



People from Black and Minority Ethnic (BME) communities and vision services: a good practice guide

Thomas Pocklington Trust

Thomas Pocklington Trust is the leading provider of housing, care and support services for people with sight loss in the UK. Each year we also commit around £700,000 to fund social and public health research and development projects.

Pocklington's operations offer a range of sheltered and supported housing, residential care, respite care, day services, home care services, resource centres and community based support services.

A Positive about Disability and an Investor in People organisation, we are adopting quality assurance systems for all our services to ensure we not only maintain our quality standards, but also seek continuous improvement in line with the changing needs and expectations of our current and future service users.

We are working in partnership with local authorities, registered social landlords and other voluntary organisations to expand our range of services.

Our research and development programme aims to identify practical ways to improve the lives of people with sight loss, by improving social inclusion, independence and quality of life, improving and developing service outcome as well as focussing on public health issues.

We are also applying our research findings by way of pilot service developments to test new service models and develop best practice.

Good Practice Guides

The Pocklington Good Practice Guide series offers advice and insight based on research projects funded by Pocklington. The guides strike a balance between giving the reader information about the background and research, and presenting findings and giving advice. They are not prescriptive, but by drawing together experiences of what works, they aim to provide support to professionals working with people with sight loss.

People from Black and Minority Ethnic (BME) communities and vision services: a good practice guide

By Nikki Joule and Ros Levenson

This good practice guide builds on an action research project and literature review by the Mary Seacole Centre, De Montfort University, and on developmental work and research in a range of national and local organisations.

It is designed to provide information on issues facing people from BME communities with sight loss who would benefit from vision services, as well as suggest ideas to improve BME access to vision services.

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Foreword

Repeatedly research, audit and review have demonstrated that health, housing and care services often provide poor access and quality of service to people from Black and minority ethnic (BME) communities. When compared with the majority 'white' community, people from BME communities who have health or social care needs are more likely to have difficulty finding and using appropriate services and are more likely to experience poor outcomes.

Attention to issues of race and culture in access to, and use of, vision services is limited in practice and research. Research findings show that access to these services is often difficult, services are poorly able to respond to cultural diversity, and outcomes for BME people with sight loss are less satisfactory.

The value of research findings is enhanced when they inform practice, and this guide aims to do that. It has been produced to support those who commission and provide health and social care, and other support services for people living with sight loss by providing information and good practice examples. It builds on an action research project and literature review by the Mary Seacole Centre, De Montfort University, commissioned by Thomas Pocklington Trust in 2005, and on developmental work and research in a range of national and local organisations.

During the preparation of this guide it was clear that, while the needs for vision services among people in BME communities may be recognised and barriers understood, examples of sustained good practice to improve access and take-up are rare, and very few approaches have been evaluated. This guide is a welcome compilation of examples that, at the time of writing, were recognised as good practice in this field. It is hoped that it will enable service providers to meet their requirements under the equalities legislation.

The challenge to commissioners and service providers alike is to develop services that are not added on to other commitments but are a part of mainstream services. Only in this way can effective developments for inclusive practice be achieved and this very important and neglected area of care and support be addressed.

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Who will find this guide useful?

This guide is designed to assist those who commission and provide health and social care, and other support services, better to meet the needs of Black and minority ethnic (BME) people with sight loss.

The audience includes people working in:

- **Primary Care Trusts (PCTs)**
- **social care services for adults in the voluntary and statutory sectors**
- **physical and sensory disability teams**
- **low vision and sensory loss teams**
- **housing services**
- **older people's services**
- **ophthalmology and optometric services**
- **disability organisations**
- **BME and minority religious and cultural organisations.**

The policy framework for vision services described in this guide relates to England in 2008. Whilst the overall direction of policy is similar across the UK, the framework varies between the four nations and this should be borne in mind when applying information. Issues of good practice are however consistent across the UK, as is the need for more work to initiate and sustain good practice.

What does this guide aim to do?

This guide is designed to:

- **provide a structure for the discussion of issues facing people from BME communities with sight loss, and the responses of commissioners and providers**
- **suggest ideas to improve BME access and take-up of vision services**
- **stimulate action to extend good practice.**

It may also provide a stimulus to bring people and organisations together at local level to plan how combined efforts may support good practice.

Why is this guide needed?

The health needs of BME people have increasingly been on the agenda of health and social care organisations in recent years and it is recognised that action should be taken to meet these needs if health and care inequalities are to be addressed. Research shows that when people from BME communities have a disability, they are more likely than other people to experience poor outcomes.¹ The needs of BME people in relation to visual impairment have had a limited profile in research or practice development. With some notable exceptions, research and guidance on vision services does not address issues of ethnicity, race or culture and awareness of vision issues is missing from guidance and research about BME access to and use of health and social care services. This was a key finding of an action research project and literature review conducted for Thomas Pocklington Trust in 2005.^{2 3}

This guide summarises the key issues to be addressed, drawing on previous work conducted for Pocklington and on evidence from the wider literature on race, ethnicity and services for disabled people from BME communities. Where possible examples of good practice are provided, but it should be noted that when developing this guide there was very little sustained and evaluated practice on which to draw. The challenge to commissioners and service providers in statutory and voluntary organisations is to initiate, build and develop good practice, often building on examples of short-term and aspirational practice, that can address this very important and neglected area of care and support.

