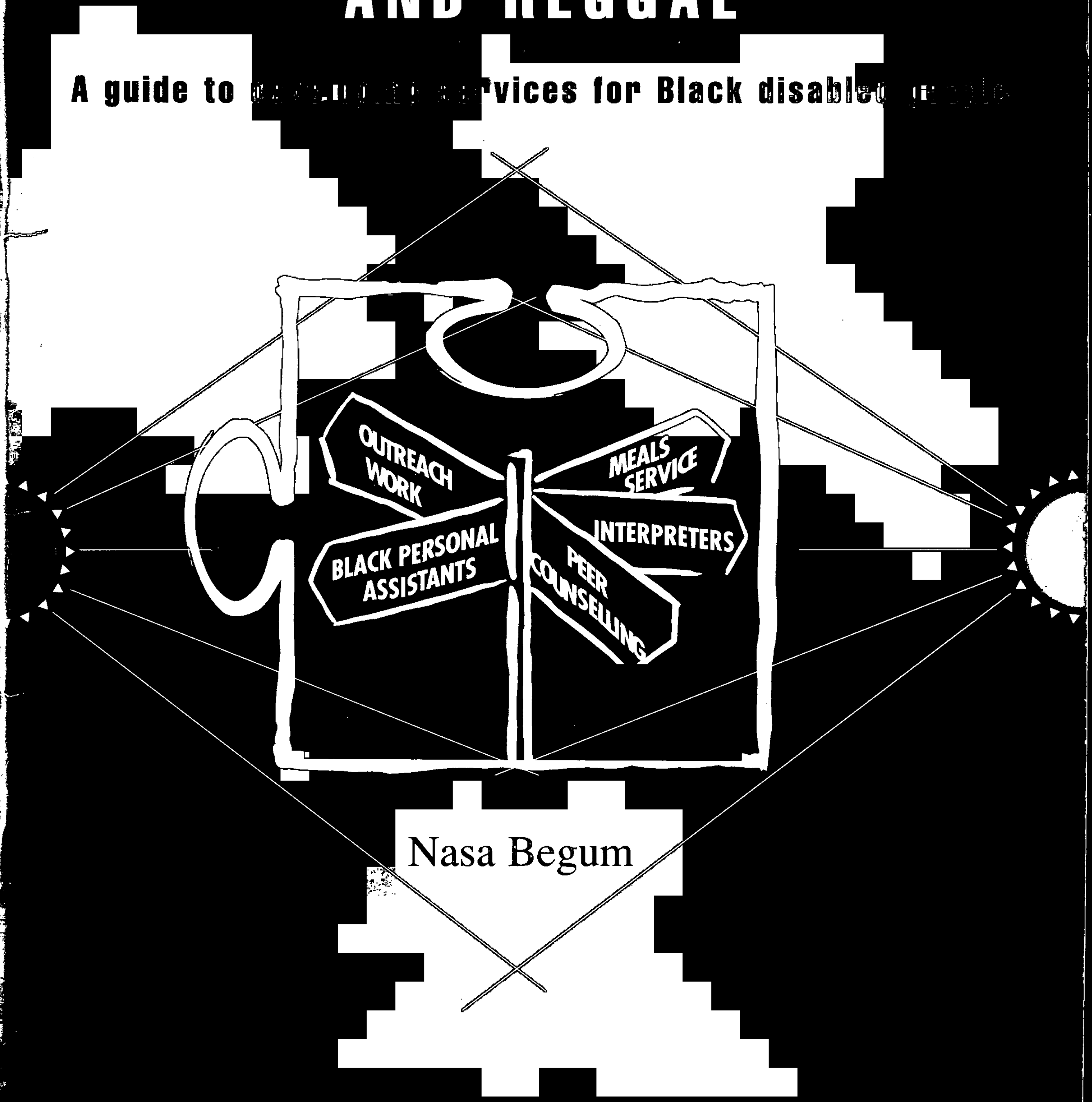
BEYOND SAMOSAS AND REGGAE

A guide to developing services for Black disabled people



Nasa Begum

THE PRINCE OF WALES'
ADVISORY GROUP
ON DISABILITY

LIVING
OPTIONS
PARTNERSHIP

King's Fund

BEYOND SAMOSAS AND REGGAE

A guide to developing services for Black disabled people

Nasa Begum

Contents

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

ISBN 1 85717 095 4

Graphic design and production Shapes Design Consultants.

Printed in Great Britain.

ACKNOWLEDGEMENTS

Many thanks to all the individuals, organisations and Living Options Areas that have worked with Living Options Partnership to share their experiences of developing services for Black disabled people, particularly those involved with the Kirklees and Wiltshire Living Options Partnership projects.

A special thanks to Tahera Aanchawan, Giovanna Ceroni, Pauline Fleming, Laxmi Jamdagni, Kunbi Jones, Minuche Mazumdar and Janice Robinson for their support and assistance with the production of this publication.

Foreword

Disabled people and members of Black and minority ethnic communities are often faced with the barrier of poor access to health and social services. Sadly, when it comes to Black disabled people, they are particularly at a disadvantage.

Produced by Living Options Partnership at the King's Fund Centre, this comprehensive and easy-to-use guide will help purchasers and providers to develop appropriate and sensitive services for their Black and minority ethnic disabled users. It identifies principles of good practice and shows how to implement them by means of real examples from the field and case histories. It also shows how establishing links with the local community through partnership with users leads to services more appropriate to the needs of Black disabled people.

The approach outlined in this guide is one which I wholeheartedly recommend. I look forward to positive outcomes from its use which will satisfy the needs of Black disabled people.

Dr Michael Chan
Director
NHS Ethnic Health Unit
Leeds

A note on terminology

Black

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.

Disabled people

The term ‘disabled people’ is used to refer to people with physical and/or sensory impairments.

Disablism

Disablism is the prejudice and discrimination that disabled people face. This usually takes the form of attitudinal, institutional and environmental barriers.

Racism

The term ‘racism’ is used to refer to the historical and institutional processes which lead to Black people being treated less fairly because of their racial identity. This is attributed to those who have the power to turn prejudicial beliefs into acts of discrimination or unfair treatment at an individual or institutional level.

1 Introduction

Over the last few years the low take-up of services by Black disabled people and their general absence from a range of user involvement initiatives have become a source of great concern.

There is no reason to believe that Black disabled people do not need or wish to use services, yet evidence [1-5] suggests that poor access to information, communication barriers, inappropriate services and discrimination are all factors preventing Black disabled people from having their health and social care needs met.

In some areas efforts have been made to improve services for Black disabled people, while in other parts the foundation stones for addressing race and disability issues still have to be laid.

This publication provides a practical guide to addressing race and disability issues for statutory and voluntary organisations in rural and urban areas. It starts by briefly clarifying key issues for Black disabled people, identifying levers for change, and then goes on to suggests ways of getting started, improving access to services, changing service provision and addressing policy issues.

This guide draws on Living Options Partnership (LOP)'s experience of developing services with Black disabled people across Britain and, through case studies, highlights issues and provides examples of the way in which the health and social care needs of Black disabled people can be met. It particularly draws on two development projects funded by the King's Fund Centre in Kirklees and Wiltshire.

Many of the issues and ideas discussed are not new or even unique to Black disabled people, but given that services for Black disabled people are the Cinderella of Cinderella services, they cannot be stated too often. There is a statutory obligation to meet the needs of Black disabled people, yet there has been very little guidance on what service agencies can do to improve access to services. This publication tries to fill that gap by helping commissioners and providers through the maze.

The title *Beyond Samosas and Reggae* is a reflection of the fact that to improve health and social care services it is essential to tackle race equality issues in a strategic and comprehensive way. All too often initiatives to promote race equality become tokenistic gestures which only scratch the surface.

2 Clarifying the issues

Mildrette Hill, founder of the Black Disabled People's Association argues that 'Black disabled people frequently find themselves caught between a rock and a hard place'.[6] She goes on to point out that 'services that are developed for white disabled people and Black non-disabled people do not necessarily meet the specific needs of the Black disabled communities'.[7]

Perhaps the situation is illustrated most graphically by Joseph's experience.

Joseph's story

At the age of 18 Joseph left residential education and returned home to live with his family. No adaptations had been made to his family home, and relationships became strained because Joseph had no formal support to meet his personal care needs.

Eventually the situation became intolerable, and Joseph was placed in a residential home in a predominately white rural area, 40 miles away from his family home. Joseph has now lived in the residential home for nine years, experiences bouts of severe depression and has virtually no contact with his family or other Black people.

