Better Services, Better Health

The healthcare experiences of Black and minority ethnic disabled people

What seems to be the problem?

INFIRMARY
OUTPATIENTS
MATERNITY UNIT
PAEDIATRICS
CASUALTY
RENAL UNIT

SURGERY

ENGLISH-HINDI

HINDI-ENGLISH

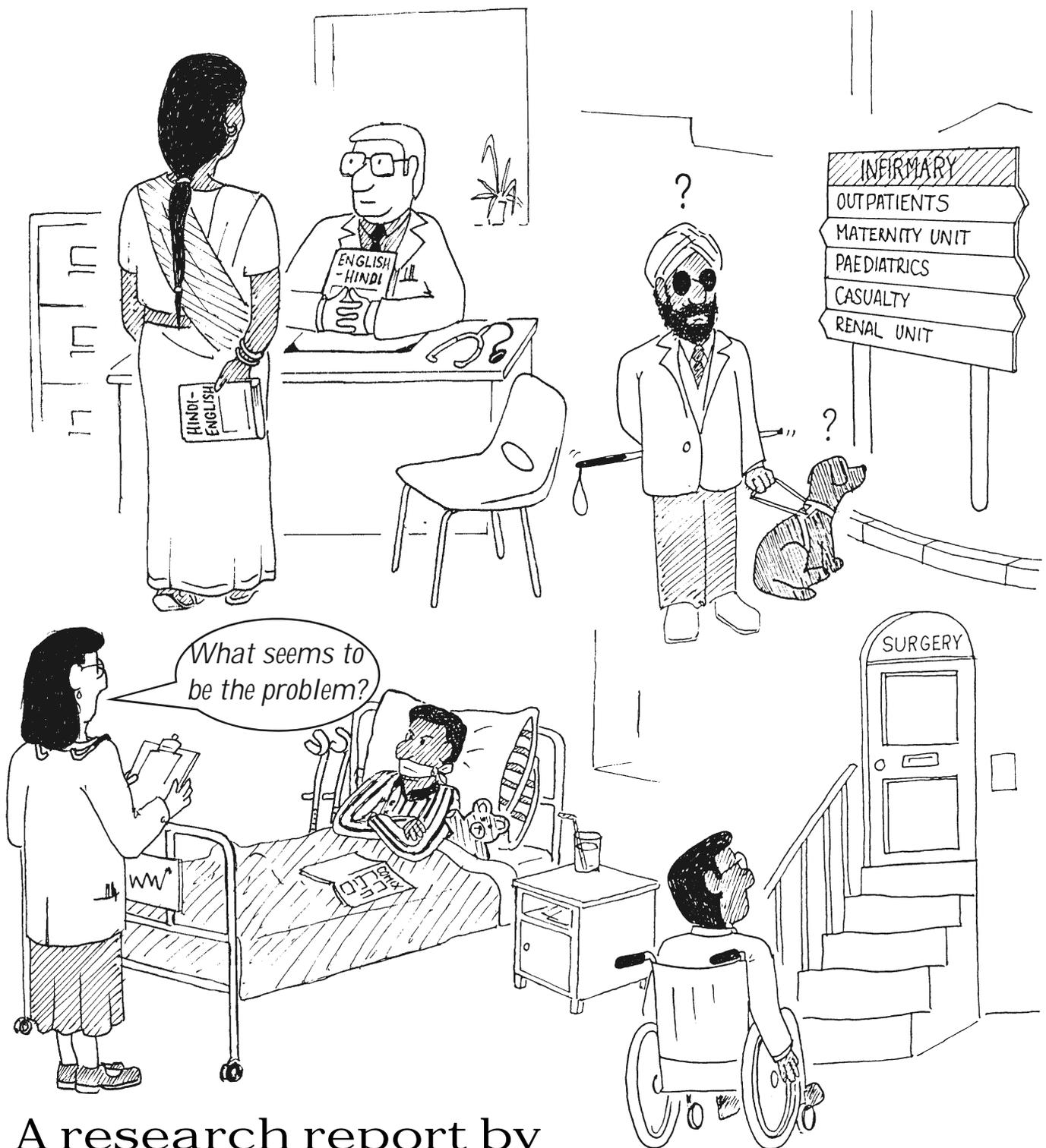**A research report by Sonali Shah and Mark Priestley for Leeds Involvement Project**

Better Services, Better Health:

the healthcare experiences of Black and minority ethnic disabled people

A research report for Leeds Involvement Project

by Sonali Shah and Mark Priestley

Better Services, Better Health: the healthcare experiences of Black and minority ethnic disabled people

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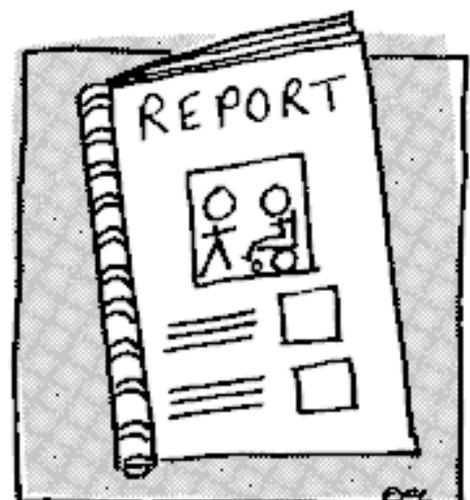
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What's in this Report?

The report is divided into sections, dealing with different issues, experiences and conclusions as follows:

contents

Background

What this report is about

This report is about the healthcare experiences of disabled people from ethnic minorities. It includes their views, and those of their allies, about the kinds of services and choices they receive, and about ideas for improvement in the future.

Who is disabled?

We wanted to include disabled people with a wide range of experiences, and we did not wish to exclude anyone who might want to take part. This report includes the views of people with different experiences of disability and with different kinds of impairments. During the project, we met people with learning difficulties, with physical impairments and visual impairments. We met Deaf people and people who had experienced mental distress.

Which ethnic minorities?

In the time available, we were not able to meet with people from the whole range of local ethnic minorities. We wanted to reflect the experiences of disabled people from the most prominent communities in Leeds. We were also aware that people from Black or 'visible' minorities experience particular kinds of racism in Britain.

This report is therefore primarily about the views of disabled people from South Asian and African-Caribbean communities in Leeds. However, we believe these experiences are also relevant to people from other local minorities.

What is healthcare?

For the purposes of this report, health care covers quite a broad range of things. Much of the material is about people's experiences of meeting with doctors and going to hospital. However, there are also views about aftercare support and about a wide range of health professions and services.

We were particularly keen to include areas of primary care provision, and there are comments about therapy and dental services, as well as midwifery and community support.

We also wanted to think about health in more general way, in terms of looking after yourself and feeling healthy. As one person put it:

> *"I think if you feel good that improves your health. If you feel happy and contented with your circumstances then you feel better as a person and you're less likely to feel depressed and down, and then illness doesn't come to you as much as it would if you were depressed and sad."*

Acknowledgements

Introduction

There have been a number of recent research studies about the experiences of Black and minority ethnic disabled people, and the reasons why they are often marginalised from services.

Some providers are beginning to reflect the needs of Black and minority ethnic disabled people in delivering services but there is a still a long way to go.

The low take up of healthcare services by Black and minority ethnic disabled people, and their general absence from a range of service user involvement initiatives, has become a source of great concern.

There is no reason to believe that Black and minority ethnic disabled people do not need or wish to use services. Yet evidence suggests that poor access to information, communication barriers, lack of sensitivity for culture and traditions, and discrimination on the basis of race and disability may prevent them from doing so.

This report identifies the key issues, as seen by Black and minority ethnic disabled people, preventing access to good standards of healthcare. It includes their experiences, and suggests ways in which service delivery could be improved.