Equalities framework

The Race Relations (Amendment) Act 2000 places a general duty on public sector organisations to promote race equality. It aims to help them provide fair and accessible services and to improve equal opportunities in employment.

NHS organisations and local authorities need to produce and maintain a race equality scheme (RES) which addresses the duty to promote good race relations and provide adequate resources for implementation. The Healthcare Commission (2006) has criticised NHS organisations for failing to keep adequate records of service use by people from BME communities (ethnic monitoring).

¹ Prime Minister's Strategy Unit 2005.

² Johnson and Morjaria-Keval 2005.

³ Johnson and Morjaria-Keval 2007.

Setting out an RES means that local authorities should, for example, encourage dialogue between different racial groups on the adequacy of service provision and keep accurate records of the ethnic groups in the area and their needs. At the same time, NHS organisations should, for example, promote participation by people from all racial groups in decision-making about the ways in which health services are provided, and promote partnership with voluntary and community organisations.

The Disability Discrimination Act 2005 places a duty on all public sector organisations to promote disability equality. The Act recognises 400 disabilities, including sight loss. The Disability Equality Duty came into force in December 2006 and requires all public sector organisations to publish a Disability Equality Scheme (DES) setting out, over a three-year timetable, actions to increase equality for disabled people. This requires the sector to be proactive in ensuring that disabled people are treated fairly and given equal access to opportunities.

Guidance on implementing both duties is available from the Equality and Human Rights Commission website.⁴

Policy framework

Recent health and social care policy and guidance highlights the need to commission and provide services that support people with disabilities to lead more independent lives.⁵ The need to individualise care and make it more 'person-centred' is also stressed.

Our NHS, Our Future⁶ describes a personalised service that is 'tailored to the needs and wants of each individual, especially the most vulnerable and those in greatest need, providing access to services at the time and place of their choice'.

Our Health, Our Care, Our Say⁷ promises that 'ultimately, everyone who requires and wants one has a personal health and social care plan as part of an integrated health and social care record'.

Putting people first: a shared vision and commitment to the transformation of Adult Social Care⁸ seeks to set out and support the Government's commitment to independent living for all adults. It proposes a collaborative approach between central and local Government, adult social care

⁴ <http://www.equalityhumanrights.com>

⁵ DH 2006.

⁶ DH 2007.

⁷ DH 2006.

⁸ DH 2007.

service leaders, providers and regulators and promotes the participation of service users and carers in defining public service reform.

Fair Access to Care Services (FACS) guidance provides councils with a framework for setting their eligibility criteria for adult social care. The framework is based on individuals' needs and associated risks to independence. It includes four eligibility bands – critical, substantial, moderate and low. The guidance stresses that, when placing individuals in these bands, local authorities should identify immediate needs and needs that would worsen for the lack of timely help.

The Single Assessment Process (SAP) was introduced in the National Service Framework for Older People. It is increasingly being used for other adult groups as well as older people. National policy documents are promoting the SAP as a model for a Comprehensive Assessment Framework (CAF) to deliver person-centred care and seamless delivery of services across health and social care, based on a proportionate assessment according to an individual's level of need.

National Service Frameworks (NSFs) Several of the NSFs are relevant. In particular, the NSF for older people⁹ and the NSF for diabetes¹⁰ set relevant standards. For example, the NSF for older people states that staff should communicate 'in ways which meet the needs of all users and carers, including those with sensory impairment, physical or mental frailty, or learning disability or those whose first or preferred language is not English. ... Interpreting and translation services should be made available.'

It goes on to say that the NHS, with local authorities, 'should ensure that older people have fair access to programmes of disease prevention and health promotion. ... These should take account of the impact of cultural and religious beliefs and lifestyles.'¹¹

The NSF for diabetes¹² states that:

'Early detection of sight-threatening diabetic retinopathy and treatment with laser therapy can prevent visual impairment. The quality of life of those who develop visual impairment can be improved by access to low vision aids, information, psychological support and appropriate welfare benefits.'

⁹ DH 2001a.

¹⁰ DH 2001b.

¹¹ DH 2001a.

¹² DH 2001b.

This NSF sets the following standard (standard 10):

'All young people and adults with diabetes will receive regular surveillance for the long-term complications of diabetes.'

The **New Deal for Carers** (expected 2008) promises to update the 1999 Prime Minister's Strategy for Carers and respond to issues raised in consultation on *Our Health, Our Care our Say* about carers' needs. A helpline, support for carers' breaks and information and training via expert carers are expected and steps are likely to be taken to ensure that carers have increased choice and control and are empowered to have a life outside caring.

Statutory guidance in **Social Care for Deafblind Children and Adults**¹³ outlines the rights of deafblind people and the duties placed on local authorities, including:

- **identifying deafblind people**
- **the provision of trained people to make assessments**
- **the provision of appropriate services and information in appropriate formats.**

The guidance and its duties are mandatory and the Commission for Social Care Inspection (CSCI) reviews compliance as part of its regular inspection process.