Joseph is anxious not to spend the rest of his life in a residential institution, isolated from his family.[8]

For policy makers and practitioners to work effectively with Black disabled people and respond to their needs appropriately, it is important that they understand the reality of Black disabled people's lives. The situation Black disabled people are confronted with when trying to access services, or live within a community setting, suggests that there are particular factors contributing to their daily reality. A growing body of literature (see list in Fig.1) draws attention to the specific issues shaping Black disabled people's lives. The issues emerging from the research and literature are summarised below.

- **Invisibility**
  Black disabled people are not easily identifiable within the community. They tend to be absent from both the networks commonly used by disabled people and those used by Black non-disabled people. Consequently, not only is it difficult to reach Black disabled people, but also there is a greater risk that they will not find out about the services or support available to them. Black disabled people seem to fall through the net and not be accounted for in any analysis of the needs of the local population.

Fig. 1 Key references

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- **Multiple discrimination**

  Terms like 'double' or 'triple' discrimination have become a popular shorthand way of describing the combined impact of racism and disablism, or racism, disablism and sexism. Increasingly, such descriptions have been recognised as problematic, as they endorse a mentality of 'hitting the jackpot'or 'political correctness', but fail to portray Black disabled people's lives in their entirety.

  Black disabled people cannot separate different aspects of their identity and hang them on different pegs. In order to meet Black disabled people's needs effectively, there has to be an acknowledgement that discrimination on the grounds of race, disability and sex operates simultaneously and interacts in different ways to shape the lives of Black disabled people.

- **Racism**

  Individual and institutional racism operates at many different levels and is often a major factor preventing Black disabled people from accessing services.
  For example, people with sickle-cell anaemia and thalassaemia sometimes find it difficult to receive the treatment they need, because symptoms such as shivering or requiring painkillers are often interpreted as Black people trying to

obtain drugs through falsely claiming to be affetcted by these conditions. Similarly, a reluctance to treat refugee disabled people because of their legal status creates substantial difficulties.

In some ways direct racism (although wholly unacceptable) is easier to deal with, such as when a district nurse refuses to go to an Asian person's house because it 'smells'. It is much more difficult to tackle the institutional policies and practices which prevent Black disabled people from having their needs met. For example, a social services department may not be able to provide an assessor or care manager who can take account of the specific needs of a young Vietnamese disabled person.

- **Disablism**

Attitudinal, environmental and institutional barriers operate to exclude or marginalise Black disabled people, both within mainstream society and within local communities. These barriers are evidenced in employment, leisure and access to public and welfare services. They can take many different forms, from an over-reliance on a medical model of disability to inaccessible public transport systems or a refusal to allow a Black disabled person into a community centre.

It is widely believed that Black communities are particularly negative towards disability. This is a myth which feeds into racist stereotypes and does little to improve the lives of Black disabled people. There is no doubt that Black disabled people do face negative attitudes and other disabling barriers within the Black communities. Nevertheless, disablism is not a characteristic confined to the Black communities.

- **Low service take-up**

The take-up of services by Black disabled people appears to be very low. Yet, there is no evidence to suggest that Black disabled people do not need or wish to use health and social services. Indeed some Black disabled people appear to be struggling with little or no support from statutory agencies.

Securing essential services can be like an obstacle course that has to be carefully negotiated. Lack of communication, poor access to information and inappropriate assessment procedures and service provision have all been identified as additional barriers that prevent Black disabled people from taking up services.

3 Levers for change

For people working in the field of health and social care, there are considerable demands and pressures, and meeting the needs of Black disabled people is not likely to be high on their list of priorities. Yet, there is growing pressure for race and disability issues to be addressed properly within service provision.

Apart from moral arguments, there are now some persuasive factors which serve as levers for change in terms of ensuring that services are designed and delivered to meet the needs of Black disabled people.

- **Statutory obligations**
  The NHS and Community Care Act 1990 places a clear legal duty on statutory services to take account of people's religious, cultural and linguistic requirements. The Race Relations Act 1976 prohibits discrimination in the provision of goods and services. The legislation covers both direct and indirect discrimination. It is the latter which statutory agencies need to be particularly aware of, as more often than not there may be no direct refusal to allow a Black disabled person to use a resource, but the nature of the assessment process or service provision is such that it makes it much more difficult for Black disabled people to use it.

  In addition to the legislative obligations, there is also an abundance of guidance, codes of practice and Government directives, such as the *Patient's Charter,* that require commissioners and providers to ensure that services are accessible to all sections of the community.

- **Population's needs**
  The 1991 Census revealed that there is virtually no part of Britain where Black people are not present within the population, and in some areas Black people constitute almost 50 per cent of the population.

  According to the Office of Population Censuses & Surveys (OPCS) survey, the rate of disability among Asian and West Indian disabled people is 12.6 and 15 per cent respectively (after adjustment for age distribution), compared to an equivalent figure of 13.7 per cent for white people.[9] However, this is generally thought to be an extremely conservative figure, as the definition of disability used in the 1991 Census was very narrow, and the sample of Black disabled people was extremely small.[10]

It is estimated that one in four people in Britain is disabled,[11] and that there is a larger proportion of Black disabled people. Although there is no comprehensive research looking at the incidence of disability within the Black population, there is evidence[12] to suggest that there is a high rate of:

- strokes
- multiple impairments (i.e. physical, sensory and/or learning difficulties)
- sickle-cell anaemia and thalassaemia
- lupus
- diabetes
- coronary heart disease.

Consequently, there are large numbers of Black disabled people who require health and social services, although they may not be easily identifiable in population surveys.

- **Increasing demands of Black disabled people**

It is widely recognised now that the notion that 'Black communities look after their own' is a myth. Family relationships are constantly changing, and although some Black disabled people may choose to live with their family, they still require services to be able to retain control over their own life. Also, more and more Black disabled people are living in situations where they have no access to the support and services they require, therefore they will need to rely on health and social services to have their needs met.

In the early 1990s Black disabled people's needs were rarely included in purchasing plans, community care plans or other service development initiatives because there was very little understanding of the extent of unmet need, particularly as very few people came forward to use health and social services. Now that the level of awareness is growing and attempts are being made to reach Black disabled people, unmet needs are being identified. This, combined with the fact that in some parts of Britain Black disabled people are becoming much more active and acquiring information about their entitlements, means that there is a greater demand for services.

- **Needs-led approach**

Community care places a duty on statutory agencies to develop a needs-led approach. Instead of trying to fit people into whatever services are available, the emphasis is on identifying needs and then developing a package of care which reflects those needs. The philosophy of a needs-led approach is invaluable, as it provides a mechanism for ensuring that Black disabled people are not simply expected to use the services available but that care managers will put together a package of care to respond to the Black disabled person's needs.

- **Flexible and responsive services**
  Flexibility, value for money and choice are the underlying principles for developing health and social services. The split between commissioning and providing services, combined with an emphasis on a contract culture, growth in the independent sector and the care management process creates an environment where services can be more flexible and responsive to the needs of the local population. This framework offers real opportunities to open up services in ways which meet the needs of Black disabled people.

  Commissioners will have to ensure that in drawing up service specifications, setting quality standards and awarding contracts, there is proper provision for making services accessible and responsive to the needs of Black disabled people. This has to be checked through the monitoring, review and evaluation process of all contracts so that resources are invested in services which provide good-quality services in an appropriate way.

  Providers will have to accept that traditional service provision is often inflexible and inappropriate for many users' needs. Some providers are already starting to work on developing services which are responsive to the diverse needs of the community.

- **Pressure from the Black voluntary sector**
  For many years the Black voluntary sector has played a critical role in meeting the needs of the Black population. It has often stepped in to provide advice, information and essential services where statutory agencies have not responded. Nevertheless, younger Black people with physical or sensory disabilities have still often remained on the sidelines of such provision, as the emphasis has tended to be much more on Black elders and Black people with mental health problems.

  As the resources available to the voluntary sector have dwindled and statutory agencies have found themselves with an obligation to consult with and develop an independent sector, Black voluntary groups have become more vocal on the issues for Black service users and Black carers, drawing attention to the inadequacies of current service provision and highlighting the need for future services.

  Simultaneously, Black disabled people have started to meet and establish groups through which they can share information, support each other, raise awareness of their needs and campaign for changes in the way services are designed and delivered. Some organisations such as the Asian People with Disabilities Alliance are actually providing services directly to Asian disabled people.

Black Disabled People's Association

This organisation has worked in London for several years to:

- raise awareness around race and disability issues;
- campaign for improvements in services;
- offer support to Black disabled people;
- provide advice and training to statutory agencies;
- promote the rights of Black disabled people.