Black or disabled, is that the question?

Black and minority ethnic people may suffer discrimination in many areas of their lives. This is also true for disabled people. Policies and practices have evolved to serve the needs of Black and minority ethnic

people and of disabled people but rarely both at the same time.

There has been concern that African-Caribbean and Asian disabled people are often 'invisible' in their own communities as disabled people, whilst also being invisible in disability communities as Black people. This has been explained by highlighting disabling attitudes and practices, and by pointing to institutional racism in disability service provision.

Within disability organisations and within services, impairment can easily be seen as the main part of a person's identity, ignoring other aspects such as race, ethnicity, gender or class and caste.

As Mildrette Hill, founder of the Black Disabled People's Association, argues:

> *"Black disabled people frequently find themselves caught between a rock and a hard place"*

They may have unique needs and wants, which cannot necessarily be met by services developed for white disabled people or for Black non-disabled people.

There have been calls for more culturally sensitive or 'culturally competent' services, and for resources to support self-advocacy and disability awareness within minority communities. There has been concern about the provision of information and about communication at the point of service delivery.

However, there has been very little disability research into issues of healthcare.

background

background

Description of research

The research was carried out between November 2000 and February 2001. The researcher was herself a Black disabled woman with some personal experiences of healthcare provision (although not in the Leeds area).

Local contacts were made through the Leeds Involvement Project and the Centre for Disability Studies at the University of Leeds. Both of these organisations had considerable experience of working directly with local Black and minority ethnic disabled people in the past.

The research itself was small-scale and involved talking in detail to people about their experiences of healthcare.

We met first with four 'key informants', two disabled people and two not. All four were from minority ethnic backgrounds. These four people were chosen because they had a lot of knowledge about other people's experiences as well as their own (either because they provided a service or because they were involved with local user groups of Black and minority ethnic disabled people).

We then met with a range of local disabled people. We met most people in small groups, where they could share their experiences with others. We met a small number of people on their own, because they preferred to talk to us that way.

We organised four group visits in all, including a group of adults with learning difficulties, a group of older people, a group of people with visual impairments, and a group of younger Deaf people.

Some of the people we met did not use the same language as the researcher and so we used interpreters to help us understand what people were saying (particularly where they used Punjabi or British Sign Language).

The people in our groups were mostly from South Asian communities, many of whom were from Pakistani Muslim families (the largest local minority community). Using groups and individual interviews, we also involved people of Indian, Bangladeshi and African-Caribbean descent.

We asked people about their experiences of health and healthcare, and about their preferences for the way in which healthcare information and services might be provided.

Local background

Health services in Leeds are currently purchased by Leeds Health Authority, within the same boundaries as Leeds City Council. The total population served is around 724,000.

Leeds Health Authority commissions services from Leeds Community and Mental Health Services NHS Trust, the Leeds Teaching Hospitals Trust, and five Primary Care Groups soon to become Trusts: North West PCG,

North East PCG, West PCG, East PCG and South PCG.

From April 2002 new Primary Care Trusts will aim to change the way that local services are delivered, to improve services and to reduce inequalities in healthcare. Our intention in this research is to influence practice in the local area.

Culturally sensitive services

The views of those involved with this project suggest that services all too often give the impression of being culturally inappropriate or insensitive to Black and minority ethnic disabled people.

> *"I think one of the main reasons why families are reluctant to actually pass their child over to the system is because they know their child's requirements, and are culturally sensitive to whatever the needs are."*

This may relate to very practical things, like the provision of appropriate food, or to more general features of the way in which a service is organised or delivered. For example, the cultural backgrounds of other service users and staff may affect the character of a service, and the kind of procedures or expectations involved in using it.

> *"A lot of African Caribbean people are not getting their skin and hair taken care of because it's quite different to other people. So a lot of people are not getting good quality and standards of care in their care home because people are not fully aware of their needs really."*

It is important not to reduce people's concerns about services to tokens of cultural sensitivity (the 'saris, samosas and steel pans'

approach). However, small things do matter to people, in making them feel welcome and trustful of those who provide services.

The following examples illustrate some of the concerns raised in our research.

Diet and food

A common example, which appears in previous research as well as our own, is the issue of food in residential, day care and hospital provision. Despite raised awareness and other developments amongst providers, this issue continues to be raised by minority ethnic people using healthcare services.

Given these developments, it was surprising to hear continuing stories of people's difficulties in meeting their dietary needs, in accordance with culture preferences or religious observance.

For example, one young man noted that although it was easy to get Halal food at the voluntary sector social group he attended, this had been difficult in hospital:

> *"I was on a Kosher diet. They put me on a Kosher diet. They know that I don't like meat. Halal would have been better, I like what we eat here, I don't like the food in hospital. It was cold, very cold, but I didn't complain."*

A young woman in the same group echoed his story:

culture

"When they bring the meat, I've told them I'm not allowed to eat certain meat. It's got to be Halal meat, and I'll ask for vegetarian. And that's been a problem."

Service sensitivity to dietary preferences was important, not simply where certain foods were allowed or not allowed, but also where they made people feel more comfortable with the service itself - feeling welcome and not isolated.

"The main problems with African Caribbean people who might not benefit from existing services, are mainly because sometimes those services are not culturally sensitive in terms of they don't provide. Say for instance it's a day care centre, they don't provide food that they would enjoy eating, they may not listen to the kind of music etc"

There has been work to address dietary issues in Leeds hospitals, co-ordinated by the Equal Access Unit. Whilst a 'multicultural menu' is available on request - including Halal, Kosher, vegetarian (Asian) and African-Caribbean options—it does not appear on the main weekly menu offered to all patients. There are plans to correct this and promote to local communities (e.g. via Asian radio stations and community groups) so that more people become aware of the choices. Menus will also be available in Braille and large print.

Trust

The issue of cultural sensitivity and trust was important, because it affected how disabled people and their families viewed services and how they felt about using them. Indeed, there was a perception within some communities that lack of trust was a barrier that prevented some people from using certain kinds of services (for example, respite or overnight care)

In social care, purchasers or providers may spend time developing familiarity between a family and a service to allay such concerns. In the area of healthcare such time is not always available, for example in an acute medical situation or when long-term family carers find themselves suddenly unable to cope.

"Problems occur when parents have been looking after a disabled person for so many years and all of a sudden a crisis occurs in the family and that person has to go to respite or short term care somewhere. And the people who care for them don't know where they've come from, don't know the language, don't know what their cultural needs are."

Later in this report we talk more about the effect of racism, disabling barriers and lack of information in explaining why some minority families make less use of important support services.

Establishing a greater level of familiarity and trust within under-served communities is an important first step in redressing the inequality of access and provision highlighted in research.

Gender roles

Another important area of cultural sensitivity related to expectations and preferences about the roles of men and women in healthcare.

The most obvious situation where this became an issue was in face to face consultations with individual medical and health professionals.

Unsurprisingly, there was a clear preference for female doctors amongst female patients. Such preferences usually depended on the kind of advice or treatment sought. For women at least, the gender of the doctor or other professional was significantly more important than their ethnicity.

> *"If it's headache then that's all right, if it's a man. If it's a private thing, it's got to be a woman. I don't mind what colour they are."*

In a national survey of NHS patients, women in Leeds were more likely to seek a female GP than the average (especially younger women). Overall, women are more likely than men to seek a GP from the same ethnic group (especially amongst older people).

This presents difficulties for some minority ethnic disabled women who may require advice, examination or treatment in very specialist areas (because of their impairment) where no female specialist is available.

Culture: Summary

The focus on impairment within specialist healthcare means that such services may adopt a 'colour neutral' approach. In this situation, white needs, wants and wishes become 'standard' and the needs and experiences of Black and minority ethnic disabled people may become less visible.