Prevention and screening

In January 2008 the Prime Minister stated his desire for the NHS to focus more on the prevention of illness and to offer easier access to health checks and screening services.¹⁴ Early detection through screening is important in eye health and the prevention of sight loss. It will be important to ensure that vulnerable groups, including BME people with visual impairment and in particular people with learning disabilities, are able to take advantage of interventions to improve access to early screening and health promotion, for example by extending access to information about preventive interventions and by providing invitations to screening in appropriate formats and accessible venues and with support to attend.

Regulation and inspection

Health and social care services are subject to regular inspections. The **Commission for Social Care Inspection (CSCI)** inspects and reports on care services and the **Healthcare Commission** inspects and reports on health services. In 2008 a merger is planned, dependent on legislation, to create a single Care Quality Commission.

¹³ DH 2001c.

¹⁴ Brown 2008.

CSCI examines how far local authority disability services are serving the needs of diverse communities and whether the service users and carers involved in development and improvement work fully reflect local diversity. They also ensure that take-up of services and outcomes for disabled people and carers from BME communities are monitored.¹⁵ CSCI may examine whether the workforce reflects local diversity, how sensitive staff are to issues of race and whether they are 'skilled and knowledgeable about culturally defined disability and alternative perspectives of independence'.¹⁶

Ofsted inspects all work-based learning and training for employment schemes and looks at how related organisations promote equality and diversity.

Numbers of BME people with sight loss

There has been very little research on blind and partially sighted people from BME populations in the UK and there is a need for more research to enable proper planning.¹⁷ It is important that this is not just seen as an issue for areas with substantial minority ethnic populations. It may be that in areas with smaller numbers of BME people appropriate provision is more limited than in other areas and that obstacles to gaining access to appropriate services are greater.

It is likely that, due to a lack of awareness of the registration process and the benefits of registration, people from BME communities are underrepresented amongst those who register as blind or partially sighted.^{18 19}

People of African-Caribbean descent are eight times more likely to develop glaucoma than the general population and it tends to appear 10-15 years earlier than in other ethnic groups. Glaucoma is a major cause of irreversible blindness though it is avoidable with early detection and treatment.²⁰

The Royal National Institute of Blind People (RNIB) and others estimate that there are about 2 million people in the UK with sight loss that is severe enough to affect everyday life and that around 1 million people have serious sight loss that is registerable as blind or partially sighted.²¹ Given the normal ageing processes of the eye,²² most of the 13 million people in the UK aged over 60 could benefit from action to

¹⁵ For example, CSCI 2006.

¹⁶ For example, CSCI 2005.

¹⁷ Nzegwu and Dooley 2008.

¹⁸ Johnson and Morjaria-Keval 2005.

¹⁹ Nzegwu and Dooley 2008.

²⁰ Cross et al. 2005.

²¹ http://www.rnib.org.uk/xpedio/groups/public/documents/PublicWebsite/public_researchstats.hcsp

²² Weale 1963.

improve their vision – such as lighting, housing design and some aids and adaptations.

An MRC study²³ estimates that 1 in 8 people aged over 75 and 1 in 3 people aged over 90 have serious (registerable) sight loss. It is estimated that among people aged over 65 in the UK around 300,000 have sight loss that meets the registration criteria²⁴ and around a further 800,000 have sight loss which seriously affects their everyday life.²⁵ A recent study found that over 10% of people of 75 and above were visually impaired and 2% were blind.²⁶

Among people aged under 65, it is estimated that around 105,000 people have serious sight loss. Women over 65 with moderate to severe visual impairment outnumber visually impaired men by nearly three to one.²⁷

About half of the people aged 75 and over with moderate to severe visual impairment have cataracts or refractive error for which treatment is available that could considerably improve their vision.²⁸

As the BME population in the UK is ageing the number of BME people with sight loss is likely to rise.

People with impaired vision have other health and care needs too. While estimates vary widely, research suggests that:

- people with poor vision or blind are three times more likely to report their health as poor or fair than other people
- increasing levels of visual impairment are related to increased risk of falls²⁹
- concurrent hearing and sight loss may affect as many as 2 million older people; across all ages it is accepted that the 23,000 people who are registered as both hearing impaired and blind or partially sighted is an underestimate of numbers affected by dual sensory loss.³⁰ SENSE estimates that it is more likely that some 243,000 people are affected.

²³ Evans 2006.

²⁴ Visual acuity <6/18.

²⁵ Visual acuity <6/12.

²⁶ Evans et al. 2002.

²⁷ Charles, N. 2007.

²⁸ Charles, N. 2007.

²⁹ Nazroo and Gjonca 2005.

³⁰ Douglas and Hodges 2007.

Commissioning and providing services to BME people with visual impairments

Core Principles

Core principles that should underpin the commissioning and provision of services to BME communities are identified in research, audit and local experience.³¹

Needs are universal; solutions may be different

People who have impaired vision and are from BME communities mostly have the same needs as other people with impaired vision. However, they are likely to experience more barriers in accessing services and culturally sensitive ways of enabling people to access services are required. Some services may need to adapt the way they are provided to meet the needs of particular communities and different communities are likely to require different approaches to meet the same needs.