- **Job satisfaction**

Working to address race and disability issues can feel like hard work, with very little reward when there are so many competing demands. Additionally, some workers may feel that their lack of knowledge, or fear about doing things wrong, presents further barriers to improving services for Black disabled people.

There is no doubt that incorporating the needs of Black disabled people into service development can be hard work and requires time, effort and resources. Therefore it is important that staff (at all levels) are supported to be able to respond positively and feel that they are doing their jobs well. A failure to do anything will leave people open to accusations about racism and criticisms about the nature of services provided. Defensiveness will not resolve the problem, nor will it make people feel better equipped to do their jobs.

A clear strategy and practical guidance on incorporating race equality issues into the different aspects of people's work, plus allocating time and resources, are crucial. Planners and practitioners have to be encouraged to develop their skills and knowledge so that they are not in a position of leaving themselves open for criticism, progress is recognised and they are able to achieve a greater degree of job satisfaction.

4 Getting started

In many ways the hardest part to addressing race and disability issues is knowing where to begin. Unfortunately, there are no easy answers, but whether working at local level with a small Black population or nationally, the task in hand is essentially the same. There are a lot of different steps that can be taken to start the process of meeting Black disabled people's needs effectively.

➢ FINDING BLACK DISABLED PEOPLE

As Black disabled people are not easily visible, it will be necessary to use different community outreach techniques to find them.

- Identify and establish contact with local community groups, places of worship, establishments where disabled people go and advice centres, particularly those working with Black community groups.
- Distribute information and hold 'surgeries' within community settings, such as local Black churches, to raise awareness about the work.
- Recruit community outreach worker(s) to identify and visit Black disabled people.
- Use a snowball-effect approach, where one Black disabled person or Black family provides information about other Black disabled people known to them.
- Work with Black carers to reach Black disabled people, as carers may be an easier group to come into contact with.
- Work with GPs and primary health care teams (PHCTs), as this often is the only point of contact that Black disabled people may have with statutory services.

Kirklees' experience

Kirklees felt that in order to reach people with sickle-cell anaemia and thalassaemia it was necessary to raise public awareness about the condition and how it affects people. They achieved this through running a jingle on a community radio station, advertising widely through local newspapers and newsletters, having direct contact with community groups and putting on displays at a range of events.

This not only encouraged people to come forward who knew someone else with the condition, but also was useful for informing people who may have the condition but were not in contact with service agencies.

Wiltshire's experience

The Black population in Wiltshire presents a very mixed picture. In the more urban areas like Swindon there are concentrated pockets of particular communities (predominately Asian and African Caribbean), whereas in the more rural districts Black people are more difficult to locate, as they are much more dispersed.

To find Black disabled people a development worker was employed to do outreach work and help Black disabled people set up appropriate packages of care. The development worker identified Black disabled people by working with an Asian advice and information service, directly talking to members of the community (but not relying solely on community leaders), spending time at luncheon clubs and with church leaders where there was thought to be a larger Black congregation.

The intensive outreach work initially yielded very poor results because there were not large numbers of Black disabled people known of anywhere, but gradually information was acquired through other people.

An important element of Wiltshire's success in finding Black disabled people is that once people were identified there was an opportunity for them to have their needs met. If the work had concentrated on asking Black disabled people to join a planning group or attend a group, it is unlikely that they would have been quite as forthcoming.

➢ ESTABLISHING LINKS WITH THE LOCAL COMMUNITY

In order to embark upon a consultation exercise, disseminate information, identify needs or actually provide services, it is important to develop links with the local community.

- Contact community groups and identify when it may be a good time to visit or hold meetings (taking account of religious and cultural events).
- Hold discussions with community radio stations, particularly to raise awareness about how service agencies work and what they can offer. This is a good way to publicise events and services.
- Set up information stalls, give talks and possibly hold advice surgeries at community events, or in local centres.
- Agree the best way to undertake consultation exercises, as many people and organisations cannot cope with a large amount of paperwork (e.g. Community Care Plans) or attend endless meetings.

- Ensure that information about grants or service level agreements (or other contracts) is given to user-controlled and Black community organisations, as there may be areas of work that they wish to undertake.
- Set up a Black community care forum which can act as a mechanism whereby Black community groups (including Black disabled people) receive information, share ideas and discuss issues, while also feeding information back into statutory agencies.

Wiltshire's experience

Wiltshire has established a steering group of users and members of the Black communities that has regular contact with representatives from health and social services to voice views and provide suggestions on how to improve services and encourage access to services within rural areas for Black disabled people. Mainstream purchasers and providers are able to use the forum as a consultation mechanism.

➢ IDENTIFYING NEEDS

Inevitably it is difficult to plan and provide services for Black disabled people without having any real knowledge of what the level of needs may be. While it is advisable not to get into the 'numbers game' too much, it is reasonable to assume that there will be a certain proportion of the local population that will be Black disabled people who will have health and social care needs.

- Ask Black disabled people what their needs are and, where appropriate, undertake assessments.
- Find out from local GPs about any Black disabled people they may be in contact with. This may have to be arranged through medical ethics committees, or by sending letters from surgeries to patients.
- Work with local groups to find out what the needs of Black disabled people are.
- Identify the number of Black disabled people who have been through the segregated education system, and find out what has happened to them. Also project the number of Black disabled people who will require adult services.
- Analyse the needs of Black disabled people who are currently in contact with service providers and collate this information.
- Conduct research into the needs of local Black disabled people. Wherever possible, draw on other research and try to identify specific issues for the local area. Be careful that research is not used as a delaying tactic or a strategy for avoiding implementing necessary changes.

Northamptonshire

Northamptonshire conducted a survey[13] of the needs of Black physically disabled people and incorporated these into the joint purchasing strategy for services to people with physical disabilities.

Greater London Association of Disabled People

The Greater London Association of Disabled People brought Black disabled people together at a conference to find out what their needs and priorities were. This information was presented to statutory agencies.[14]

➢ INVOLVING USERS

Black disabled people should be involved in the development of services wherever possible, but there are only a handful of Black user groups. Through self-helps groups people are able to develop their self-confidence, consider different options and prepare a collective response, reflecting a diverse range of needs. Therefore further work needs to be done to support the development of Black disabled people's groups as a means of promoting user involvement.

- Recognise that there is a whole spectrum of user involvement, ranging from working with Black disabled people at an individual level, holding group meetings, to contracting with Black user-controlled organisations for services. Therefore try to be clear about what type of user involvement may be appropriate according to particular circumstances.
- Identify whether there are any organisations of Black disabled people locally or even nationally who may be able to support other Black disabled people to come together.
- Arrange opportunities for Black disabled people to come together to share experiences, exchange information and offer support to each other, and eventually become a user group that feeds into service development.
- Link advice sessions, assessments and actual service provision to attract Black disabled people to attend meetings. Note that it may be difficult to encourage Black disabled people to take part in service development initiatives unless their service needs are addressed.
- Encourage other organisations of disabled people and Black community groups to support Black disabled people who may want to develop the confidence and skills to feed into service development.

Jawaan aur Azaad (Young and Free)

This is a group open to all young Black disabled people of African, Asian and Caribbean background, aged 13-25, who live in the Greater Manchester region.

The purpose of Jawaan aur Azaad is to improve public services, get the people in top positions to take notice, and empower other young Black disabled people.

The group was set up through a series of training days which were designed to give the young people skills and confidence in voicing their concerns. The young Black disabled people used art, video, poetry and other creative methods to develop their self-confidence and explore what they wanted from community care. They went on to organise and run a two-day residential conference to tell service agencies what they wanted.

Members of Jawaan Aur Azaad explain why they took part in the project:

'To achieve more rights for disabled people.

To learn how to communicate in a way agency workers will be able to understand.

To voice our concerns on disabled rights.

To identify different community needs.

To push for better access.

To make others more aware of disabled people's rights and needs.

To push for better educational opportunities and job opportunities.

To solve transport problems.

To get better media coverage.'[15]

The fact that the group is only open to young Black disabled people has been central to the success of this project. It has also ensured that the needs and concerns of adolescents are not mixed up with those of older Black disabled people. While there may be a lot of common ground, the work created through this project highlights particular issues around transition to adulthood.

In areas where Black disabled people are very dispersed, user involvement may have to work much on an individual level and have a greater emphasis on alternatives to formal meetings, such as telephone hotlines, surveys or even competitions on designing future services. Although there is a difference between users being involved at an individual level and larger groups influencing provision for a wider population, it is important that the individual views, ideas and suggestions of Black disabled people are recognised and put into a wider context.