Consequently, culturally different needs and requests may sometimes be ignored, overlooked, or treated as 'special'. Lack of respect for different cultural beliefs and religious traditions can have a detrimental effect on the health and social well-being of disabled people from ethnic minorities.

While there have been challenges to such problems in many services, the situation of minority disabled people remains difficult, because of the relatively small number using specialist disability services. The most dramatic advances in cultural sensitivity have often been made by self-advocacy groups and community groups, involving local disabled people, rather than by mainstream service providers. For example, in Leeds, groups like the Association of Blind Asians and the Leeds Black Users Group have taken a positive lead.

In many ways this has been a very positive thing, allowing Black and minority disabled people to influence the agenda and to make sure that competent, welcoming services are available. However, such groups will always be additional to public healthcare, rather than an alternative to it. The central responsibility for cultural competence cannot be passed over.

racism

Feeling racism

Racism, either individual or institutional, is often identified as a major factor preventing Black disabled people from accessing services. Although this report is not simply about racism, it is important to note that Black disabled people and their advocates did perceive racism in their healthcare experiences.

Racism is an evocative term and it can mean many things to different people. It may be seen in individual attitudes (such as the manner or comments of individual healthcare staff) or as institutional racism (in the way that health services are organised, delivered or managed).

> *'I really do think there is a lot of in-house racism in the health service.'*

There has been a great deal of recent concern about racism in public services, and within the National Health Service (for example, Leeds Health Authority's Inequalities Policy). However, much of this concern has focused on equal opportunities in employment within healthcare services (where Black and minority ethnic staff are under-represented in higher grades).

The concerns of Black disabled people involved in our project were not about this but about their own experiences, as patients and users of healthcare services.

For example, some people were concerned that they were not always taken seriously by healthcare professionals when they went for help or treatment, or that staff assumed they would not understand what was being said.

> *"The GPs and specialists don't try hard enough, they make you feel as though you're in the wrong department. They don't take you serious. Oh it's very common in Asians, it's one of those things you have to put up with." (Asian woman)*

In health matters there is a danger that Black people may suffer twice; not only from disease or illness but also from the negative attitudes of health professionals. For example, previous research in other parts of the country has found racist assumptions in medical diagnosis, such as attributing the health problems of Black people to assumed cultural practices (e.g. diet, first cousin marriages, Asian medicines, etc.).

> *"Once I heard a doctor talking down to a women... She spoke English but he never even bothered to check, he just looked at the colour of the skin." (advocate)*

Some Black people with chronic illnesses such as sickle cell anaemia or Thalassaemia have found it difficult to obtain treatment, because their symptoms were interpreted by doctors as odd behaviour or an attempt to obtain recreational drugs.

In our project too, some people felt that healthcare professionals made racist assumptions about them as disabled people (for example because they made associations between their ethnicity and their impairment). As one person noted:

I've been told by GPs that (my impairment) is quite common in the Asian community, which I well know it isn't common. For them to say that, I think it's racist, you know. It's very racist for them to make that judgement."

Another example might be Rubella, which is more common among minority ethnic communities in Britain, raising the number of children with learning difficulties and sensory impairments. It is not unknown for medical professionals and researchers to blame low rates of immunisation on cultural practices rather than on barriers to information and communication.

Racism: Summary

There is already a good deal of research showing that Black and minority ethnic people experience poorer health, and have less access to good health care information and services, than white people. Concerns have been expressed about access to information, communication barriers, inappropriate services, lack of sensitivity for culture and traditions, and discrimination on the basis of racism.

"There were other women there who had the same problem as I, and they were just treated so differently by the nurses." (Asian woman)

Our research adds to this, by highlighting the very particular situations of disabled people from ethnic minorities. For many of these people, the pressures of individual or institutional racism may be added to by disabling attitudes and barriers.

Racist assumptions can undermine whole communities as well as individuals. Disability services, in particular, need to address issues of racism and cultural competence more clearly.

racism

disability

Thinking about disability

Disabled people in Britain have argued strongly that we should think about disability as a social problem, rather than a medical problem, as the following quotation illustrates:

> *'In our view, it is society which disables… Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.'*
>
> *(Union of Physically Impaired Against Segregation 1976)*

This social model of disability argues that people are not disabled by their impairments but by attitudes, structures and practices in the wider society. That is what we mean when we talk about disability in this report.

These kind of ideas were strongly resisted within medical and therapeutic services for a long time, where disabled people continued to be seen, first and foremost, as people with impairments requiring care or a medical cure.

The 'social model' is becoming more familiar now within white British society. It is also starting to influence the training of health professionals. We have seen the introduction of anti-discrimination legislation, which requires adjustments to ensure equal service to disabled people.

However, Black and minority ethnic disabled people have often been excluded from these arguments within the disability community. Consequently, social model ideas have also been slower to spread into Black British communities.

This has placed some minority disabled people at a disadvantage to their white peers. In particular, they have been less able to draw, as easily, on peer support within the disabled people's movement, to claim legal rights and entitlements to equal treatment.

There is a double jeopardy for Black disabled people because they may experience both racism and disabling barriers at the same time.

Disability and ethnicity

When disability and ethnicity go together people sometimes have to make difficult choices between the two. For example, parents may want to access a service that addresses their child's impairment needs but in the end choose another kind of service because it appears to be more culturally sensitive.

Some researchers have argued that this puts Black and minority ethnic disabled people in a difficult position, having to choose between their disability identity and their ethnicity.

For some people this was quite a straightforward choice. For example, when we asked young Deaf Asian people about this, they felt that being Deaf had much more effect on the services they received than being Asian.

"It doesn't matter who you are, it's definitely Deafness".

"The biggest experience of discrimination I have had is by able bodied people. They decide what is good for you and what is not good for you, and I'm thinking 'sod it, I'll do what I need to do'."

Some of the people we met were unhappy about attitudes towards disabled people within their own ethnic communities.

There was sometimes a feeling that they had fewer opportunities to mix socially and to access good services compared to white disabled people.

"Black and Asian disabled people don't actually go out. They are sort of hidden. And that's where some education is needed."

## *Disability and healthcare*

There are many disability issues to think about in healthcare services. These range from the attitudes of healthcare staff to the accessibility of health information and buildings. There may also be barriers to transport, and to personal communication.

For example, some Black disabled people were very unhappy about attitudes which they felt treated them as lesser people.

"As far as the diabetic clinic goes, initially I wasn't very happy. I think the typical doctor's scenario of 'I'm telling you do this' , and it's a very talking down kind of attitude. How can you know better than us? We know better than you. It's my body, I'm living with it every day, I know what happens."

disability

Care workers and advocates who often went with disabled people to medical appointments, or other health services, spoke about similar concerns.

> *"When I supported one of the group down at the hospital, they've actually spoken to me not him. They actually tried to straighten him up when he's got a concaved back."*
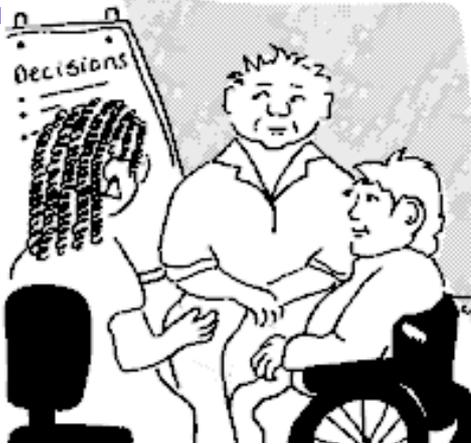
When Black people talked about these kinds of disabling experiences, they did not mention ethnicity or racism very often.

Disabling environments

Surprisingly, the places where healthcare services are provided (like hospitals, clinics and surgeries) sometimes had very poor access for people with physical impairments, or were difficult and confusing for people with sensory or cognitive impairments.