Recognise multiple need

People with visual impairment from BME communities – like other people – are likely to have multiple needs and may be living with other health conditions such as diabetes.

Involve users, carers and the voluntary sector

Service users, carers, community and voluntary organisations can play a big part in informing and supporting providers to make services more accessible and better able to meet needs.

Sustain and mainstream BME provision

Services for BME communities (and not just in respect of visual impairment) are often set up on a time-limited project basis, and are not always properly evaluated. As a result, they are vulnerable when project funding ends. When planning a service, it is important to consider how the service will be mainstreamed if it proves to be successful. It is essential not to rely on the enthusiasm of one individual or even a few people. Service developments that are justified need to be supported and promoted by the whole organisation.

Monitor, evaluate and collect data

It is important to know who is using a service and whether strategies to increase accessibility or reach out to people in BME communities are effective. If improved health or wellbeing outcomes can be demonstrated, services will be more sustainable. If interventions are not shown to be effective then resources may be redirected.

³¹ For example, Audit Commission 2002; Johnson and Morjaria-Keval 2005.

Needs at a local level

Key issues

- Census data provide broad information about the local population, but other and more up-to-date information may be needed at a local level. For example census data may not provide sufficient detail about the range of minority groups in a local area. 'Black African' or 'Asian – other' can include a range of communities with specific linguistic or cultural needs.
- The range of BME communities in the UK is expanding and in addition to diverse Black and Asian communities there are a number of white minority communities.
- Race equality schemes are often absent or hard to find: the Healthcare Commission suggests that in the NHS there is widespread non-compliance with legislation on race relations designed to promote equality.³²
- Ethnic monitoring by services is often inadequate. Where it exists there is usually insufficient information about sight loss in BME communities and about the numbers of BME people on the visual impairment registers.
- Lack of data on gender and age in BME groups means that pictures of need or responses may not be clear.
- It is not always easy to get a clear picture of services available locally across the statutory and voluntary sectors and this can result in duplication in provision or gaps in services.

What can be done?

- All organisations – statutory and voluntary – and commissioners and providers need to review monitoring procedures, share and use data collected to develop appropriate services that may improve access and use by people from local BME communities. This applies just as much in areas where there are relatively few people from BME communities as in areas with larger, established communities.
- More use should be made of census data at ward level to develop local profiles that may then be checked against service use and local understanding of community make-up.
- Be aware of diversity within diversity: for example, men and women or different age groups within a particular community may face different issues in accessing services.

³² Healthcare Commission 2006.

Raising the level of awareness

Key issues

- Generally, in BME communities there is a low level of awareness of the impact of visual impairment and services that may reduce sight loss or improve management.
- Among some BME communities sight loss may carry a stigma that may make access to screening and other services difficult.
- For people from BME communities with a learning disability, sight loss issues may be overlooked.
- Visual impairment is often accepted as an inevitable part of ageing or as part of ill-health in general.
- There is under-use of low vision services by black and minority ethnic groups and possibly under-registration.³³
- Health and care professionals, including specialists in visual impairment, may lack awareness of the needs of BME communities. People with a good understanding of communities may not have knowledge of visual impairment.

What can be done?

- Provide information and services that reach out proactively to BME communities in general and target people with visual impairments (see Outreach section below).
- Routinely disseminate information about prevention, screening and support services to all BME communities, using diverse and targeted media in community languages, including television and radio channels targeted at specific BME communities.

Birmingham Focus on Blindness

Since 2006 Birmingham Focus on Blindness has led a three-year Big Lottery Funded project (in partnership with RNIB, Action for Blind People, Thomas Pocklington Trust, Birmingham City Council and local NHS trusts). The project aims to raise awareness within BME communities of sight loss and services that can help, and to raise competencies within sight loss services to meet the needs of BME users. The approach to this builds on the Pocklington-commissioned research at De Montfort (2005) and includes 'Sight Loss Information Fairs' that bring partner organisations to community venues throughout the city.

A new role of 'community champions for sight loss' is being developed through training members/people from the local community in sight loss issues and supporting them to train others in their organisations and communities to be more aware of sight loss.

For more information, contact Community View Co-ordinator:
Email: info@birminghamfocus.org.uk Tel: 0121 478 5200

³³ Johnson and Morjaria-Keval 2005.

Screening and early detection

Key issues

There is considerable evidence that eye conditions within BME communities are not picked up as soon as they could be. This is due to a range of factors, including:

- Low awareness in some communities of how to access services, combined with a sense of fatalism about eye health or a lack of understanding of what can be done to help.³⁴ This may particularly affect older people and/or people with learning disabilities.
- Communities may be generally health conscious, but may not see eyes and vision as part of health or related to some physical conditions, such as diabetes.
- Many communities see poor vision as an inevitable part of ageing, with little prospect of treatment or improvement.
- BME people may have had poor experiences of using other services and may assume that their needs will neither be understood nor met.
- GPs may not be well informed about low vision services and rely on optical services to make the necessary referrals. However, people in BME communities may make their GP their first point of contact with health and care services.
- Early detection, and treatment, is important in treating some eye conditions to reduce sight loss.
- Some health conditions associated with sight loss – notably diabetes – are more prevalent among people from BME communities than in the population as a whole.³⁵

What can be done?