Kirklees' experience

Kirklees has established three groups of Black disabled people:

- African Caribbean Action Group;
- African Caribbean Disabled Women's Group;
- Paddock - Asian Disability Group.

As a result of meeting together, the groups have provided: mutual support; empowerment; training; and consultation with local and health authorities.

Brent Black Disabled People's Association

The Brent Black Disabled People's Association has identified the following aims and objectives:

- To rectify the bias in services to Black disabled people.
- To provide information and support through self-help to members.
- To highlight the needs of Black disabled people in Brent.
- To provide a meeting place for Black disabled people.
- To work in conjunction with other disability groups to achieve more appropriate services for disabled people.

➢ ESTABLISHING PRIORITIES

The agenda for addressing race and disability issues is potentially very large. To avoid disillusionment and frustration it will be important to agree some priorities for action early on.

- Ask Black disabled people what their priorities are in terms of improving services and collectively try to agree some tangible goals.
- Identify some short- and long-term goals for addressing race and disability issues. For example, in a rural area the focus may initially be upon trying to find Black disabled people and identifying needs, whereas in an urban area where there is a larger Black population it may be more appropriate to concentrate on one or two service areas.
- Agree an action plan with other colleagues and agencies which clearly identifies who will take the lead on particular areas of work and set a realistic timetable for the work to be completed.
- Find out if similar work has been undertaken in other parts of the country and try to learn from that to avoid reinventing the wheel.
- Secure the backing of senior officers to the action plan so that the work is recognised as being important and senior management are seen to be committed to race equality work.
- Report back on progress and achievements to the different stakeholders at regular intervals so that people are not only aware of any difficulties or successes, but also so that they know the results of their efforts. All too often time, energy and resources are invested into different bits of work, but people do not find out about the end product.

5 Access to services

To improve the take-up of services by Black disabled people and ensure their health and social care needs are met, ways need to be found of making access to services easier.

IMPROVING COMMUNICATION

Communication is probably the biggest issue that springs to mind when considering the needs of the Black population. People tend to focus on the fact that English may not be a Black person's first language, rather than also taking on the broader issues about the way people talk to each other or use jargon excessively in their written and verbal communication.

The fact that English may be a second (or even third) language for some people has very practical repercussions. Therefore the availability of language interpreters and bilingual workers is central to determining access to services. However, for some Black disabled people there may be additional factors which need to be taken into consideration, for example some Asian Deaf people may adopt their own form of sign language which combines both British Sign Language and a family version of Urdu Sign Language.

Many Black disabled people will speak English, particularly groups like African Caribbean disabled people, but unless measures are taken to communicate in a straightforward and effective way, communication barriers are likely to remain a deterrent.

- Avoid jargon at all cost.
- Establish a pool of community language and sign-language interpreters.
- Identify where interpreters can be found if it is not practical to have a pool of interpreters (e.g. in very rural districts).
- Provide training and guidelines on working with interpreters.
- Use face-to-face contact to communicate with Black disabled people, rather than relying on printed information.
- Check out what form of sign language Black Deaf people are using.

ACCESS TO INFORMATION

A lack of information in an appropriate format prevents Black disabled people from not only finding out about different services and resources available, but also knowing what their rights and entitlements might be.

Although in some areas information has been produced in user-friendly formats and in appropriate languages, much of this information is not getting through to Black disabled people. Isolation and access barriers often mean Black disabled people do not use many of the channels (e.g. libraries) through which information is traditionally distributed.

Information on its own is of limited value if there is no support available to help people use it. Therefore advice centres and advocacy services are crucial for enabling people to use the information available effectively.

- Produce jargon-free information in a short and precise format, as few people read lengthy material. Incorporate pictures and symbols wherever possible.
- Translate information into other languages, particularly using audio-tapes as many people cannot read community languages.
- Distribute information through places where Black disabled people may go, such as post offices, Asian video shops, community centres, Black churches and other places of worship.
- Ensure that information about a whole range of services is easily available at hospital clinics, welfare rights centres and GP surgeries.
- Publicise services by setting up information stalls, holding advice sessions at community events and working directly with local people.
- Use face-to-face contact wherever possible to inform people about services, as this appears to be the most effective way of enabling Black disabled people to understand how the information applies to them.

➢ ADVOCACY

Many Black disabled people will need help to identify their needs and secure the support they require. This may mean developing self-advocacy skills, or using another person to act as an advocate in a formal or informal capacity.

- Identify advocacy projects that can support Black disabled people.
- Recognise the role that Black community groups and user-controlled organisations can play in providing advocacy services.
- Fund advocacy work targeted at Black disabled people.
- Provide self-advocacy training for Black disabled people who would like the opportunity to develop their skills.
- Develop a one-page guide to working with advocates for practitioners in the statutory sector.

Wiltshire's experience

Zaina's story

When the development worker in Wiltshire came across Zaina, a woman in her 20s with a visual impairment and a severe skin condition, she was spending most of her time 'incubated in her small room'. Zaina's father also had a disability and, as her mother supported both of them, there was very few options open to Zaina.

After some advocacy work and one-to-one support, Zaina's confidence has grown substantially, and she is now exploring the prospect of doing an Open University course and undergoing some medical treatment.

Zaina explains, 'I am more confident that I have the right to ask what the success rate is for such an operation . . . I do want to tell the consultant about my worries. It is important that he is aware of how I feel.'

Advocacy project

An advocacy service for Asian people was jointly funded by health and social services commissioners. Advocates engaged in outreach work, making contact with people who were not regular users of primary care services as well as those that were. They enabled people to sign up with GPs; increased communications between GPs and their Asian patients about the medication they were prescribed; and acted as independent advisers in the assessment and care management procedures carried out by social services staff.

The following commissioning intentions were put into the Joint Commissioning Plan:

- to encourage GPs to target Asian men and women over the age of 40 to attend once a year for a general health check;
- to request that local providers of domiciliary care recruit Asian care workers so that they can provide culturally sensitive services.[16]

➢ REFERRAL ROUTES

It is rarely possible to have direct access to services, therefore the path which Black disabled people take to reach an assessment or service provision will be a key factor in determining their experiences.

- Ensure that practitioners have the right paperwork and support (e.g. access to language interpreters) to be able to make referrals speedily.

- Provide clear information about how the referral system works and the timescales people might expect to work to.
- Explore ways of introducing a self-referral scheme.
- Take referrals directly from Black community groups and user-controlled organisations.
- Supply contact details of someone (e.g. care manager, practice manager, nurse) who can liaise with and support a Black disabled person through the maze.

ASSESSMENT

The process which people have to go through to have their needs identified and met can present particular difficulties for Black disabled people as there is a tendency not to use a holistic approach. Practitioners often only focus on the very obvious practical requirements, and do not address all of a Black disabled person's requirements. For example, an assessor might identify that a Somali disabled woman needs counselling or residential care, but unless there is also a recognition that these needs have to be addressed by taking account of this woman's religion, culture, language, experience of racism and other factors, it will not be possible to meet her needs appropriately. Equally, one needs to be wary of making assumptions about religious or cultural needs, as there are always varying degrees of orthodoxy in any religion or culture. Just like two Christian families may be totally different, similarly two Hindu families are likely to be different.

It is important to recognise that assessment work is not confined to social services, although the assessment and care management process provides a much clearer framework for social services to work than there is for other agencies. GPs, nurses and a whole range of other practitioners are constantly assessing needs as part of their work, therefore their role in identifying the treatment or support to be provided will be determined by how well equipped they are to assess the needs of Black disabled people.

Imran's story

Imran was being prepared for hospital discharge from a spinal injuries unit. He had broken his back and had repeatedly been told that he would never walk again, but as he could communicate to some extent in English, no-one recognised his need for a language interpreter. Unfortunately, it was not until the hospital discharge arrangements were in place that an interpreter was used, and the ward staff discovered Imran had not understood at all the extent of his injuries.[17]

Health service agencies have a key role to play in assessment, both in terms of access to community care services and the provision of community or specialist health services.

Given that assessment plays a central role in identifying people's needs, it is important that practitioners are in a position to work effectively with Black disabled people.

- Adopt a holistic approach to assessment which clearly identifies needs, rather than being defined by existing service provision.
- Produce and distribute a summary of myths and assumptions about different racial and cultural groups to prevent stereotyping.
- Develop a checklist of basic do's and don'ts when working with Black disabled people. This could be used by nursing staff, social workers and a range of other practitioners as a quick *aide-mémoire,* and not the definitive answer.
- Ensure that you have access to a pool of bilingual or multilingual assessors. Avoid using interpreters as assessors, as the tasks are distinctly different.
- Train Black community groups and user-controlled organisations to undertake assessments, and where necessary work with staff from statutory agencies to prepare a joint assessment.
- Minimise the amount of paperwork and, wherever possible, avoid duplication between different agencies.

