be offered for discussion at the relevant planning and decision making groups for elderly care services and community care. The outcomes of these discussions will identify whether stroke services for Black elderly people require:

- joint commissioning
- development of new services
- specific service specifications
- specific quality standards
- monitoring mechanisms.

Discussion

This research raised the following issues in relation to the commissioning process.

Firstly, services for stroke patients are currently delivered by a broad range of providers. Purchasers therefore have a relatively large number of service managers to liaise with and try to influence. The process is thus likely to take longer and require more work, i.e. the same report travelling across many agendas, over perhaps several contract cycles, as well as considerable monitoring, to ensure that all the issues are taken on board.

Secondly, there are diverse opportunities available through this process which can be used to lever both funds and decisions to make the necessary changes: social services, the voluntary sector, community care implementation and monitoring, the joint planning process, elderly care services, services for people with disabilities, quality standards and monitoring, and stroke service reviews driven by the *Health of the Nation*. In turn, *Health of the Nation* targets cannot be achieved without addressing the needs of Black communities because of their higher mortality rates from strokes.

Finally, the project demonstrated that the purchaser needs to have good relationships with the main providers in order to negotiate these mechanisms smoothly. Moreover, a shared understanding of institutional racism, and a commitment to change, is required across *all* the relevant providers. The timetable of the planning and contracting cycle needs to offer structured opportunities for training on the race dimension of such contract negotiations. This is where a clearly defined Black local voices strategy, a mutually respected piece of research work, and the outcome of direct Black user involvement would be put to the test.

Mental health advocacy

This service focus was the second main priority area selected by the community. The health authority also identified in this the potential to replicate mental health advocacy work to other service areas. The intention was to produce a service specification for an advocacy service to meet the needs of Black mental health service users, and to feed this into the 1995/96 contracting round for funding.

A joint purchaser/provider working group was set up to oversee this research, which included representatives from the community mental health Trust, MIND, Sandwell Citizen's Advocacy, public health and the commissioning manager for mental health services.

Current, previous and potential users were interviewed for this study. (See the Appendix, p. 69.)

Service outcomes

☐ The key characteristics of an advocacy service were identified in the work with users. They were:

- a service in relevant community languages;
- staff to have a knowledge and understanding of the social, cultural and religious realities for Black people;
- staff to be able to facilitate an appropriate response to users' social, cultural, family, religious and gender-specific needs;
- availability of a choice of same gender and same race staff.

The experience of service users highlighted that all these factors were central to improving existing experiences of services. For example:

> *'This person was involved in a road traffic accident and suffered brain damage. He was admitted to All Saints Hospital where he was being treated for emotional problems (mood swings). He was then referred to ASRA* [Asian Sheltered Residential Accommodation for Black Elders], *because he couldn't speak any English.'* [56]

> *'All the staff that dealt with me treated me as if I was a problem rather than an individual. They didn't give me any respect or seem to listen to what I was saying ... They were very quick to refer me onto other people.'* [57]

An analysis of the unmet needs expressed by users indicated that some needs could be met by professionals changing existing practice, but that many needs required a specific advocacy-type of service to enable Black people to access mental health services.

☐ Based on the findings, the purchaser/provider working group developed the idea of an advocacy project to run as a pilot service for three years in the first instance.

☐ A service specification was developed which described:

- *the type of advocacy support required* – focusing on the rights of service users and responding to their needs and concerns;
- *the scope of the service* – within inpatient care, outpatient treatment, care in the community and at primary care level;
- *the model of service provision* – the scheme to be located in an agency which is independent of the statutory sector, but which has a contact point based in the community mental health team to facilitate access;

- *the resources required* – £33-34,000 per year, to include a project co-ordinator, interpreters/ sessional workers, support and supervision; and an advisory/steering group to take forward actions on a long-term basis.

☐ The health authority has agreed that an advocacy project targeted to African Caribbean users in the south-east locality of the district is a high priority to receive development funding in 1995/96. This is in the light of national evidence of the over-representation of African Caribbean users among people who are compulsorily admitted under the Mental Health Act 1983.