There were difficulties with steps, unmanageable heavy doors, and inadequate lifts. Some people encountered misunderstandings about their impairments, and unjustified assumptions about their quality of life.

Making health professionals and health service providers more fully aware of the social model of disability will be an important task in changing perceptions, practices, buildings and equipment, to improve access to health care for all disabled people.

> *"People's acceptance of anyone who's different is a problem. So I think that would be a problem for any person with a learning disability or physical disability, to go into an environment that's strange and make themselves heard and be respected straight away." (advocate)*

Locally, there have been some efforts to improve things. For example, the Access Committee for Leeds are producing basic information leaflets on access to services for disabled people, and these will be distributed through health services.

Trainee doctors and nurses at Leeds Teaching hospitals now receive a brief introduction to the social model of disability as a normal part of their courses.

> *In the past, disabled people have fought so hard to challenge the medicalisation of their lives that concerns about health needs have tended to be minimised. [This] has made disabled people wary of putting health issues on the public or political agenda. (Nasa Begum, 1996)*

Feeling lonely?

One of the strongest themes from Black disabled people and their advocates was about experiences of being isolated from social activity. This was not only in healthcare settings but also in community life. Feeling isolated was unpleasant and also raised concerns about people becoming less healthy through depression.

> *"I think a lot of Black people I know with disabilities are very isolated. They have problems making friends, going out independently, doing things that they really want to do in their local community. So you find a lot of people stay at home on their own a lot, or they're in their care home environments, and they're not accessing anything outside."*

Being disabled and being ill at the same time can make it very difficult to maintain social contacts. For some minority ethnic disabled people the range of social opportunities may become very restricted, either because healthcare environments are not culturally appropriate or because community activities are not very accessible.

For example, one woman talked about her experience of being the only Asian woman on a hospital ward. This made her feel uncomfortable and suggested a deeper problem.

> *"You were left isolated. I think putting an Asian woman in a ward with a majority of white women says something in itself."*

Feeling isolated on a hospital ward was something that happened to people not just because of ethnicity, culture or racism but also because of disabling experiences.

For example, Deaf people and people with visual impairments talked about the potential for isolation due to communication barriers. Being from an ethnic minority made this more difficult.

> *"Because I couldn't see their faces, you didn't know who to call. Had I spoken to this nurse before? So you come up with that kind of isolating feeling. Because of my visual impairment, because I wasn't just like everybody else. I had English but I didn't have the kind of inclination or dialect. They were little barriers but still isolating."*

(there is more about communication later in this report)

isolation

One of our key informants raised similar concerns about the situation of other Black disabled people in nursing or care homes:

"I've been on quite a few visits to residential care homes, to visit some African Caribbean people, and just looking at their environment, when I arrived there, they are the only African Caribbean person there, and I'm sure that is isolating in itself."

The situation in hospital may be helped by the introduction of a new scheme in Leeds, involving 15 PATH trainees from a variety of ethnic communities, based in reception areas, clinics and wards (particular unmet needs have been identified in coronary care, diabetic and renal clinics). The new trainees will be able to approach patients directly, to offer support and assistance in meeting their cultural needs.

Isolation was also a factor for those living at home, who often felt that people in their communities were insensitive to disability issues (sometimes due to cultural differences in thinking about people with impairments).

In the most extreme case, one advocate remembered how older members of her community had died soon after the diagnosis of their impairment, arguing that fear of isolation, associated with blindness amongst Asian elders, posed a serious threat to their mental health and well-being.

"The isolation from that, they don't go out of the house. They just internalised all their problems and they died. Isolation is a big problem and I think group work is the way forward for healthcare."

Helping through groups

In response to such fears, local Black-led disability groups have emphasised the need for social contact and shared experience.

By creating opportunities for social contact and peer support, such groups have made a real difference to people's mental health and well-being. At the same time, bringing people together has provided an opportunity to share experiences and health information.

Being part of a group can help to reduce feelings of isolation, and may provide access to culturally competent help and support in dealing with services when people are ill or need treatment.

Some groups also provide telephone advice to people who feel isolated, someone to talk to, someone to visit, or to accompany them to appointments if necessary.

However, such groups often have limited resources and may therefore find it difficult to respond to large numbers of people seeking social support.

Taking a broad view of health and well-being is important if the isolation of disabled people within Black communities is to be properly addressed.

Not just a language problem

Communication was a very important issue for the people we met in our research. Sometimes they had particular communication styles and sometimes they did not have English as a first language.

Previous research has shown how language and communication barriers can greatly reduce the quality of service provision received by Black and ethnic minority disabled people. Language difficulties have been regularly highlighted as a major cause of concern for Asian disabled people using services.

However, language was not the only communication issue in our research, and simply translating or interpreting was not seen as enough of a solution.

"It's like a first and second class service, and you're pushed into the bottom unless you're the white community. And because they can speak fluent English, or whatever, they were getting their words across. As for an Asian person it would take longer."
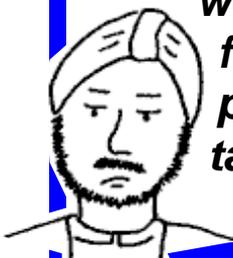
Time

Whether it was due to language or impairment, we often found worries about the amount of time needed to communicate effectively in healthcare settings. Many people told us of difficulty in getting their point across or in understanding what was happening, due to lack of time.

"I had trouble feeding, and I had problems with the nurses at that stage, because the paediatrician was saying take your time, don't worry, but the nurses want to finish you off and go and do something else."
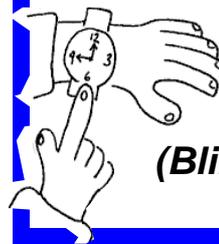
(Blind Asian mother)

"The nurses do not have a lot of time. So people with disabilities do suffer, because they cannot take out that time to devote to the person with learning or physical handicap. When giving tablets, medication, they just leave it on the sides of the table. It's because of the shortages as well. You can't blame them. It's up to the patient to take the tablet. So, if you are in any way impaired, it's very difficult for you to do things, like going to the toilet, asking for help to start with." (nurse)

communication

communication

Formal healthcare settings, particularly clinics and hospitals can be complicated and intimidating places for some people (especially when they are very crowded and busy). Being unsure of what is happening, and being ill or in pain at the same time, can be a frightening experience.

In fast moving situations, some disabled people, especially those who do not use English as a first language, may feel particularly rushed and confused. Spending more time with people and taking care to respond to their communication needs can be an important factor in improving their experience of healthcare.

For example, a young Deaf Asian man explained to us just how frightening it had been when he was taken into hospital for surgery.

Stress and confusion in new environments can make people very uncomfortable, restless and sometimes panic stricken. However, sometimes, acting more quickly rather than less quickly may be the answer. For example, a care worker related the story of an Asian woman with learning difficulties who spoke very little English, explaining that systems and procedures in hospital might need to be more flexible for some people.

"We did go to accident and emergency and we did say to them, because she's got a learning disability, plus mental health problems, she was finding the whole experience quite distressing and could the thing be speeded up. I know we were jumping the queue, but purely for her sake we didn't want to create a scene. And we wanted to have safety for her and people around her. They didn't actually give us much support. They just said, you'll still have to wait your turn."

"I was told I had to stay. Got told I had to go to sleep through the night. Woke up the next morning in shock. 'Cos all of a sudden I was moved across, with a mask on, onto a trolley. I didn't know what was happening. No communication. Going down this corridor on the back of a trolley, into a theatre. Somebody verbalised, 'cos they didn't know I was Deaf. They also had a mask across their mouth and I couldn't tell what they were saying. Two of them were trying to talk to me. I was totally stunned. I had an injection put in my arm. What happened, why it happened, I don't know. Eventually I discovered…But I knew none of this until afterwards. Nobody told me. Nobody explained anything."