- Much can be done to take screening services into the community, to where people are. For example, integration of sight loss screening with other services used by older people could reach a significant proportion of people at risk of sight loss.
- Diabetes is the leading cause of blindness in the UK working age population, so better access to retinal screening is required for everyone over the age of 12 with diabetes (in line with the government's target to do so by the end of 2007). Diabetes UK recommends that every PCT should have a systematic call and recall system to make sure that people with diabetes receive an annual invitation to be screened.³⁶
- There is evidence that opportunistic screening can reach people who, for various reasons, may not use appointment-only services.

³⁴ Cross et al. 2005.

³⁵ For example, NHS National diabetes support team: Diabetes in BME communities www.diabetes.nhs.uk/downloads/BME_flyer1g.pdf; Acheson 1998.

³⁶ Your Vision – Diabetes UK Eye Care Campaign http://www.diabetes.org.uk/Get_involved/Campaigning/Current_campaigns/Diabetes_and_eyes/

Outreach: Encouraging access

Key issues

BME people may find it difficult to access services for many reasons:

- language barriers exist for some
- referral patterns are not the same in all communities, and in some instances self-referral is less likely to happen
- some migrant communities are unfamiliar with primary care services and think of health services mainly as hospital-based, and geared to emergency treatment³⁷
- some new migrant communities may not be aware that health services in the UK are free at the point of use
- some people are more comfortable with walk-in services and find appointments systems off-putting, particularly when they are associated with long waiting lists
- previous experiences of feeling unwelcome deter people from approaching services³⁸
- geographical isolation, transport difficulties and social exclusion also make access difficult
- support for carers is essential so that they may enable those they care for to access services.³⁹

What can be done?

- There is a great deal of evidence that awareness and uptake of services by BME communities is increased when health and social care professionals go out to where people are, rather than waiting for potential service users to seek out the help they need. Much of the early work on outreach, and the evidence for its success, comes from the use of 'assertive outreach' in mental health services⁴⁰ but outreach has been used in other health and care services too, including maternity and falls prevention⁴¹ and can apply equally to visual impairment services.^{42 43 44}
- Voluntary and statutory organisations hold events, health fairs and, where appropriate, clinic sessions in the community, choosing times and places that people visit for other purposes. Many people feel more comfortable in such non-clinical settings.

³⁷ Higginbottom et al. 2006.

³⁸ Johnson and Morjaria-Keval 2005.

³⁹ National Black Carers and Carers' Workers Network with the Afiya Trust 2002; 2008.

⁴⁰ Sainsbury Centre 2001.

⁴¹ Help the Aged 2005.

⁴² Johnson and Morjaria-Keval 2005.

⁴³ Khan 2003.

⁴⁴ Thomas Pocklington Trust 2002.

- People in BME communities may be trained and supported as volunteers who play a part in linking health and care organisations with the local community.
- A range of access points to information and services is likely to be important: for some people and communities one-stop points may be suitable (especially if various services are integrated) but for others and for areas where one-stop points do not exist it will be important to help people move between different services or parts of a service as their needs indicate.
- It is helpful to define clear pathways for professional staff and service users so that when people access one part of a service (such as a high-street optician) they can be encouraged to use other services that may help them.
- Local experience in some community-based projects has shown that active support and follow-up (from community organisations and health and care professionals) helps ensure that people do not fall by the wayside after initial consultations.
- Encouraging people from BME communities to use services may require a targeted approach such as providing opportunistic assessments of needs for low vision aids alongside other services, rather than waiting for people to be referred.

Other ways of improving access include:

- targeting information to BME communities (see section on Information and communication)
- providing open-access clinic sessions
- taking services to places where people meet others or use other services, to raise awareness, give information and offer initial screening, or in their own homes for individualised assessment, rehabilitation and support
- offering advocacy services that can support and empower people to use services
- including and involving key family members, where this is culturally preferred and appropriate for the individual with visual impairment
- making links with local BME organisations, including voluntary and community organisations, faith, cultural and religious organisations.

Living Options Devon

Living Options Devon is a voluntary organisation that runs outreach forums across Devon approximately once a month, usually attended by 15-20 people. The forums are open to people with a physical or sensory disability and their carers. The forums empower people to raise issues of concern with the appropriate organisations.

For more information, please contact Living Options.

Email: info@livingoptions.org

Tel: 01392 459222

Developing pathways in the London Borough of Tower Hamlets

Tower Hamlets is a London borough with a very diverse community, including a high percentage of people of Bangladeshi origin. There has been concern about poor access to services for these communities, and that people find the system confusing and so do not call on follow-up, rehabilitation or other community-based services. With support from an effective multi-disciplinary Low Vision Services Committee, and funding from the PCT, the local authority and the PCT are jointly leading work to develop clear pathways through local services. It is envisaged that services will be provided locally to meet local needs, based in the community and accessible to those for whom English is not a first language. The assessment, provision of equipment and onward referral to rehabilitation and other services will be followed up through home visits.