Discussion

The evidence highlighted the extent to which existing provision had neglected the needs of Black people. The method of using the purchaser/provider working group proved useful as a vehicle for sharing responsibility to address this. The group had worked together for six months. This example shows the benefit of collaborative work *within* the contract cycle, as opposed to simply *around* the contract negotiations timetable.

NEWCASTLE and NORTH TYNESIDE

Background and purpose

The development of interpreting services was a key objective for the project, as it was an outstanding priority for action, identified through earlier community consultation.

Interpreting service

The Newcastle interpreting service had been established in 1991. Newcastle DHA appointed 20 people as sessional interpreters, who had attended an Institute of Linguists course. Further development was required to address the following areas: management, recruitment, training, supervision and quality monitoring.

Service outcomes

☐ Joint finance funding was secured for three years for a manager and the addition of Turkish, Farsi and Serbo-Croat to the existing languages.

☐ The social services and health interpreters have been amalgamated to provide a centralised service based at the City Health Trust. The new service should encourage co-ordinated development through a combined service specification.

☐ Policies for recruitment, selection, training and monitoring are being developed.

☐ The use of interpreters in hospitals, in the community unit and within primary health care has doubled during the past 18 months.

☐ Standards for the use of interpreters have been introduced.

☐ The service is provided at no cost to GPs, which assists implementation of the shift to a primary care-led NHS.

☐ The needs of Black communities for bi-lingual advocacy services will be incorporated into the future development of a range of advocacy services for the whole population.

Discussion

The historic difficulties in establishing professional language services in the NHS remain a nationwide problem. In London, where services in some districts have existed for ten or more years, the same problems regarding funding and management are still being encountered. Effective work with local providers during the course of the project resulted in improved awareness about the urgent need to remove language barriers. This, in turn, led to improved access to the interpreting service. The health authority has prioritised further improvement on this performance through the 1995/96 purchasing and contracting intentions, with reference to both quality standards and *Patient's Charter* principles:

> *'It is not acceptable for friends and relatives to act as informal interpreters both on the grounds of effectiveness and the dignity and privacy of the client.'* [58]

As in other districts, there is an acknowledgement that language services should play a clear role in users' accessing rights to health services which they may otherwise be denied. The bi-lingual advocacy model was pioneered in the City and Hackney CHC in 1980.[59]

Mental health

The project decided to focus on mental health services firstly to address the previously identified issues of training and referrals; and secondly, to commission some focus group research with the Chinese community whose unmet mental health needs had come to light as a result of earlier research on coronary heart disease. (See the Appendix, p. 73.)

In Newcastle, members of the Black communities have tended to self-refer to the Black voluntary sector for support. Workers within these organisations have had limited access to mental health training, receive no supervision and have limited contact with primary health care staff. There are no structures to facilitate referral between these organisations and the psychiatric services when it is required.

Service outcomes

☐ Three Black women are being supported to complete a three- year diploma in counselling course which is accredited by the British Association for Counselling. The students have been based with Black GPs for their community placement.

☐ Structured referral systems between the independent sector and primary health care are being established in order to provide a culturally acceptable and accessible counselling service for the Black community.

☐ These two service developments will also help to meet the needs of the Chinese community, who expressed a clear preference for counselling services in primary health care settings.

Discussion

These service developments are significant in forging new relationships between the health authority and the voluntary sector. Historically, specific services for the local Black community have been provided by the voluntary sector. There has also been limited contact between the six Black independent sector projects and the health authority. The lead taken by the project in developing services to meet outstanding and unmet needs will have prepared the ground for future joint work through the commissioning process.

Identification of the health needs of the Chinese community was important for two main reasons. Firstly, research on the general health status of the Chinese community in Britain is a relatively neglected area, borne out by the fact that the Chinese community is the only ethnic group in the

1991 Census mainframe categories to be omitted from analysis in *Ethnicity and Health – A Guide for the NHS*,[60] due to the lack of epidemiological data. While the project did not seek to fill this gap, the qualitative work through focus groups did, however, facilitate access to a dispersed community and identified both clear needs and service preferences.