Time is a problem for everyone in hospitals, but some work is being done on waiting times for people with learning difficulties in Accident and Emergency Departments.

Language and interpreting

As we had anticipated, there was widespread concern that interpreters (both for English and for British Sign Language) were not generally available in healthcare settings.

> *"By now they should have interpreters in hospital. When you want them they are not there. All right, they have a list of interpreters but those are people employed by the hospital: doctors, nurses, they don't have time to devote to the patient, to explain things to them. So the basics are not there. Things become more and more difficult."*

There have been various attempts to address these concerns. The Health Authority has a contract with Leeds Sign Language Interpretation service to provide BSL interpreters, note-takers and lipspeakers. Clinics are responsible for booking an interpreter.

For community languages there is an interpreting service, Language Link, funded by the Health Action Zone and used by a variety of health care providers. There is a dedicated phone number for staff to ring to book interpreters.

Even in Accident and Emergency, there should be an attempt to book interpreters, though this may be harder to achieve at short notice. Unfortunately, patients are not always aware that these services exist, and sometimes referrals do not state that an interpreter is required (or state "patient does not speak English" without specifying a language!).

> *"You get so frustrated inside. Sometimes you have to draw for instance to get the message over. You get so frustrated so many times."*

Having your say

Advocacy was something that had made a real difference in people's access to services. There were different approaches to this. Some people had learned to speak up for themselves and to become more confident in dealing with healthcare providers.

> *"I do go on my own, so they have to talk to me and not my mother. There's only me there. I found that they would mainly talk to my mother. I didn't really say much really…but I'm old enough to go on my own now. After all, it's me that's got the problem not my mother. Talk to me."*

communication

communication

"This particular female doctor that I went to see, she wanted me out of the room before I got to what I wanted to see her for. So I just sat there and told her. I got to see her in the end."

Another strategy was to use key members of staff to get the point across or to request help.

"If I needed anything medical I just had a word with one of the district nurses. They were quite straight forward at giving their views across and getting things done. They would make a phone call or something. They seemed to have some kind of leverage in that when they asked for something, they got it."

Experience and confidence enabled some people to begin getting their views across more effectively. But this was often difficult and sometimes required support, to develop confidence and self-advocacy skills.

Services (such as the former Council-run Health Advocates scheme) helped many local minority ethnic disabled people in healthcare situations. Self-help groups and community groups have also made a significant contribution. The NHS Plan provides for new advocates in all hospitals.

"My advocacy started in the maternity area and you'd be amazed to find how little information they got. I worked with women from the Asian sub-continent and they didn't have language, and obviously needed me to be there." (advocate)

Communication: Summary

Communication was a big issue in our research. Disabled people should always be consulted about their communication preferences and may need flexibility and time to convey their views.

Health service providers should be aware of hidden impairments (such as Deafness) and be prepared to learn the skills to communicate with people who have visual, hearing or speech impairments, in order to provide an equal and effective service.

Other communication barriers may include the scarcity of adequate equipment and reliable access to good interpreters.
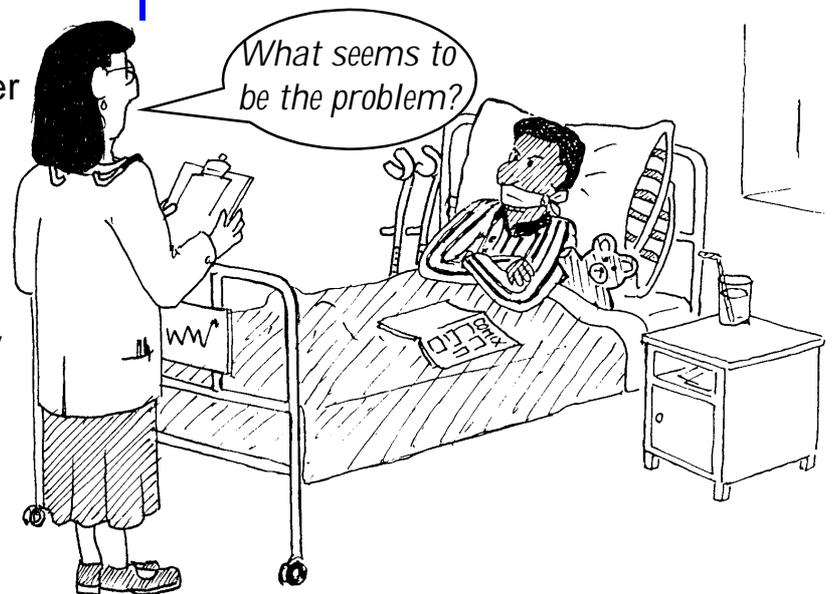
Ignorance can damage your health

In individual cases, lack of knowledge and information about healthcare placed people in difficult situations. Indeed, lack of information can have a direct effect on people's health and recovery. As one nurse explained:

"If the instructions that are given by the hospital are not understood by the patient, when they go home, nurse thinks she's done her duty and patient goes home not knowing what to do, and the recovery becomes difficult."

Similarly, one Asian woman told us (through an interpreter) how lack of information and after care support led to complications after her operation.

"There was no after care. She wasn't told what to do with the stitching or anything. She was in a lot of pain. And then after a while, after a couple of weeks, her doctor sent her to the hospital. At first she thought he wasn't listening to her and he kept saying its getting better...She felt as though he was lying. Anyway, when she went to the hospital they found out that…she got a little bit of an infection because she had no after care. She didn't know what to do, how to bathe, or anything."

This apparent lack of support was a real concern for Black disabled people coming out of hospital, especially for disabled women with family responsibilities. For example, another woman explained (through an informal interpreter) how she had to depend on her school-aged children for help with domestic chores, when she returned home after an operation:

"What she found was, she couldn't do work in the house, like normal everyday chores. So she had to keep the older daughters, who should be in high school, at home, just to do the normal functions like cooking the food and the household chores.

She got problems from school, who were saying 'You should have sent your daughters to school'. They also said to her 'If you send the daughters to school we'll give you some help. Somebody can come to the house and they'll help you clean and wash your clothes'. But nobody came.

She didn't know which office to go to because she doesn't speak English and then that was it…They didn't give her any numbers and she was left with the same problem again."

information

Getting the message?

Lack of knowledge and information about services meant that some minority ethnic disabled people missed out on benefits and entitlements. For some, it was only years later that they discovered information that would have been useful to them.

> *"As I had no understanding of the two registers, I was denied some of the benefits that you get as a registered blind person."*

There were concerns that Black people with impairments might be more reluctant than white people to identify themselves as disabled and to ask for help. Sometimes this was due to a lack of information about the potential benefits. For example, one woman explained how her attempts to show she was self-reliant when arriving in Britain might have worked against her as a disabled person.

> *"I think they (the hospital) were very pleased to see how I coped with my disability. They thought I had the right kind of attitude, and all I had said was that I don't consider myself as disabled... In some ways I put a stop to some information that would have come to me."*

In addition, there was a fear of stigma within some minority communities associated with being seen as disabled. The combined pressures of communication, racism and disability stigma meant that people who experienced isolation also missed out on information (because they were isolated from their families and communities).

There was some concern that information or knowledge about local services was much less widespread amongst local minority ethnic communities than amongst white communities. As one person put it…

> *"People in Black communities, Asian communities is what I mean by that, they don't have a lot of access to information. There's a problem there, especially if there's a barrier in our own culture where we don't go out enough."*

The reasons for such feelings are complicated. They may be related to a real absence of information, to communication barriers, or to misunderstandings about how much information white communities really have.

There may also be problems with the way that service information is generally distributed to local communities. For example, local people have identified problems with the persistent non-delivery of free newspapers and Council bulletins to households in minority ethnic communities (such as North East Leeds).