Asian People with Disabilities Advice and Information Service

Asian People with Disabilities Advice and Information Service works with users to communicate and mediate on their behalf. Also it facilitates and helps obtain appropriate services, benefit entitlements, independent living and other opportunities to enable Asian disabled people to live fuller lives.

The organisation works closely with service agencies to assess the needs of Asian disabled people and, where appropriate, take on a case management role.

➢ CARE MANAGEMENT

Potentially care management provides a valuable opportunity for meeting Black disabled people's needs in a much more flexible and responsive way.

- Build flexibility into the cost of care packages so that if a Black disabled person does not want to use the residential or day service available, the money can be used easily to set up alternative arrangements.
- Compile a list of service providers who may be able to respond to the specific needs of Black disabled people. This may involve approaching neighbouring areas to find out whether they have any services that could be spot-purchased.
- Encourage care managers to be creative in putting together a care package and publicise good practice. For example, a Vietnamese disabled person may require day services, but there is no appropriate provision available, therefore the care manager might want to purchase a service from elsewhere, or consider paying for someone to support the service user to participate in the local community by going to college, using leisure facilities, etc.
- Explore whether Black community groups and local user-controlled organisations are in a position to take on the role of care manager.
- Establish joint working arrangements with Black workers in the statutory and voluntary sector so that they can take on the role of care manager if appropriate.
- Locate some care managers in GP surgeries.
- Ensure that unmet needs are recorded and fed back into strategic planning so that information is easily available on the unmet needs of Black disabled people and future service provision can be planned appropriately.

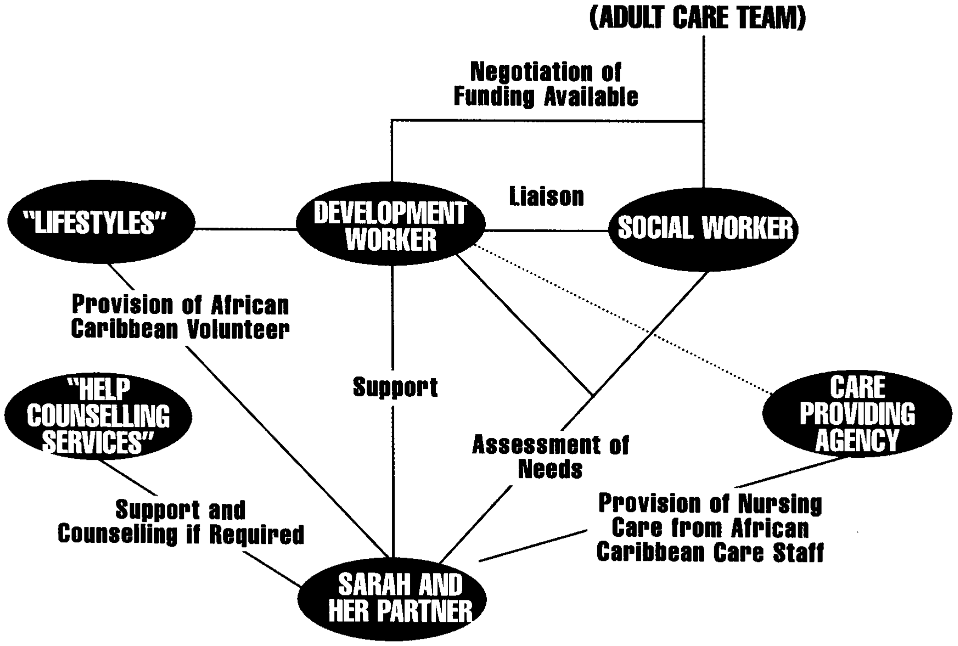
Wiltshire's experience

Sarah's story

Sarah, an African Caribbean disabled woman, lives in a very rural area and requires 24-hour personal assistance. Her relationship with her husband is under considerable pressure, as she is totally dependent upon him. Sarah has considered spending a week in a residential home, but is not happy with the food provided and the personal care is not sensitive to her requirement.

The development worker has been negotiating with the social worker and the adult care manager to enable Sarah to remain at home while her husband goes away for a week. Additional support has been built into the care package to provide counselling as a means of trying to maintain the relationship.

Care management diagram for the provision of tailor-made respite care at home



Although a volunteer has been recruited to minimise the cost of the care package, and the residential alternative is not appropriate for Sarah's needs, it has not been possible to implement the proposed care package at the moment because of a shortfall of £70 between the local authority's allocation and the cost of the care package. There is still work to be done to find the flexibility to respond to Sarah's requirements within the care management process.

➢ CHARGING POLICIES

In the current economic climate charging for services is a reality in many a local authority and other service provision agencies. Such charges may deter people from taking up services and even asking for help.

Clearly, charging policies are equally applicable to all sections of the population, but agencies need to ensure that the policies do not adversely affect Black disabled people to a greater degree.

- Check whether the financial assessment is likely to be particularly detrimental to Black disabled people. For example, if financial assessments work on the basis that the whole household income is taken into account, then Black disabled people may be more disadvantaged, as there is a greater likelihood that they do not live in a nuclear family, but live in larger households.
- Minimise the amount of paperwork involved, and make sure that essential papers are translated properly so that Black disabled people are clear about what they are signing.
- Provide welfare rights advice to enable Black disabled people to secure any social security entitlements.
- Find ways of ensuring that Black disabled people do not have to pay higher costs because of the limited number of service providers able to cater for their specific needs.
- Build safeguards into the financial assessment and collection arrangements so that Black disabled people who do not speak or read English are not vulnerable to abuse. For example, this may mean that financial assessments are not undertaken unless there is someone who speaks the same language as the person being assessed, and equally money is only collected by someone who speaks the same language.
- Ensure that any anti-poverty strategies adopted recognise the position of Black disabled people.

6 Changing services

Historically, services have been planned and developed taking into account the needs of the white population, and Black disabled people have been expected to accept the services available or go without. A eurocentric and assimilationist model of working has done little to encourage Black disabled people to use services, although they appear to have a substantial level of needs.

Mrs Patel's story

Mrs Patel, a 55-year-old widow who lives with her adult son, returns home from hospital after a stroke. She receives meals on wheels, district nursing and home care services. However, none of these service providers speak Mrs Patel's language, and she becomes depressed and distressed especially as she finds the visits by occasional male service providers very difficult to cope with. Her ability to be at home on her own while her son and daughter-in-law are out at work diminishes and eventually she is admitted to residential care.[18]

Elizabeth's story

Elizabeth explains the difficulties she encounters with current service provision: 'One of the things that annoy me is that they [family aides] don't take account of our culture. Ideally, I should be able to have a helper who can do my hair... White people generally don't know how to look after Afro hair'.[19]

Over the past decade statutory agencies have acknowledged that Britain is a multiracial country and not everyone shares the same language, culture, religion or sense of identity. Therefore some attempts have been made to change the nature of service provision by developing specific services for Black people, usually through community groups and by promoting initiatives such as recruiting Black workers in home care, providing link workers in hospitals and supplying food that is appropriate for different religious groups. All this goes a long way to improving services for Black disabled people.

There are lots of different ways service agencies can continue to improve the provision of health and social care to Black disabled people. Sometimes this involves making changes to current service provision, while in other circumstances new developments need to be encouraged.

INDEPENDENT LIVING

The popular notion is that independent living is about living alone and not having any assistance. As many Black disabled people live within family settings, it is thought that independent living is not an arrangement which will be acceptable to Black disabled people. This is a myth which is incorrect on two counts.

First, independent living is a term used by the Disability Movement to describe having choice and control over one's life. This usually means receiving money to be able to buy in the support required, by either employing personal assistants or purchasing directly from a service-providing agency. The key component of independent living is that the disabled person holds the purse strings and has choice and control over their own affairs. Second, there are many Black disabled people who do not live with their families. Equally, those who do live with their families may not want to have to depend on them for the assistance they require. Therefore the concept of independent living is very important for Black disabled people, as it offers a means of putting together a support system which is tailor-made to meet individual requirements.

Elizabeth's story

Elizabeth has set up her own independent living arrangements to meet her specific requirements. This has enabled Elizabeth to have choice and control over her life and not have to rely on informal networks of support to have essential needs met.

Independent living schemes are a particularly good way of meeting Black disabled people's needs because they can be set up to cater for any individual requirements and offer a mechanism for meeting a diverse range of racial, cultural, linguistic, dietary or other needs.