Secondly, this needs assessment was significant at the local level because although the Chinese community in Newcastle is relatively small, i.e. 1,177 people,[61] it is the second largest minority ethnic community after the South Asian groups.

TOWER HAMLETS

Background and purpose

Tower Hamlets has a Black population of 36 per cent. Of this figure, 23 per cent is represented by the Bangladeshi community.[62] There is also a significant number of Somalis, although precise figures are unavailable as the 1991 Census did not make provision for assessment of the numbers of Somalis.[63]

Located in East London and the City Health Authority, the project aimed to access the views of Bangladeshi and Somali users of mental health services. Service improvements were to be identified by concentrating on access issues, particularly in relation to admission into hospital and discharge arrangements. After the initial project co-ordinator left, two part-time workers (one from each community) were recruited to continue this work. The outcomes of interviews with 20 mental health users from each community, covering both inpatients and those who have been discharged into the community, will be fed into the commissioning process to influence future services.

Initial findings

Interviews so far have been undertaken with nine Bangladeshi inpatients of the mental health services of the Tower Hamlets Healthcare Trust.[64] These identified gaps within existing services including:

- lack of information about the range of services, procedures and entitlements;
- lack of respect for their culture, and racism from staff;
- lack of interpreting and advocacy services;

- inability to meet the *Patient's Charter* standard of a named health professional responsible for individual patient care.

The following examples illustrate these points:

> *'Four patients have no particular expectations from the service. They are unaware of any standards with which to compare the service. They accept what is given and assume that staff know best.* [On the other hand, they] *were interested to know about the availability of alternative treatments and therapies.'* [65]
>
> *'Some nurses are very friendly and nice, but then sometimes there are nurses who are very rude and unapproachable. They frighten me and tell me off for things, using unfriendly language and signs.'* (user) [66]
>
> *'The nurse explained the tablets to me and I couldn't understand. For all I know, I could be giving the wrong tablets and let his condition get worse. It's just by chance that you were interviewing and happened to explain things to me. They don't care and check either. They welcome their own people, but when they see us it's treatment then get rid of.'* (carer) [67]
>
> *'Seven patients said that they had a named health professional, but someone else was always sent on their behalf.'* [68]

The work to date has identified the employment of Bangladeshi bi-lingual clinical staff and advocates as the key solution to both improving access to existing services and developing needs-led services. The role of such staff would be to provide advice, support and information about services, standards, rights, choices and the complaints system. There is also a clear indication of the need to understand and recognise the culture of patients.

Service outcomes

☐ The outcomes of this study will be fed into the commissioning process for implementation. A number of factors stemming from recent organisational restructuring in the health authority has led to the creation of greater opportunities for progress in this area:

- the newly combined authority (the DHA and the FHSA) has adopted an equalities strategy
- all directors and senior managers of the authority include equalities issues within their personal objectives
- the authority views user involvement and advocacy work as central to its equalities strategy

- the project workers are located within the development directorate as part of a team which includes a *Local Voices* and a user involvement officer. This directorate also has the designated lead on equalities work within the corporate contract.

Discussion

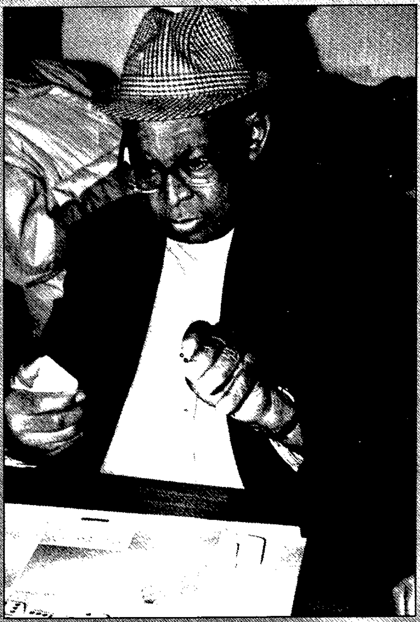
Similar work with Somali users is being undertaken to identify appropriate solutions to their needs. A comparison of the results between the Bangladeshi and the Somali communities will highlight the similarities and differences that need to be acknowledged in implementing the changes to services required. Both communities experience socio-economic conditions which are likely to cause stress and depression: poor housing and employment prospects, as well as linguistic and cultural barriers to accessing public services in general.