Learning from others

Clearly, documentation, such as hospital prospectus or notices should be prepared and distributed to accommodate the needs of disabled people. Information should be made available in formats and languages accessible to disabled people and people from ethnic minorities who require them (e.g. large print, Braille).

But translation is not enough. When people are unfamiliar with the structure of services it can be difficult to know what questions to ask. For example, one woman described how she found it difficult to understand the system of health and social services when she first came to Britain and why she did not question the lack of advice or support that she received at the time.

> *"All they said to me (at the hospital) was, 'We haven't got magic wand, You're doing very well. Keep at it'. And that's the health care!"*

Many years later, she discovered services that she had not known existed, by meeting other disabled people.

Local groups of disabled people have made an important contribution to the sharing of information and to development work. The disabled people's movement in Britain has noted the importance of information to disabled people, and local groups (like the Association of Blind Asians) have done a great deal to bridge some of the gaps in making sure that health-related

information reaches Black disabled people directly.

Similarly, groups of Deaf people and groups of people with learning difficulties have helped to overcome some of the barriers to communication outlined earlier in this report—by discussing health issues, sharing experiences, and by providing information in accessible ways.

information

access to services
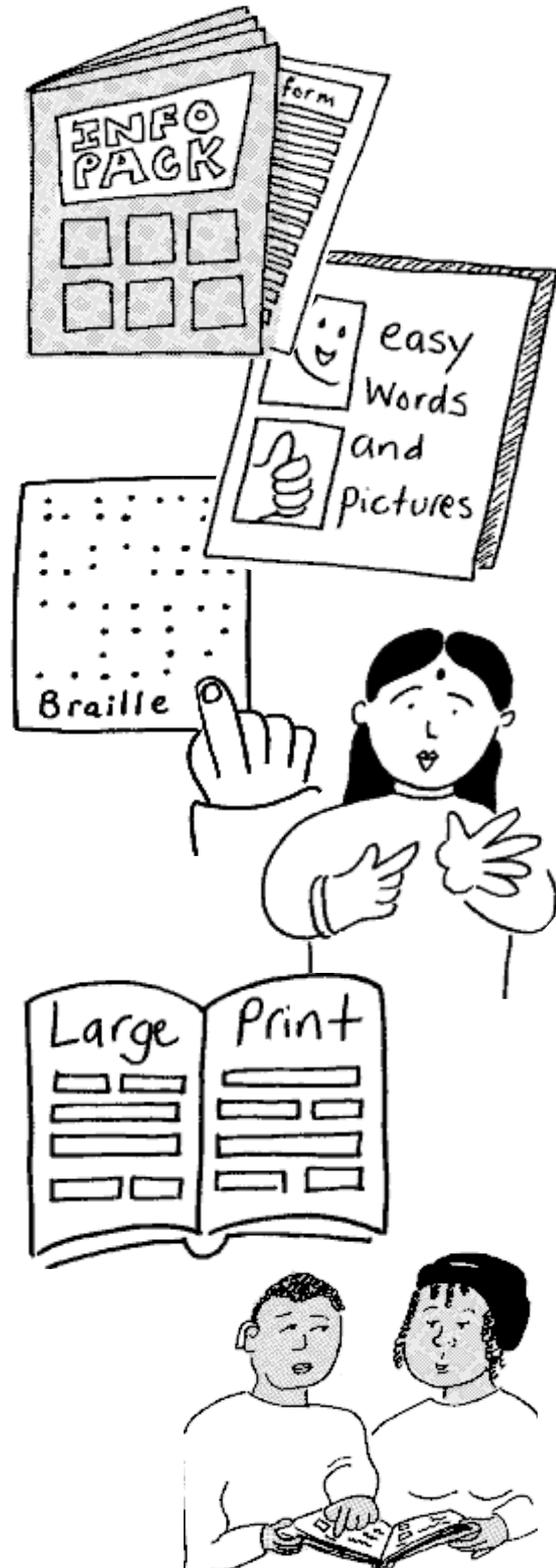
Familiarity and knowledge

The low take up of some services by Black and minority ethnic disabled people may be due to lack of information or communication, and many of the people we met were unclear about the kinds of healthcare services available to them.

As the preceding sections of this report illustrate, lack of knowledge can be a barrier to service use for minority communities, and for some groups of isolated disabled people in particular.

Health care services were not always available, or widely publicised, in the local communities where people lived. For those who did not move much beyond their locality, this could present additional barriers to accessing services. As one service provider noted...

> *"…if you're not familiar with something it prevents you from going out there and accessing it. Also, knowing where things are, geography wise, and having access to get to them, and being familiar with the environment that they're in." (service provider)*

Some people lacked the confidence to ask for help, due to their past experiences of being discriminated against on the basis of disability, race or both. This kind of difficulty affected both disabled people and their families.

> *"People are unfamiliar with certain things, or actually being confident to go out there and say 'I would like to join this service, I would like to be a part of this group', or whatever."*
>
> *(advocate)*

The problems of knowing what services were available, and where to find them, were accentuated in the transfer or sharing of responsibilities between health and social services.

For disabled people in particular, this has meant changes in the role of district nurses, therapists and home care staff. For some disabled people from minority ethnic communities, such changes were difficult to understand. Even simple tasks could involve complex negotiations.

> *"...things have been removed from what used to be a nursing requirement to social services. One case in point is I needed some adjustments doing to the poles on my bed and the OT, who was in charge of lifting and transferring, etc. went to the social services but the social services were more interested in making sure they wouldn't be sued for anything they had to do."*
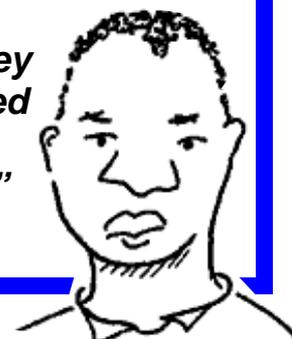
Location of services

Most of the people we met were registered with a family doctor in the neighbourhood where they lived and could get to the surgery easily, either by walking or by being driven a short distance.

Although some people travelled very little in their daily lives, most still visited their family doctor on their own or with a relative.

"I live quite near to the health centre, where I go to see the doctor and the dentist. I do get a taxi up there, but it's not too far away. I once walked it home from there."

Travel to access family doctor services was not identified as an obstacle to health care. Similarly, there were few worries about access to local health centre buildings. However, there were concerns about physical access to other premises (such as dentists') which were frequently located upstairs or hard-to-reach places.

For services that were further away (such as hospital clinics) then transport could be a problem for some people, although most were able to depend on family members or local support for help with this.

"There is a problem with transport, again because the Black and ethnic communities are not aware of that provision. I wasn't aware, and people like me weren't aware, that there is a transport service offered. So it is only when you bump into someone that you're aware of these things. But if you don't, you never would know about it."

However, there are plans to place more outreach clinics in local areas and to expand community based rehabilitation services (such as occupational therapy).

Equal service

Overall, there was a perception, amongst those we spoke to, that people from ethnic minorities get a second class treatment from healthcare services, and that white British people get a better service.

"Its very difficult for Black people, ethnic minorities in general, to actually access mainstream services, benefit from the health service and get the full quality of a service that is really supposed to be there."

family

Extended support

The widespread assumption that Black families use fewer services because they 'look after their own' was brought into question by our research. When Asian, African and Caribbean people first moved to Britain in large numbers they were often separated from their extended families, forming smaller nuclear families and support networks.

> *"In the past support used to come from the extended family, but the families are becoming smaller and smaller and most of the brothers and sisters haven't got time now to look after them."*

In addition, the stigma still attached to impairment in some ethnic minority communities in Britain means that some families of disabled people receive little support from their relatives.