In order to help Black disabled people establish independent living schemes, it is necessary to:

- publicise different ways in which independent living schemes can work;
- provide one-to-one support to enable Black disabled people to explore the options open to them and how they may work;
- ensure that financial resources can be used flexibly to pay family members or people in the community if necessary to provide personal assistance.

Wiltshire's Independent Living Scheme

In Wiltshire independent living schemes have been set up through the Wiltshire Independent Living Fund (WILF) to enable Black disabled people to have a range of health and social care needs met.

Sofia's experience

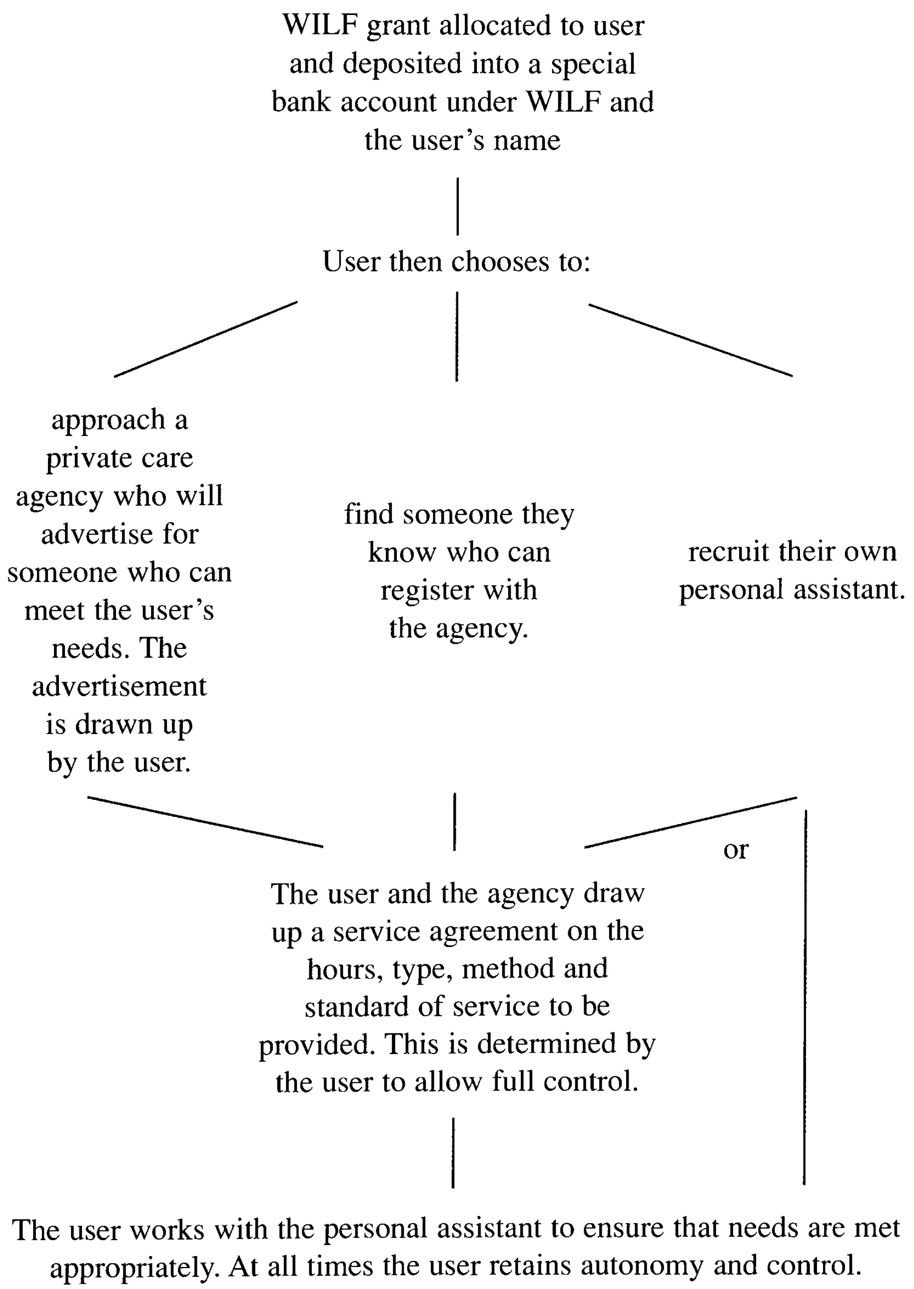
Sofia is the mother of five children and her youngest daughter has physical and learning disabilities. Sofia has been disabled for six years and although she requires assistance with all aspects of personal care, she does not use mainstream sector services because of language difficulties and a lack of understanding of her religious beliefs on the service providers' part. Sofia is a Muslim and feels that her family 'are looked down upon by the care organisations'.

Sofia has used WILF to recruit her own personal assistants. This has meant that she has not had to rely on her family for personal care and childcare.

Samuel's experience

Samuel, a Black disabled man, has used an independent living scheme to leave hospital and return to his family home. The hospital discharge arrangements did recognise that relying on family members for personal assistance was not acceptable, therefore negotiations took place to establish an independent living scheme.

The process of setting up an independent living scheme with Black disabled people used in Wiltshire



WILF grant allocated to user and deposited into a special bank account under WILF and the user's name

User then chooses to:

approach a private care agency who will advertise for someone who can meet the user's needs. The advertisement is drawn up by the user.

find someone they know who can register with the agency.

recruit their own personal assistant.

or

The user and the agency draw up a service agreement on the hours, type, method and standard of service to be provided. This is determined by the user to allow full control.

The user works with the personal assistant to ensure that needs are met appropriately. At all times the user retains autonomy and control.

DOMICILIARY SERVICES

Domiciliary services such as home care, district nurses and physiotherapists are one of the key areas of service provision that Black disabled people require. To make such services more responsive:

- Provide race equality training for domiciliary workers.
- Check out with the Black disabled user any specific requirements and build these into a service agreement.
- Identify a pool of workers who can speak different languages and meet different religious, cultural, dietary and linguistic requirements.
- Build flexibility into the allocation of domiciliary services, so that the needs of people with fluctuating conditions (e.g. sickle-cell anaemia and thalassaemia) can be met, or support can be provided during particular periods, like Ramadan when Muslims fast between sunrise and sunset.
- Negotiate with a range of private and voluntary sector providers to check out how they can respond to the needs of Black disabled people.
- Build quality standards into service specifications which address the needs of Black disabled people.

Leicestershire Home Care Survey

A review of home care services with Black disabled people looked at the assessment process and the quality of service provided.

Most of the people interviewed had a home care assistant who spoke their language or they had a language in common with the care assistant. To a large extent, people were asked about a preference in the ethnic origin of their home care assistant. In most cases their request was met but not always immediately due to shortages in Black home care assistants. One Asian user explained, ‘For the first few days we had English ladies coming to help. After that the social services department fixed us up with an Asian lady who understands us, but we didn’t ask for an Asian lady.’[20]

RESIDENTIAL CARE

Black disabled people in predominantly white residential establishments can be extremely isolated, therefore for those who may have to use such provision, on a short- or long-term basis, it is critical that steps are taken to make the service sensitive to their needs.

- Check whether the personal care, food and other religious and cultural requirements of a Black disabled person can be met.

- Establish arrangements where the Black disabled person can have contact with community groups and participate in community events.
- Review the placements of Black disabled people who have been allocated a residential home outside their local area and explore ways in which they can maintain links with their community. For example, this may mean providing opportunities for key people in the Black disabled person's life to stay for a few days in the area of the residential home, or for the user to return to their local area, from time to time.
- Investigate whether there are any alternatives to residential care, such as independent living schemes or a respite care service where the Black disabled person remains at home, and additional support services are provided to give them (or the informal carer) a break.
- Encourage the development of specific provision for Black disabled people. This may mean contracting for a Black residential unit with the private or voluntary sector.

Alicia's experience

Alicia feels that she needs residential care; however, she is concerned about being the only Black woman in the home, and whether the staff will be able to meet her needs.

To deal with some of Alicia's concerns, it has been suggested that the cook at the home should learn to prepare African Caribbean food. In view of the limited value of cookery books, discussions are taking place about the possibility of Alicia working directly with the cook to prepare food.

Alicia's need for appropriate food is only one aspect of enabling her to live confortably within the residential home. In order to make the home a safe environment for Alicia it is important to address other issues as well, for example dealing with racism from staff or other residents.

DAY SERVICES

Traditional day services have changed enormously over the past few years. The emphasis on moving people away from large scale segregated institutional provision to using local integrated, community-based resources, provides much more scope for meeting Black disabled people's needs effectively. Nevertheless, the process of change is slow, and day services will not improve for Black disabled people unless attempts are made to address their specific needs.