Added to this is the fear and/or experience of racism. One of the constraints experienced by the project in its first year was the direct consequence of a British National Party candidate winning a council seat in a local by-election. Although he lost the seat a few months later at the full council elections in May 1994, the tense atmosphere which the political campaigns created at both local and national level made it difficult for the Black project worker to work in the community with dignity and respect. This racial tension also affected the King's Fund Nursing Development Unit project in Stepney during the same period.[69]

A key difference between the Bangladeshi and Somali communities, however, is the fact that the Bangladeshi community has long been settled in Tower Hamlets, whereas the majority of the Somali community are not only more recently arrived to Britain, but many are also refugees and asylum seekers from the civil war in Somalia. The experience of war, persecution and bereavement means that the provision of health care requires an environment where feelings of safety, trust and confidence can be built up with service providers. Studies on the psychological support needs of refugees indicate the need for tailored services.[70,71]

Part 4

Lessons and recommendations



Chapter 8

Lessons learnt

☐ Despite the level of investment in planning and user consultation, the service outcomes are limited at this stage. The changes initiated take time to come to fruition. As the competing pressures on the contracting cycle do not make changes in health and race easier to achieve, race work has to be a long-term priority for purchasers.

☐ Consultation with users must lead to appropriate action and feedback to the community.

☐ The outcomes of consultation should be applied more generally where possible. This would help to promote service improvements and reduce racial discrimination in the health service at a faster pace and without wasting resources and community time.

☐ These projects introduced service improvements in the areas of diet, communication, information, mental health and respite care. Funds were also levered to give additional support to this work. This was to facilitate development work with Black voluntary sector organisations to provide them with the skills to be able to compete equally for contracts as future health service providers (two projects were funded by the NHS Ethnic Health Unit); and it enabled the appointment of commissioning managers in two of the health authorities, whose posts have lead responsibility for health and race issues.

☐ The process outcomes, which are more difficult to measure, have hopefully sown the seeds of longer term improvements. The different local voices approaches taken by these projects have been successful in accessing the health experiences and needs of Black people. The individual research findings have been translated into quality standards or contract specifications which will influence the future shape of services.

☐ The general lack of appropriate monitoring mechanisms means, however, that there is a risk of losing the few achievements that have been made. Gains made on paper in one year could be left lying dormant in the next, unless adequately prioritised.

☐ There is a need to undertake service development work all the year round, taking different opportunities in the commissioning process, rather than concentrating on the half year of contract negotiations.

☐ Joint purchaser/provider project work is a useful approach for sharing the responsibility for improving services.

☐ Financial incentives encourage work on improving services to Black communities; there is little evidence here to suggest that imposing penalties on providers would have the same effect.

☐ Setting and implementing health and race quality standards, especially in the context of the *Patient's Charter*, is a useful method of mainstreaming work on race. This can help equality issues become a core part of the service, as opposed to being viewed as an added extra.

☐ More specific planning of services would have been possible if ethnic monitoring data had been available, i.e. figures on current service take-up from specifically identified communities and on specific conditions and disease prevalence.

☐ Needs assessment should be carried out equally in areas where there are relatively small Black populations. It is harder to get race issues on the main agenda as a priority, yet Black communities may be at an even greater disadvantage, especially if they are dispersed over a wide area.

☐ The Black voluntary sector needs resourcing and supporting to be able to compete equally for contracts. There is little point in Black people being put on a waiting list if the provider cannot offer an acceptable service.

☐ The lack of effective language and advocacy services continues to prevent many Black people from accessing their rights to health services.

☐ Whether because of individual staff attitudes or through organisational procedures and behaviour, there remains direct and indirect discrimination in health service provision.

Chapter 9

Recommendations and strategies for long-term change

❑ In order to encourage action on the outcomes of consultation exercises, the NHS Executive should consider developing a *Local Voices* implementation strategy, designed to:

- assist action planning following consultation;
- co-ordinate the sharing and transfer between districts of good practice principles and service developments appropriate to the health needs of Black communities.