For more information, please contact

Email: barbara.disney@towerhamlets.gov.uk

Tel: 0207 364 2025

Note: Low Vision Services Committees have been established to facilitate multi-disciplinary and multi-agency working in order to ensure that user-centred and cost-effective services are available in local areas. (www.lowvision.org.uk)

Champion volunteers in Derbyshire Association for the Blind

Derbyshire Association for the Blind (DAB) recruited four 'Champion Volunteers' from local BME communities to become expert volunteers through information, training and support to understand eye conditions and vision services. They will also be trained to deliver talks and disseminate information in places they have identified. The volunteers will also advise DAB how to improve its work with BME communities.

For more information, please contact
Email: vip@dab.org.uk
Tel: 01332 292 262

Using Low Vision Aids Scheme to make links with BME communities

As a trial, the Derbyshire Association for the Blind (DAB) have started to offer Low Vision Assessments in the Derby Pakistani Community Centre and in the Indian Community Centre. They demonstrate low vision aids and let people try them out. If useful DAB delivers aids to those who need them.

Use of the aids will be followed up by staff and 'Champion Volunteers' to see if more support can be given.

If successful DAB will discuss this approach with other community centres and with the PCT that sponsors the scheme.

For more information, please contact
Email: vip@dab.org.uk
Tel: 01332 292 262

The Deafblind UK BME Project

This project aims to promote Deafblind UK's services to the United Kingdom's diverse range of BME communities and targets African-Caribbean, Chinese, Irish and South Asian communities. The project aims to recruit members, carers and volunteers through targeted events, information in the BME media and contact with local authorities in London and other big cities. A range of leaflets have been produced in minority languages including Urdu, Gujarati, Bengali, Punjabi and Chinese.

For more information, please contact
Email: info@deafblind.org.uk
Tel: 01733 358100

SeeAbility – Tower Hamlets

SeeAbility provided a community development service in Tower Hamlets to offer advice, information, signposting and support to people from black and minority ethnic communities who have a visual impairment. The service aimed to facilitate access to, and increase take-up of, appropriate services, improve knowledge of eye health issues and reduce social isolation. It used:

- drop-in sessions, telephone support and other regular direct contact with actual and potential service users and carers
- outreach and information sessions in a variety of community venues
- visits to community, religious and educational establishments to raise awareness of visual impairment, accessibility and inclusion.

SeeAbility has since moved from a focus on one borough to a London-wide approach.

For more information, please contact

Email: enquiries@seeability.org

Tel: 01372 755 000

Individual assessments

Key issues

- Achieving personalised care is the goal of recent health policy⁴⁵ (outlined in the policy framework above). For BME people with visual impairment this goal presents a challenge for service providers and commissioners. All too often BME service users find that assessments of their needs fail to take account of language and culture.⁴⁶
- The need for people to maintain connections with their community and its spiritual or cultural activities should be recognised.

What can be done?

- Anyone with a visual impairment should be assessed holistically to recognise and address health and social care needs that may stem from other illnesses or conditions, physical or learning disability, mental wellbeing or isolation.⁴⁷ Holistic assessments should involve appropriate specialists or expert resources.^{48 49}

⁴⁵ <http://www.ournhs.nhs.uk/2007/11/20/personalised-care/> and http://www.dh.gov.uk/en/Healthcare/Ourhealthourcareoursay/Browsable/DH_5695133

⁴⁶ Johnson and Morjaria-Keval 2005.

⁴⁷ Madge and Nzegwu 2003.

⁴⁸ SENSE 2006.

⁴⁹ Khan 2003.

Information and communication

- Carers' needs must be addressed, and these may present particular challenges in BME communities. Sensitivity to individual interests and to a possible reticence to be seen as a 'carer' is important in supporting carers and those they care for.^{50 51}
- Regular re-assessments are needed of people with a visual impairment. Carers' needs should also be regularly assessed.
- In some communities, a service seeking to increase independence may not be seen as appropriate or desirable. Then it may be important to shift the focus of assessment from the individual to the individual in the context of their family, household, community and local environment – while supporting privacy and confidentiality.⁵²

Key issues

- People from BME communities, like others with visual impairment, need clear information in a range of formats (tapes, CDs, telephone helplines, etc.). BME people may find it easier to understand spoken English than the written word, in any language.
- Each person's preferred means of communication, in language and format (e.g. large print, Braille, tape) must be ascertained and recorded – simply by asking them for their preference.
- There is a lack of written and audio information in languages other than English.⁵³
- Translations of materials may need to be supplemented with interpretation to explain some concepts (such as rehabilitation) and use of illustrations must be appropriate for the intended users and reflect the diversity of the whole community.
- People who do not access mainstream services are unlikely to find information that is only available there; targeted dissemination in the places where people normally go is important.
- Some people need support and encouragement to access and make use of information.

⁵⁰ RNIB 2003a.

⁵¹ National Black Carers and Carers' Workers Network with the Afiya Trust 2008.

⁵² Sainsbury and Alam (undated).

⁵³ National Black Carers and Carers' Workers Network with the Afiya Trust 2002.

What can be done?