- Establish a programme of activities suited to the individual Black disabled person's wishes and needs. In addition to occupation and leisure, this could include education, training and employment.
- Ensure that appropriate support is provided to enable Black disabled people to attend religious events and community activities.
- Encourage community groups to put on events and activities which are accessible to Black disabled people. For example, instead of holding a women's group in an old building with no appropriate toilet facilities, provide financial resources to hold it in an accessible venue.

Work with local education and leisure service providers to put on courses, events and other activities appropriate to different sections of the Black population. For example, it may mean providing single-sex swimming sessions or Black cookery classes.

Osman's experience

Osman wanted to go to a disability resource centre because he was lonely and bored at home on his own all day. However, he was told that he could only do this if he attended a class. He was also told that he could not attend a class because he did not have the full use of all his fingers. 'I phoned about going there but they said, "You can't do anything, you can't come in..."[21]

Asian People with Disabilities Alliance

APDA runs a user-led day respite centre to reduce isolation by arranging opportunities for socialisation; provide advice, information and support; work with statutory and voluntary organisations; and enable Asian disabled people to improve the quality of their lives while continuing to live in the community.

The centre initially ran as a pilot scheme in a local hospital hall on a one-day-a-week basis. Within a short time the service became very popular.

The organisation writes: 'It has generally been found that it is impossible to turn a conventional European day centre into a centre accepted by the majority of Asians. Food, interpreters, one or two Asian workers and translated leaflets only go part of the way. APDA's approach has been different – the respite centre is run by Asians in an Asian way.'[22]

Oldham's day services consultation

In Oldham social services, health and voluntary organisations have put together a proposal for seeking the views of disabled people about opportunities that they would wish to have to pursue activities of an occupational, educational, leisure and social nature outside their own homes.

The consultation exercise has been developed with two distinct strands: one has specifically targeted work with Black disabled people, and the other group focuses on the broader communities. This has enabled the project to address the specific needs of Black disabled people while also placing them within the wider context of the future of day services for disabled people.

African Caribbean Disablement Association

ACDA in Waltham Forest has provided training for its members and organised different social events which have proved to be very popular. This can be seen as an alternative to disabled people having to go to day centres.

➢ PRIMARY CARE SERVICES

GPs are sometimes the only point of contact Black disabled people have with statutory agencies, therefore the importance of working with primary health care teams (PHCTs) cannot be underestimated.

- Devise a basic checklist of areas that PHCTs need to look at when working with Black disabled people. This could cover areas such as diagnosis, specialist and support services specifically geared to meet the needs of Black disabled people. It is important that the checklist includes a list of agencies that Black disabled people could be referred to, if the PHCT cannot assist.
- Introduce a medical curriculum vitae scheme so that Black disabled people who may require frequent medical contact, or have to be admitted to hospital at short notice (e.g. people with sickle-cell anaemia) can give basic medical information about themselves as and when necessary.
- Set up multidisciplinary teams so that there is a clear and co-ordinated approach to the care and treatment being provided.
- Provide information and support through groups and workshops run by PHCTs who have relatively large numbers of Black disabled people with particular conditions.

- Assess how well community health services, such as district nurses and continence advisers, are in a position to respond to the needs of Black disabled people. For example, how many speak other languages, or if continence supplies can be provided in a different way to avoid any stigma or embarrassment.
- Encourage the use of different forms of complementary therapies wherever possible, as these may be much more acceptable to some Black disabled people.

Tower Hamlets Disability Advocacy Project

A Bangladeshi advocate was recruited to work with Bangladeshi disabled people. Although the project promoted self-advocacy, the greatest demand was for the worker to act as an advocate sorting out practical problems and promoting access to services.

Shaida's story

When Shaida was first referred to the project, the Bangladeshi advocate had to engage in long discussions with many health care professionals. She had no wheelchair, so the advocate spoke to the physiotherapist. Also he liaised with the occupational therapist as Shaida did not have a suitable bath. Shaida did not have a GP locally so the advocate helped her to register with a local Bangladeshi GP who had initially refused to accept her as there was a waiting list.[23]

Tower Hamlets Primary Care Users Information Project

The project has set up a Bangladeshi women's diabetic group and an arthritis self-help group.

The groups provide on-going support and information on a wide range of health topics such as diet, medication, exercise and the provision of services.

Further work has been done to establish a pharmacy advocacy project to work closely with pharmacies, as pharmacists are often used as a source of advice and information.

Errol's experience

Errol has sickle-cell anaemia. Previously, when he had a crisis, he had to go into hospital, and this caused him great distress. Now he is able to administer his own pain relief, intravenously and using a pump, having been shown by the district nursing service how to do it.[24]

HOSPITAL SERVICES

Kirklees Sickle-Cell Anaemia and Thalassaemia Project

Users involved in the project highlighted problems with the diagnosis of sickle-cell anaemia and thalassaemia, information provided and support given within hospitals.

Danielle explains: 'I found out that I had the sickle-cell trait when I was 23 years old through going to hospital for an operation. I was literally going into the theatre as I had my pre-med. They then realised that I hadn't been treated for my blood group. I actually feel they would have gone along with the operation without giving me the test but I happened to mention that my sister had the sickle-cell trait. They did not operate until the next day. I overheard the doctor on the phone (my bed was located near it) saying that I did have the sickle-cell trait. I was then informed that I had the trait and when I asked what that meant, the doctor replied, "Don't worry, it's nothing; just tell your GP if you ever get pregnant."'

Kriss talks about the difficulties with hospital admissions: 'When I am first admitted to hospital it is usually via the casualty department. I can be left there for literally hours waiting to see a doctor. I feel I should be able to show my card (haemoglobinopathy) and be seen. I also don't feel I get enough information about the way in which my condition is progressing.'

Similarly Joyce's main concern was about the lack of support upon diagnosis:

'I was not given any information at all from the health authority. I think it would have been helpful to have known about a voluntary group or a contact person who could have explained to me what the trait actually was and what the complications could be in relation to a partner and having children.'

Hammersmith & Fulham

Social services in liaison with the NHS has developed a social work service for people with sickle-cell anaemia and thalassaemia. The aim is for rapid evaluation and response to social care needs after early medical assessment and diagnosis.

Black disabled people who use hospitals are likely to need support to be enabled not only to cope with the reality of being in hospital, but also to understand and participate in the management of their condition.

- Use linkworkers to work with Black disabled people in hospitals.
- Develop a checklist of issues to be addressed upon admission and discharge, to avoid assumptions about family networks and to identify appropriate arrangements for meeting linguistic, cultural and religious needs.
- Devise a picture-and-point book which can be used by Black disabled people who do not speak English when there is no-one available to interpret. Care needs to be taken to ensure that the book does not use stereotyped or patronising images.
- Provide temporary overnight accommodation for a close friend or relative if the Black disabled person is a long way from home.
- Build in some form of flexibility into admission arrangements so that Black disabled people who are admitted into hospital regularly are not caused any unnecessary delay or distress. This might mean introducing an admission card which gives Black disabled people direct access to the ward once their GP has made a referral, or the user may be able to telephone and discuss their circumstances with a doctor and remain at home until a bed is identified.
- Ensure that clinics held in hospitals provide referrals to other agencies, such as social services or a self-help support group.

Kingston

In Kingston disabled people and the local hospital have been meeting to look at accessibility. A key issue identified has been difficulties with using the control panels to request assistance, turning off the bedside light, etc. Therefore a colour-coded system with Braille is being introduced to enable people to summon help easily even if they cannot read English.

➢ COUNSELLING AND SUPPORT SERVICES

To enable Black disabled people to overcome isolation and disempowerment and prevent mental health problems, it is very important that appropriate counselling and support are provided to those who may require them.

- Establish support groups for Black disabled people.
- Present clear information about what counselling is and how it works, as for some Black communities counselling may be a vital resource, but a concept with which they are unfamiliar.
- Target established counselling services, encouraging greater sensitivity to the needs of Black disabled people as appropriate.
- Set up and support peer counselling projects.
- Run self-advocacy and personal development training.
- Provide a telephone contact where Black disabled people can ring if they are having difficulties or need support.

Tower Hamlets Disability Counselling Service for the Bangladeshi Community

The provision of a Bangladeshi counsellor as part of the Disability Counselling Service was seen as an appropriate expansion of the service as there had been no Bangladeshi disabled people referred to the service. Formal counselling is an unfamiliar concept to many people in the Bangladeshi community as many rely heavily on informal networks of support. Nevertheless, the recruitment of the Bangladeshi counsellor has resulted in an overwhelming demand for and take-up of the counselling service.