❑ Since statutory services are largely not meeting the needs of Black populations, and change is slow, the NHS Executive should consider a policy initiative to actively promote the development of the Black voluntary sector as potential providers of health services. This should include the provision of resources and training.

❑ Since the barriers to equal access to health care are still present, the NHS Executive should consider a policy initiative to actively promote the development of independent advocates for Black users of the health service.

❑ All health authorities and commissioning agencies should adopt the strategic framework in health and race shown in Fig. 3. This identifies a range of measures which need actioning at all levels of NHS management and service delivery. It is based on the lessons from this work and the implementation of national policy guidance. It is dependent for its success on the following key elements of change:

- vision
- political will
- skills
- incentive
- resources
- action plan.

1. Corporate commitment reflected in: mission statements; policy statements and action plans on equal opportunities in employment and equal access to services	**vision, political will**
2. Designated senior managers, including chief executives, having lead responsibility for health and race	**political will**
3. The Board membership should reflect the ethnic composition of the local community	**political will**
4. Awareness and understanding of above policies among executive and non-executive board members, senior managers and all staff e.g. through training and staff development	**skills**
5. These policies integrated into the corporate contract objectives and into senior management individual performance reviews. All staff must be aware of their individual responsibilities in relation to these policies	**incentive**
6. Action plans with targets agreed with providers in order to meet the eight goals specified in *Ethnic Minority Staff in the NHS – A programme of action*	**action plan/ resources**
7. Black *Local Voices* consultation strategy integrated into the generic strategy; evidence of the outcomes of ongoing involvement of Black communities fed into the needs assessment and commissioning process	**action plan/ resources**
8. Core health and race quality standards integrated in local *Patient's Charter*, applied in contracts and monitored with user involvement: religion, diet, information, communication, choice of female clinician	**action plan/ resources**
9. *Health of the Nation* targets set for health promotion work with local Black populations	**action plan/ resources**
10. Staff training achieved to ensure that ethnic monitoring data is routinely collected for hospital in-patients, and that the resulting data is pro-actively used in service planning	**action plan/ resources**

* All the above to be adequately resourced and subject to a monitoring and evaluation process

** The principles outlined above to be included in the planning and development of primary care-led health services via GP fundholders and other local purchasing consortia

Figure 3 Strategic framework: health and race for purchasing agencies

Appendix

Summary of project methods and findings

The following material has been adapted from the individual project reports.

BRADFORD

Method

A qualitative ethnographic study was used because it was felt that this would give a fuller picture of Asian patients' experiences than would be offered by a purely quantitative study. The project focused on issues which were of specific concern to Asian patients, as opposed to those shared by the rest of the population.

The sampling frame consisted of Asian patients who had been discharged within the previous two months from Bradford Hospitals NHS Trust, having undergone an elective procedure. In total, 65 patients took part from: general surgery (14), gynaecology and urology (24), and general medicine (27). Three focus groups were held with patients from each group: women over 35 years, women under 35, and men over 35. There was insufficient interest in the under-35 male category.

Findings

Liaison officer service

- A comprehensive review of the current service (providing interpreting and a link between the patient and the provider) should be carried out. Over 60 per cent of patients interviewed were dissatisfied with this service and many nurses don't bother to 'bleep' them because of the slow response time.
- Standards needed to be set to improve quality.
- Patients expressed the need for the service at the following points:
  - at least once a day on wards with Asian patients
  - on admission
  - ward round
  - meal times
  - at night time on an 'on call' system
  - at discharge
  - at outpatients.

The following specific quality standards were raised as key issues by patients, and consequently put into the quality schedule with providers.

Patient information

- Patients leaflets to be provided in appropriate Asian languages, to include areas such as:
  - admission
  - discharge
  - managing clinical conditions post-discharge
  - services, facilities and functions and how to make best use of them
  - complaints procedure
  - life on the ward.
- Translation of appointment letter and card.
- Audio-tapes in Asian languages for those unable to read.