- Organisations should review their information and communication strategies to ensure that they meet the needs of people from BME communities with visual impairment and to take account of communication needs associated with other conditions such as dementia or hearing loss.⁵⁴
- At local level partnerships with community organisations and use of up-to-date local population data should inform translations of materials (on paper and in audio form) and use of interpreters to support understanding of unknown or complex concepts. Where materials are translated and interpreters are available these services must be actively promoted.⁵⁵ Bilingual linkworkers⁵⁶ and advocates⁵⁷ linked to services can facilitate communication.
- Because many people get information through word of mouth, general dissemination of information can be effective. Targeting people in contact with those at risk of sight loss or in need of services makes sense: advice workers, local shops and businesses that work with BME communities and community workers may all spread the word.
- Local papers, community radio stations and targeted (e.g. Asian) TV channels can be used to disseminate information and increase awareness of sight loss issues and services.
- Face-to-face communication with BME people who have a visual impairment is likely to benefit from extended appointment times in clinics, surgeries or assessment services.
- Documents in frequent use, such as NHS appointment letters and discharge information sheets, should routinely be available in large print and locally relevant community languages.
- When communicating with individuals about appointments, services or equipment, it is important to use the approach that best suits them. Some BME people prefer telephone contact to letters and people with visual impairment may also be more likely to prefer a phone call. Reminders are useful, together with a clear explanation of why the appointment, service or equipment is being offered.

⁵⁴ SENSE 2006.

⁵⁵ Johnson and Morjaria-Keval 2005.

⁵⁶ Higginbottom et al. 2006.

⁵⁷ SENSE 2006.

Information days in Bradford

In Bradford, the Local Authority Adult Services Sensory Needs Service holds regular visual impairment information days for 10-15 people, who may be newly registered or waiting for assessment. Lunch is provided and the programme includes talks, benefits advice, workshops, demonstrations of equipment, one-to-one assessments, and a session facilitated by visually impaired support workers from a voluntary organisation to enable people to share experiences.

For more information, please contact the Bradford Council Adult Services Duty Officer and ask for the sensory needs service.
Tel: 01274 435001

Dekhtay Chai

Dekhtay Chai is a voluntary organisation in Tower Hamlets that provides information and support for BME people with visual impairments, many of whom are from the Bengali community. It offers a wide range of information, for example on benefits advice, entitlement to Freedom Passes, TV licences, etc. It assists people to apply for their entitlements.

As a result Dekhtay Chai has helped to increase take-up of services. For more information, please contact
Email: m.anam@btinternet.com
Tel: 020 7790 1980

Action for Blind People – housing surgeries in Tower Hamlets

Action for Blind People has worked with Dekhtay Chai to provide monthly 'housing surgeries' that address the very high level of housing-related needs in the community. The surgeries have been useful and a number of learning points for outreach services have emerged.

For example, holding the 'surgeries' regularly and also attending local events has created a useful presence and encouraged people to make contact. It has been helpful to draw on resources from the community, for translation for example, and this has increased confidence in the service. Sensitivity and respect for local culture is important and includes observing an acceptable dress code and time spent building trust.

Action for Blind People has learned that this community prefers face-to-face contact rather than telephone calls, and that word of mouth has been the most effective way of engaging the community.

For more information, please contact
Email: info@actionforblindpeople.org.uk
Tel: 0800 915 4666

Support

Key issues

- People are likely to need a range of practical and emotional support to live with the physical, social and practical aspects of visual impairment. For people in BME communities support may be important in reducing social isolation and enabling them to get the best out of services. Yet people with visual impairment generally have a poor knowledge of sight loss support groups.⁵⁸

What can be done?

- Support for self-management of health can make a big difference to people affected by long-term conditions which may be concurrent with sight loss.⁵⁹
- Professionals can offer support directly (and specialist support nurses are often found to be particularly helpful) and put people in touch with community sources of support.
- Voluntary and community organisations are often well placed to offer a range of support: practical help, information, social contact, befriending, advocacy and advice.
- Local health and care organisations should proactively seek information about voluntary and community organisations in their area and identify how they may support people in BME communities with visual impairments.
- Support for carers should be planned and integrated with support for people with sight loss.⁶⁰

⁵⁸ Thomas Pocklington Trust 2002.

⁵⁹ Rosen and Corben 2005.

⁶⁰ National Black Carers and Carers' Workers Network with the Afiya Trust 2002; 2008.

Expert Patients Programme

The Expert Patients Programme (EPP) is an approach that provides support for people to manage their own long-term health conditions. It uses groups led by a trained lay person with experience of the condition. In Tower Hamlets the EPP aims to support people with different long-term conditions across the borough and its varied communities. People with a visual impairment are supported through materials available in large print, audio tape and Braille. To address sight loss issues, programme tutors have eye conditions and personal knowledge of visual impairment.

People are referred from a variety of sources, including the sensory team in Tower Hamlets. Taxi transport is provided where needed and this has encouraged and made it possible for people to attend.

For more information, please contact

Email: get.info@eppcic.co.uk

Website: www.expertpatients.co.uk

Tel: 020 7922 7860

Directory of services for people with a visual impairment

This directory has been produced by the London Borough of Tower Hamlets Low Vision Services Committee to support health and care professionals who may come into contact with people with sight loss. In this way it supports signposting and encouragement to people across the borough's communities to use services. The directory contains details of local services that visually impaired people may find useful including NHS and local authority services, voluntary organisations, employment services, transport, etc.