Past research has shown, across cultures, that families who support disabled relatives do not always allow them to exercise life choices, or to access outside help. There may be a number of reasons for this (for example, a lack of knowledge about available support, or concerns about how the family may be viewed within the community).

In some families individual incomes are also pooled as family income. In some cases, where a disabled person receives benefits, decisions about use of services have been taken on the basis of protecting family income rather than promoting choice for the disabled person.

> *"Benefits become the family income, not the disabled person's income. Some families will be supportive as long as money is coming in from that person."*
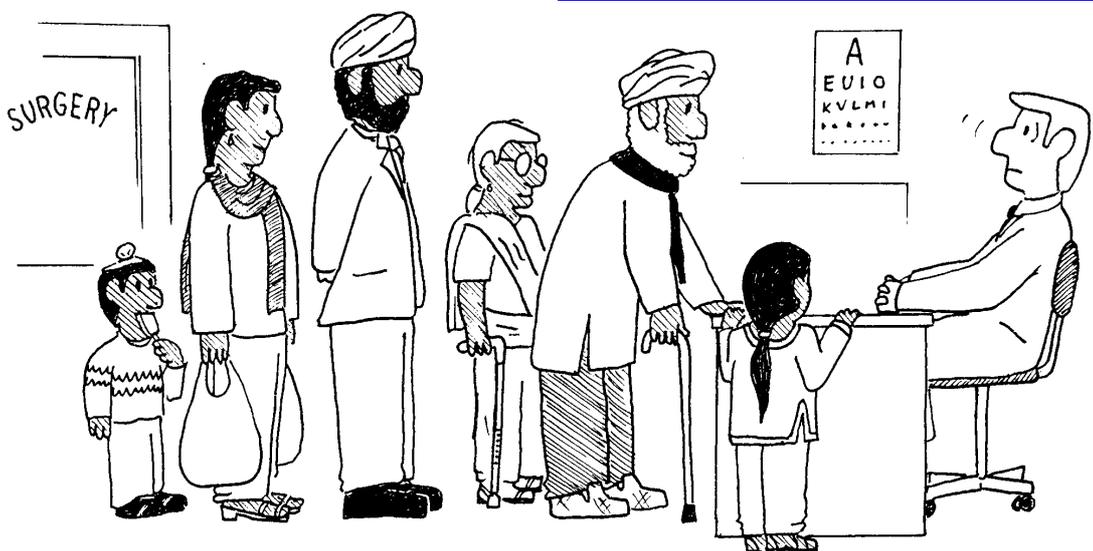
'You said I could bring somebody with me'

Families have provided great strength and support to Black and minority ethnic people living in a racist British society for many years.

However, the fact families have to look out for each other, and provide support, does not necessarily mean that Black disabled people do not need or wish to use healthcare services. As one woman pointed out...

"They (health service providers) always use the stereotype of a tight knit family. So, in other words, they want us to depend on family. It's not always the case because it's a personal thing. We maybe don't want to be depending on family every time…What about independence?"

As this example illustrates, it is important that health professionals should not use the 'close-knit family' stereotype as an excuse to deliver lower standards of service or choice to Black disabled people. The goal must be an equal level of service, regardless of ethnic background.

Aftercare?

Our research revealed a widespread concern about the perceived lack of aftercare support for Black and minority ethnic disabled people who had been in hospital. In particular, Asian women frequently expressed just how difficult it was to manage their own recovery from treatment while also carrying the responsibility of childcare and household tasks.

Often this meant making complicated arrangements for distant family members to travel to help out on short notice. For example, one woman (speaking through an interpreter) explained how she was taken into hospital and discharged while her husband was away:

"The time of the operation came. Her husband was already abroad, and she said that she had three young children at home, and there was no one to look after them. She had no support from anyone, none from her doctor and none from the hospital side. When they operated on her, the next day they sent her home. When she went home she actually got some relations, her mother-in-law from a different place. She said she still had to look after the children because her husband was abroad."

(interpreted to English)

Similarly another Asian woman told us (also through an interpreter) how her mother-in-law came to stay for a year in the house, and how no-one else came to help her in all of that time.

family

Family interpreting

For those disabled people who did not use English as a first language it was common for family members to be involved as interpreters in healthcare settings. Often this was considered as a satisfactory solution.

> *"She takes her son with her when she has to go for appointments. She doesn't have any problems because her son and daughter-in-law are both educated here and they speak fluent. They translate, and if she has any worries or anything they get it sorted out." (interpreter speaking for Asian woman)*

However, a reliance on family interpreters in health care settings was also cause for concern for some people.

On a practical level, there was a concern that family members (sometimes children) might provide inaccurate translations of particular medical or healthcare advice.

Disabled people expressed concerns about having to rely on family members to interpret, and to explain their needs to health service providers (adding to the stereotype that Black families will always provide the best form of support for Black disabled people).

Some young people expressed a preference for professional interpreters in healthcare settings instead of parents or relatives.

Confidentiality was also important, especially for young women consulting doctors about things they did not wish their family to know about.

> *"If it's a private problem. I don't want people to know. I'd rather have it one to one."*
>
> *(woman)*

For the most part, it was the younger generations of Asian families (those brought up in Britain) who took on the task of interpreting for parents, grand parents and other older relatives whose first language was not English. Although this proved satisfactory in some everyday situations (such as shopping) it was less satisfactory in medical encounters.

> *"It's so important that hospitals should offer this interpretation service and not depend on families...It might be personal. I think it's very important." (young man)*

Despite the increasing use of English and the strength of existing family support, alternative arrangements for interpreting and advocacy remain an important priority for many minority ethnic disabled people.

Getting better?

Many of the examples and stories that we heard gave quite a negative picture of healthcare for Black and minority ethnic disabled people. However, there were also positive experiences and suggestions for improvement.

For example, there was a general feeling amongst those with longer experience of health care that things were improving for Black disabled people, and that services were better now than they had been in the past.

"I think there's a lot to be said for the changes. There was a lot less available (before) than there is now."

Improvements were partly due to an overall reduction in racist attitudes towards Black people in Britain (although we found many worrying examples of how this still persists).

There was also more awareness by healthcare providers of how to respond to specific cultural needs (such as language, religious observance or diet). Again, there was concern that much more attention was needed to some of these issues.

Perceptions about the quality of healthcare often came down to experiences of meeting individual members of staff. The increase in health professionals from ethnic minorities was seen as helpful (but meeting a Black doctor was no guarantee of positive attitudes).

"The after care is sometimes good, when, for example, the doctor is from an ethnic minority background themselves. A lot depends on who you're working with, who your doctor is, and who the staff are."

Whose job?

Some of the most positive experiences were the result of local Black-led groups, providing information, advocacy and health promotion services to disabled people. However, their concern was that such small organisations could not be expected to solve all of the problems.

"What's happened, I think, is that the health authority and the main services have not necessarily taken on the ethnic minority issues, but have passed them over to smaller organisations and said, 'You deal with that'."

Clearly this presents some challenges for service planners and purchasers. On the one hand, they will wish to continue support for successful community-led organisations and advocacy services. On the other hand, they will not wish to be seen as passing responsibility on racism and ethnicity issues away from mainstream services.

improvement

improvement

There was also some concern about long-term commitments to services for minority ethnic disabled people. Many of the most positive developments and projects were funded by short-term grants with no guarantee of future funding.

"What tends to happen is, when a new idea comes that's helpful, it's project funded. And then it runs out of funding and then there's no more to carry on. It should be government funded and then it will continue and it will always be there to support."

Listening

The main goal of this research was to listen to what Black and minority ethnic disabled people had to say about their experiences of healthcare. One of the things that came across strongly was that this process should continue in the future, and that it should be seen as part of normal practice.