Respect for privacy, dignity, religious and cultural beliefs

- Meeting basic spiritual needs, including:
  - multi-faith chaplaincy (to include prayer mats and private prayer room)
  - access to spiritual adviser of the patient's choice
  - improved ablution facilities.
- Patient dignity, including:
  - providing clothing for patients while on the ward, during transport to other departments and theatres, etc. which meets the religious, cultural and personal dignity of the patient (this was especially raised by Asian female patients)
  - offering choice, where available, of male or female professional when examinations are carried out.
- Religious and cultural needs assessment
  - patients should have religious, cultural, language and social needs assessed on admission to ensure both that ward staff's attention is drawn to the language needs of the patient and that liaison officer service is made available if needed; and that social needs assessment informs ward staff of patient needs at discharge, such as social worker advice and home support (the project findings suggest that social workers are not informed early enough to be constructively involved in discharge arrangements).
- Information database
  - adequate information to be available to staff to help meet religious/spiritual/cultural needs of any patient.

Treatment – choice of professional

- Except in emergencies, patients should be offered the choice to be examined by a male or female professional. Where a choice does not exist the provider should take positive action when recruiting.

Catering

- The patient catering service should be improved to better meet the cultural and religious needs of Asian patients by a variety of means, such as:
  - translation of menu cards to include description of what's on the menu ('Asian menu' in itself does not inform the patient of what the Asian menu might contain) and the catering standards they can expect
  - improved portion size or raise awareness that different portion sizes are available
  - improving the quality of chapattis
  - reintroduction of halal meat (this was stopped in 1990/91 because patients, lack of faith in meat being halal, and complaints about poor taste and quality led to high wastage) with support from Council of Mosques and/or Race Equality Council also bringing members of the Asian community into the kitchens to check the taste and quality of food
  - making meal times more sensitive to the needs of patients who are fasting during religious festivals.

The following quality standards were not raised as issues by patients but are included in the quality schedule as good practice.

Bereavement

- In the event of death, there should be arrangements for viewing in private. In addition, a trained member of staff should be available to offer bereavement counselling.

Privacy

- Patients to be assured of adequate privacy at all times.

Name policy

- Staff to ask patients whether they wish to be called by first or last name and preference to be respected.

REDBRIDGE AND WALTHAM FOREST

Method

The A&E department at Whipps Cross Hospital carried out ethnic monitoring of patients admitted to hospital via casualty, during a four-month period. This identified 48 patients, with whom hospital discharge interviews were undertaken. The sample was made up of 32 men and 16 women. Forty-five of these were Asian and 3 African Caribbean.

Two community fora were held, one for each community. About 50 older people attended the forum for the African Caribbean community, while the Asian forum was attended by a few users and a larger number of Asian community workers.

Findings

Discharge interviews – hospital and community services

- Of the 15 Asian women interviewed, none could speak or understand verbal or written English. In none of the cases was the services of an interpreter offered. Relatives, and in one case a nurse, acted as interpreters.

- A few patients felt that staff did not bother to explain things to them because they could not speak English.

- No patients had been given any form of written communication about their care, treatment or discharge plan.

- Thirty-five per cent of patients felt that the food was unsatisfactory in terms of both quality and choice. Many arranged for relatives to bring them food from home.

- Twenty per cent of the sample felt that they had religious needs and practices that were not met, namely the lack of ablution facilities. Some, however, stated that they were too ill to pray and/or did not expect to stick to their religious practices while in hospital.

- A minority of patients would have preferred to be in a single-sex ward.

- Only 20 per cent of respondents knew how to make a complaint about their care or treatment while in hospital. Some said they would get their family to do it, or tell their GP about it when they next visited. A number said that they did not think it was right to complain about the service at all.

- Only 20 per cent of respondents were asked what help they might need on discharge from hospital. The majority of patients felt that if they needed support, their family would provide it.

- A number of patients were told that they would get a district nurse in to see them, but this never happened.

- A couple of people were referred to a social worker. Three patients felt that they would have liked to have seen a social worker while in hospital, but were not offered the service.

- Ninety-eight per cent of patients felt that their care was satisfactory, some describing it as very good or excellent.