Measurable outcomes have included: use of new services; return to employment; reduction of medication; and increase in confidence measured by use of public transport, foreign travel and use of health services.[25]

Kirklees Peer Counselling Project

In Kirklees a group of Black disabled people have been trained to provide peer counselling to people with sickle-cell anaemia and thalassaemia. There were three different strands to the training, reflecting the combination of skills, knowledge and experience people with sickle-cell anaemia and thalassaemia need in order to undertake peer counselling:

- *Race and disability equality training* to provide a framework for understanding the experience of Black disabled people and how the social model of disability affects them.
- *Introduction to counselling skills training* to enable people to understand the principles of counselling and to develop counselling skills. This has recently included grief, loss and bereavement skills; assertiveness skills; and presentation skills.
- *Sickle-cell anaemia and thalassaemia information training* so that people had a better understanding of the condition and its impact on people's lifestyle. The training was not aimed at providing a detailed medical knowledge, but rather a framework for understanding other people's experiences.

There is a recognition that further training will be needed to support the development of the peer counsellors. Also there is a need for continuous support from an experienced counsellor to provide supervision.

There will be two peer counsellors at any given time, and they will work from a social services building on a rota basis.

7 Addressing policy issues

Making health and social care sensitive to the needs of Black disabled people will have policy implications. Questions are raised in terms of strategic planning, resource allocation, design and delivery of services, commissioning and monitoring arrangements. These questions are often used to block or delay any further developments which may be organisational or service wide. It is important that policy officers put forward the arguments to overcome this resistance and recognise that there are ways of not only improving services, but also measuring how much progress is being made.

While it is not possible to explore all the policy implications here, it is useful to briefly consider some of the key questions that might be posed for commissioners and providers.

- **Catering for relatively small numbers of Black disabled people**

  Although there are Black disabled people in all parts of the country, and work will be required to identify their needs, the fact that in some areas Black disabled people may be in relatively small numbers raises issues about how statutory agencies can respond.

  The reality is that whether there is one Black disabled person or several hundreds, statutory agencies must be able to fulfil their obligations to meet Black disabled people's health and social care needs. This means tackling racism and building sensitivity into service provision, regardless of whether there are any identified users.

  One needs to be wary of falling into the trap of thinking 'there are no Black disabled people here so race and disability is not an issue for us'.

Wiltshire's experience

Although Black disabled people in Wiltshire initially seemed to be non-existent, through the community outreach work undertaken, a number of Black disabled people were identified. Most of these people had little or no support despite the fact that they had substantial health and social care needs.

The use of independent living schemes and discussions with statutory sector providers was used as a means of finding appropriate ways of meeting Black disabled people's needs.

Developing services which cater for a diverse range of needs and offer flexibility and choice, will benefit all users. For example, independent living schemes may offer a practical solution to meeting potentially very diverse needs.

It is much easier to incorporate the needs of Black disabled people into policies and procedures, rather than having to struggle when potential users come to light and are requiring services in a crisis.

- **Mainstream versus specialist services**

A constant tension for many statutory agencies is whether time and effort should be invested in making existing service provision more sensitive to the needs of Black disabled people, or whether it is quicker, easier and more cost-effective to develop specific services exclusively for them.

In the first instance, it is important to recognise that it might not be an either/or situation, because both mainstream and specialist services may be required. To some extent, the strategy taken will depend upon the area, local population's needs and the range of resources available. However, commissioners and providers need to ensure that all the basic mainstream services are accessible and appropriate, particularly in areas where there is very little room to consider developing separate and specialist services.

In some situations it may be necessary to work with Black disabled people by developing specific provision in certain areas. For example, specific outreach and support work may be needed to enable Black disabled people to set up independent living arrangements, or a specialist resource might be required to offer counselling and advocacy services to Chinese disabled people.

The establishment of specialist services does not negate the need to make mainstream services more accessible.

Targeted services should not be perceived as being divisive or threatening to other forms of provision, but rather a more practical way of meeting often complex needs in an appropriate way.

- **Resource allocation**

Fears about the resource implications of developing services for Black disabled people are likely to be a major barrier to initiating change. First of all, it is important to recognise that not everything involved in meeting the needs of Black disabled people means additional expenditure. Second, if policy makers and practitioners ensure that race and disability issues are addressed throughout the design and delivery of services, then resources will be used much more efficiently.

Clearly, there will be some additional demands upon resources which may seem unrealistic, especially in an environment where there is considerable pressure upon limited resources. Nevertheless, there is an obligation to meet the health and social care needs of the whole community. Fundamental questions have to be asked about whether existing resources are being used most effectively, and whether there are options for reallocating resources to ensure a much more equitable distribution.

- **Ethnic monitoring**

There is no way of knowing what proportion of users are accessing services, and whether this is a reflection of what may be expected from population estimates, unless adequate ethnic monitoring arrangements are in place.

The routine collection of information about ethnic origin during referrals, assessments and service delivery has been an important development, in both assessing the take-up of services and feeding into strategic planning.

Agencies have taken different approaches to implementing ethnic monitoring arrangements and essentially there have been three main areas of difficulty:[26-28]

1. Different categories have been used for ethnic monitoring, resulting in confusion and disparity. Agencies need to collect information about ethnic origin using a standardised approach. Adopting the 1991 Census ethnic origin classifications could provide a mechanism for collecting routine data. Since April 1995 it has been mandatory to collect ethnic monitoring data using the OPCS Census Classification for all hospital in-patients. This is part of admitted patient care contract minimum data set and hospital episode statistics returns.[29] It would be extremely valuable if the collection of ethnic monitoring data in a standardised form was required as an integral part of the statistical returns for other parts of health and social services.

2. A reluctance to collect information about ethnic origin sometimes makes practitioners avoid asking such questions when working with users. The perception that users will not want to discuss their ethnic origin is misguided, particularly if this information is collected as part of standard information such as name, address and age. Training and guidance on ethnic monitoring are essential to encourage practitioners to implement ethnic monitoring policies.
3. Ethnic monitoring is a pointless exercise if the data collected are not used to feed into strategic planning. Often, even when information is collected, there is very little analysis of it, or it is not cross-referenced with other sources of information. For example, there may be ethnic monitoring information from referrals to eye hospitals, but very little information about actual treatment or service provided.

EVALUATING SERVICES

Commissioners and providers cannot afford to invest in services which fail to meet the needs of Black disabled people. Therefore it is important to ensure that meaningful standards are set within service specifications, local charters, performance indicators and other monitoring mechanisms to address race and disability issues.

Black disabled people need to be encouraged to provide feedback on the different elements of health and social care provision. This may entail surveys, focus groups, quality circles and regular reviews. It will be important to use evaluation techniques where people do not feel that their access to service provision is threatened.

The involvement of Black disabled people in shaping and carrying out any evaluations is central to ensuring that the results and recommendations which emerge are an accurate reflection of their concerns and priorities.

Evaluation exercises should be used as part of an ongoing process to identify unmet needs, assess the quality of services, highlight improvements and recommend changes.

8 Conclusion

The task of developing services for Black disabled people is something that all policy makers and practitioners will have to address. Race and disability is not simply an issue of 'political correctness', but a statutory responsibility that health and social care agencies need to be able to respond to.

Black disabled people are not going to disappear, and whether living in a rural or urban area, they will be requiring services. Therefore rather than wasting resources on services which are inappropriate and difficult to access, commissioners and providers need to ensure that the health and social care needs of Black disabled people are met in a way which offers choice, flexibility and value for money.

New and innovative developments are emerging which demonstrate that, with creative thinking and commitment, it is possible to improve services for Black disabled people. However, the real challenge lies in ensuring that such developments are not just a cosmetic exercise, but a real breakthrough in securing long-term improvements for Black disabled people.

Summary Checklist

- **Find Black disabled people**
- **Establish links with the community**
- **Identify needs**
- **Involve users**
- **Review existing services**
- **Establish priorities**
- **Find ways of improving access to services**
- **Change health and social care services where necessary**
- **Address policy issues**
- **Evaluate services**

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Over the past few years the low take-up of services by Black disabled people and their general absence from user involvement initiatives have become a source of concern. Evidence suggests that poor access to information, communication barriers and inappropriate services are all factors preventing Black disabled people from having their health and social care needs met. This publication provides a practical guide to addressing race and disability issues for statutory and voluntary organisations. It identifies principles of good practice and shows how to implement them by means of real examples from the field and case histories.

ISBN 1-85717-095-4

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