"One solution could be that the officials in health and in disability listen more to people from ethnic minority communities, and take notice of what they are actually saying and then, from there, actually do something about it ."

Effective consultation and listening is always a two-way process. It is not only healthcare providers that need education, but also many non-disabled people in the community (including those in minority ethnic communities).

"If the person dealing with the disabled person does something wrong, the parents will jump on them. How are service providers going to know how to do things without the opportunity to try. So it's a two-way thing isn't it? They have to use the service to educate people." (service provider)

Communicating

Our research supports the findings of other research projects, which suggest that information and communication are still very great issues of concern for disabled people from ethnic minorities.

Although there have been many very exciting and positive developments in working towards equal opportunities in healthcare, people either do not know about them or have little trust in the potential benefits.

For this reason, the problem of communicating information from large organisations, like health services, to minority ethnic communities remains a major obstacle. Unfortunately, some of the more obvious approaches (such as translating information

leaflets into minority languages) have had very little impact.

Our research, and the experience of local Black-led groups, suggests that there is a need for more focused community development work in this area to get the message across.

"I think there's got to be outreach work as well. I've not even heard of the Primary Group. Who are they? What do they do?

They've started sending out leaflets. That's not the way about it. They need to start getting into the communities, temples, mosques.

Asian people are not aware of things. There's no point interpreting information into Urdu, Punjabi, languages, if it's not going to get to their homes or to their communities.

So health services really need to reach out to the communities. The reason I emphasise that is that the Black and ethnic communities are really missing out here on vital information. And I can say that for a lot of the older generation as well, because they don't get out anyway. They depend on us, the younger generation, to pick up on that."

"The Department of Health has started to bring out leaflets in all the languages, in all the formats, but how accessible are those leaflets. Tape is a better format to give out to people in their languages. If somebody doesn't read English they probably won't read their own language."

The whole picture

Local user-led initiatives have been particularly successful in health promotion for Black disabled people. Part of the reason for this is that they have often adopted a much broader vision of health than mainstream services tend to do.

Recognising that health is about the whole person is important, and this includes thinking about cultural needs and about participation in community living.

"Basically the health care unit don't acknowledge us and do not acknowledge our disabilities. Yes I think they think we're no different to any others, but I'd like to see that equality offered to us. In other words, it's OK for a white person to have a disability, where they get all the help and support and aftercare, whereas a Black person has to go out and look for that and it's not always there."

improvement

summary

General summary

This report is about the healthcare experiences of Black and ethnic minority disabled people in Leeds. The views expressed are drawn from groups discussions and interviews with 28 local disabled people, and five key informants (service providers and advocates).

Overall, the research suggests that there have been improvements in the healthcare experiences of Black disabled people, but that there are still some important issues to address. A number of key themes come out of the research.

Cultural sensitivity

There have been attempts to make local healthcare services more culturally sensitive, but there are still concerns amongst minority disabled people about issues of diet, religious observance, gender roles, staffing, and trust. Local Black-led user groups have been more successful in making cultural competence work.

Racism

There have been moves to address institutional racism within healthcare services. However, some Black disabled people and their allies still perceive racism in the attitudes of healthcare professionals, and in the way services are organised.

Disabling barriers

There is an increasing awareness of disability rights and access issues in healthcare services. However, Black disabled people encountered disabling attitudes and barriers within those services and within their own communities. These disabling experiences affected their health and healthcare.

Isolation

The research raised significant concerns about the social isolation of some Black disabled people (both at home and in using services). Local groups have been trying to address these issues.

Communication

The report includes many examples of barriers to effective communication in healthcare settings. There were concerns about the availability of interpreting services and about issues of time and sensitivity.

Information

Efforts to provide information about health and healthcare still have some way to go in reaching minority communities, and disabled people in particular. The research suggests that community led development and advocacy work may be a more effective strategy.

Access to services

There were some problems with physical access to healthcare premises (such as dentist surgeries). However, lack of familiarity, knowledge and trust of services was a more significant access issue.

Family support

While many Black disabled people rely heavily on family for important tasks (such as interpreting and aftercare) the myth that Black families 'look after their own' creates difficulty for others.

Monitoring and audit

1. Ethnic monitoring of GP, primary and hospital services would assist in providing more evidence of current provision and future progress. There should be ethnic monitoring of all key performance indicators (waiting times, treatment outcomes, etc.) but with particular attention to smaller areas of disability specialism (e.g. blind registration, low vision clinic, hearing aids, wheelchair service, etc.).

2. Specific work to monitor Black disabled people's experience and satisfaction with specialist and mainstream services would help to target areas for priority action.

3. There would be benefit in an audit of cultural competence and sensitivity in healthcare services., and particularly in services targeted at disabled people and their families (which often escape attention).

4. Implementation of action required by the Macpherson Report to combat institutional racism should be monitored for impact on disability services

Staffing and training

1. Positive action to recruit Black and minority ethnic staff may help to increase visibility and trust in healthcare services, particularly in specialist disability service areas.

2. Inclusion of disability equality and anti-racist issues during in-service training for GP surgery staff and in PCT induction training. This should include reference to the simultaneous experiences of Black disabled people.

3. Further implementation of new proactive initiatives towards cultural competence in hospital and residential services (e.g. PATH trainees) should be encouraged.

Point of service issues

1. Consideration to systems for reducing appointment waiting times for people with learning difficulties or who experience distress.

2. Hospital admissions should include an assessment of disability and cultural support needs, not only those associated with the presenting reason for admission.

3. New PALs workers (particularly in Accident and Emergency) should alerted to the often complex issues facing Black disabled people.

4. Work should be done with staff to raise awareness of interpreting services and booking procedures for interpreters.

Community based issues

1. There should be greater action to combat the isolation of disabled people within minority ethnic communities (e.g. as a health promotion or positive mental health issue). For example, asking about the adequacy of social networks and contacts in any community healthcare assessment.

recommendations

2. There should be increased funding to expand Black-led community development work on disability issues within minority communities, and group work on sharing experience and knowledge amongst Black disabled people (building on existing good practice).

3. Outreach workers and those making home visits to disabled people should receive training in cultural competence as a matter of course.

4. There may be benefit in developing a specific pilot of integrated care pathways for Black and minority ethnic disabled people leaving hospital.

5. The availability of hospital transport and interpreting services (including BSL) should be more effectively communicated to Black disabled people.

6. More consultation may be needed within Black communities about the location of new community based services.

Information and health promotion

1. Black-led user groups should be encouraged and supported to continue their role in disseminating health information to Black disabled people.

2. Disability equality should be considered as a positive health issue in health promotion work with minority communities.

3. Signposting information should be more widely available to GPs and primary care staff, to enable them to access appropriate forms of advocacy and support for Black disabled people (including minority language interpreters, Black-led advocacy services, and disabled people's organisations).

4. There should be a review of the accessibility of complaints procedures and a strategy to advertise their existence to groups where Black disabled people are likely to attend.

Dissemination and development

1. There should be greater promotion and dissemination of good practice on cultural sensitivity, so that statutory and voluntary sector organisations can learn from each other. This might be linked to good practice in access for disabled people.

2. A lead officer in the health authority, teaching hospitals trust, community and mental health trust, and North East PCG should be nominated to work on recommendations contained in this report.

3. A monitoring group of Black and minority ethnic disabled people should be supported to meet periodically with lead officers to write an action plan and to review progress on the recommendations.

4. A report should be produced annually on the progress of this action plan.

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further reading

Better Services, Better Health

This report is about the healthcare experiences of Black and minority ethnic disabled people.

The experiences and views are drawn from group discussions and interviews carried out by researchers at the Centre for Disability Studies at the University of Leeds, in collaboration with the Leeds Involvement Project. The research was funded by a grant from the Leeds Health Action Zone.

Price: £5.00

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