Community fora – GP services

- Medication instructions are not translated or explained properly; consequently, some Asian people are not taking their medication appropriately.

- It was felt that GPs should carry out health checks and screening of Black people regularly in order to prevent, or to treat earlier, conditions such as coronary heart disease and hypertension, i.e. conditions where it is known that Black people have an above-average morbidity rate.

- Asian women have difficulty talking to and being examined by male doctors.

CAMDEN AND ISLINGTON

Community workers' perspective

Method

The community workers were sent questionnaires. Approximately 50 per cent of the sample of 120 organisations responded.

Findings

- Three-quarters of the respondents were aware of only three or fewer of the 11 listed services for carers. The three best known were: home care provision and residential respite provided by the local authority, and the respite support scheme offered by Crossroads.

- All respondents agreed that a specific contact point or person was required to provide them guidance to access services for their communities.

- Information was needed on the services available. This was especially important as the respondents felt that there was little evidence of inter-sectoral communication between related providers.

- Nearly half the respondents had come across people who could not or who chose not to use services. This suggests that services were not acceptable in their present form – 'the language barrier and cultural insensitivity remain the major obstacles preventing people from using mainstream services.'(p16)

Users' and carers' perspective

Method

The sample of users and carers was compiled from the following sources:

- referrals from community organisations
- responses from mailshots to restaurants and takeaways
- snowballing – one respondent referring another

- the Camden and Islington Register of People with Learning Difficulties
- the Islington Special Services Team.

To ensure adequate numbers from some of the chosen communities, it was also necessary to circulate publicity in selected public venues e.g. churches and football grounds.

A group of sessional workers, recruited from the same language communities as the interviewees, conducted semi-structured interviews from 92 households. These were previous, current or potential users and carers. Where possible, interviews were conducted separately.

Findings

- Eighty-three per cent of the sample carers were female: 32 per cent were mothers caring for sons or daughters; 23 per cent were daughters caring for their parents.

- Almost half the respondents were receiving income support and housing benefit. 22 per cent had disability living allowance and 17 per cent were receiving invalid care allowance.

- English was not the first language for almost two-thirds of the carers and 80 per cent of the potential users. Overall, the majority spoke little or no English.

- All but two of the respondents were registered with a GP but none realised that their GP could refer them onto the services.

- Fifty per cent of the respondents had not had contact with social services.

- Twelve per cent of these were then referred to the social services and Crossroads to access services.

- Twenty-eight per cent of carers did not want to be put in touch with either social services or a mainstream voluntary organisation because of previous bad experience and language barriers.

- A further 25 per cent were referred to related agencies for other support or services.

- Most respondents were unaware of the range of respite care services available. The lack of information on services was a key barrier.

- Sixty-two per cent of respondent carers had not had a break in the last year.

- There was a clear need of a range of respite care services, especially as many carers were suffering from different forms of ill health, ranging from bad backs to heart conditions. The most favoured types of services were day care facilities and in-home respite care.

- Services would have to be run by members of their own communities for them to feel confident in using them.

- New ways of meeting some existing needs were identified through the commissioning and contracting process:
  - spot purchase of day places at Black community centres
  - commissioning information to be produced on services/eligibility criteria
  - bi-lingual sessional workers to undertake needs assessment for Crossroads.

SANDWELL – STROKE

Method

The aim was to identify the experiences of older Black people with strokes from the main Black communities in Sandwell. Thirty-seven in-depth one-to-one interviews were conducted with current and previous users of a range of stroke services. They were from the Pakistani, Indian, Bangladeshi and African Caribbean communities, who were contacted through:

- Black voluntary organisations
- sheltered housing schemes
- hospital wards for stroke rehabilitation
- community centres
- religious centres.

Some interviews took place over two or three sessions with the user, if the user's disabilities made it difficult to concentrate, remember and respond to more than a few questions at a time.

Findings

Characteristics of users

- About 68 per cent of the sample were over 60 years of age, and over half were male.
- The ethnicity of users was as follows:

Indian	43%
African Caribbean	27%
Pakistani	16%
Bengali	13%

- All the users in the 36–59 year age range were from the Asian communities.
- None of the Asian users were able to communicate in English.
- Over 54 per cent of the sample had had more than one stroke. According to the age at the time of the first stroke, 10 per cent were in the 35–45 year age range, and all were Indian men.

- The majority of users had more than one disability as a result of their strokes, the most commonly cited being: movement of hands, arms, legs and feet; balance; speech; eyesight; reading and writing.
- In terms of housing situation, the majority of the sample were owner occupiers, and from the Asian communities. The rest lived in sheltered accommodation, council housing and residential nursing homes, and were mainly African Caribbean.
- Only 5 per cent of the sample had their extended family network as their main carers. Sixty per cent had only their elderly spouse as their main carer, who users described as being overburdened and often struggling to manage their care.

SANDWELL – MENTAL HEALTH

Method

The aim was to identify the characteristics of an advocacy service that would be appropriate to users; at what points in the system the needs were greatest, and the type of provider that users wanted to deliver the service.

Forty-one current, previous and potential users were identified through Black voluntary sector organisations, statutory sector user groups and self-referral to health workers at health fairs. Of these, 27 were female and 14 were male; 11 were Pakistani, 12 Indian, 10 Bangladeshi and 8 African Caribbean; and six were previous users, 25 were current users and 10 were non users.

One-to-one, semi-structured Interviews were carried out. Some were carried out over two or three sessions to prevent interviewees being overwhelmed and fatigued by the list of questions.

Findings

- From the experience of services, users disliked:
    - tendency to prescribe drugs/medication
    - lack of appropriate counselling services
    - lack of information on treatments
    - number of professionals involved in care
    - hospital food.

- From the experience of staff behaviour, users disliked:
    - lack of understanding
    - inappropriate advice
    - assumptions, judgements, stereotypes about needs and preferences
    - lack of time to listen
    - non-verbal disapproval/lack of patience
    - lack of interest.

- An appropriate service is described on the following page.

Sandwell draft black mental health advocacy service specification

1. Description of service

An advocacy service in the Sandwell context is defined as service which will:

- inform service users of their rights to services and their rights within the system
- enable and facilitate service users to get their needs met
- represent the needs, concerns and wishes of the service users as requested by the user
- acknowledge and listen to the needs of the service users
- respond to identified needs appropriately following consultation with the service user
- support the service user in any other appropriate activities.

2. Scope of service

The advocacy service will offer a range of activities within:

- inpatient treatment and consultation
- outpatient treatment and consultations
- care in community settings such as day centres and in the home
- at a primary care level.

3. Service specification

The advocacy service will be pro-actively offered at the various identified points in the service in terms of:

- inpatient care:
  - post-admission
  - formulation of nursing care/treatment plan
  - ward round representation
- outpatient treatment and consultations:
  - during outpatient clinics
- care/treatment in the community
  - during initial assessments by the CMHT
  - reviews in the home, day centres, etc.
  - at multi-disciplinary team meetings
- primary care level
  - GP appointments.

NEWCASTLE AND NORTH TYNESIDE

Method

Two Chinese research workers were commissioned to undertake focus group work with 30 members of the community.The aim was to identify how access to both primary health care and mental health services could be improved.

Findings

Primary care

- There was a need to promote the role of members of the primary health care team other than the GP.
- There was a need for an increase in the use of interpreter services.
- There was a need for information available in translation and other forms of media.
- More female GPs were required.
- A more flexible GP appointment system was needed.

Mental health services

- There was limited knowledge of mental health problems, especially of more severe forms of mental illness.
- There was a general lack of awareness of both statutory and voluntary sector service provision.
- There was a clear need to develop mental health service support in primary health care.

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Purchasing for Black Populations describes the work of six King's Fund projects where the views of local Black communities were used to influence a range of service developments through changes in commissioning, quality standards and contracts.

By bringing together the local lessons within a broad framework, the report maps the progress of the individual projects and highlights the barriers to change which remain.

Purchasing for Black Populations will be of interest to purchasers, providers, mainstream as well as Black voluntary sector organisations, researchers, and race and health specialists.

ISBN 1-85717-105-5

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