For more information, please contact

Email: barbara.disney@towerhamlets.gov.uk

Tel: 0207 364 2025

Culturally sensitive services

Key issues

- Services are not always appropriate to the culture of those who need them. Particular issues may need to be addressed for particular communities. For example, in some cultures visual impairment has a stigmatising effect.^{61 62}
- Some professional approaches and services may be more rooted in a particular culture than is immediately apparent. For example, vision rehabilitation does not 'translate' across cultures where visual impairment is seen

⁶¹ Higginbottom et al. 2006.

⁶² Johnson and Morjaria-Keval 2005.

as an illness and a medical issue for which rehabilitation as conventionally defined is not seen to be appropriate.

- Cultural and religious issues may influence whether service users prefer contact with workers of their own gender. A man might find it problematic to be guided by a woman or to receive mobility training from a woman, and vice versa.⁶³
- For some communities some days of the week (e.g. Fridays for Muslims, Saturday for orthodox Jews) are less suitable for community events or for personal appointments. All religious and cultural groups have times during which people may prefer not to engage with health, care or support services.
- Some vision services may be more appropriate for some communities than others. For example, guide dogs may not be seen as appropriate by some Muslims.⁶⁴

What can be done?

- Services need to be organised so that cultural preferences, such as the gender of the worker, can be accommodated as far as is practical. It is impossible to set out what is appropriate for each community, and far less for each individual, but services should:
 - be aware of cultural differences
 - avoid making culturally specific assumptions
 - ask people how their needs can be met in an appropriate way.
- Whilst all professionals can be sensitive to cultural needs and all services can be designed to be culturally competent, a workforce that reflects the local community is also helpful.
- In the absence of a same-culture worker, community organisations can sometimes work alongside a health or care service to support both parties. In contrast, some people may prefer assistance from someone outside their immediate community so that confidentiality is assured.
- Vision rehabilitation and support for independent living must be geared to cultural needs and family patterns. Help with shopping and cooking requirements must reflect cultural issues and religious beliefs.
- Direct payments or individual budgets may help people to obtain services that meet their specific preferences. However, some may find it difficult to manage this approach and the onus should be on all services to develop cultural sensitivity.

⁶³ RNIB 2003b.

⁶⁴ Higginbottom et al. 2006.

- In services where food is provided, dietary requirements must be met and a single meal choice for all cannot be assumed.⁶⁵
- Day care and services designed to give a carer and cared-for person a break must be culturally appropriate.⁶⁶
- Some BME people express a clear demand for supported housing where they can be with people who share their culture,⁶⁷ but others do not express a preference for this.
- Training that increases awareness among visual impairment workers about equalities and diversity can help to deliver culturally competent services. Where BME people and/or local community organisations contribute to such training, local knowledge can also be enhanced.
- Health and care organisations should employ and enable people from BME communities to acquire the knowledge and skills required in sight loss and other services.

Own-language reading material

Some people are uncomfortable with the material they are asked to read when being assessed because it is culturally inappropriate or because they cannot read English. This makes it almost impossible to provide a useful assessment.

At the Royal Hallamshire Hospital the support nurse for the visual impairment service asks people to bring in something that they want to read, leaving it to them to provide materials in their own language or English and of a level of complexity of their choice.

For more information, please contact

Email: Karen.Dolling@sth.nhs.uk

Tel: 01142 261 262

or email pals@sth.nhs.uk (ask for the support nurse for the visual impairment service) Tel: 01142 712 450

⁶⁵ Thomas Pocklington Trust 2006.

⁶⁶ National Black Carers and Carers' Workers Network with the Afiya Trust 2002.

⁶⁷ Thomas Pocklington Trust 2006.

Working in partnership

Key issues

- Some health and care staff and volunteers have a good awareness of BME communities and their needs but not of visual impairment, whilst for others the opposite is true. Few people have both kinds of awareness and expertise. Individuals and organisations need to find ways of sharing their understanding so that they can better meet the needs of people from ethnic minorities with visual impairments.
- Working in partnership is a key to bridging gaps in awareness and to helping people access and use services, and pass between one service and another to address different areas of need.

What can be done?

- Efficient ways of working across organisations and teams are needed to make joined-up services a reality. For example, generic social work teams and specialist sensory loss specialists need to work more closely together, and both need to work with older people's teams in the NHS. NHS and social care teams that work with older people need to cooperate with those who support people with physical and sensory impairments in order to deliver person-centred care.
- Joint meetings and training events can help overcome boundary issues within and between organisations.
- Attitude and flexibility are key. If workers understand issues outside their own specialism, they will be more likely to liaise with colleagues and refer service users to other services or organisations as required.
- Statutory, voluntary and community organisations need to work together in ways that complement one another's roles and to ensure that they have information about the range of services available locally.
- Within NHS services there are opportunities for effective partnerships: diabetes services are well placed to promote a greater awareness of eye health and to provide information about services that may help people manage visual impairment.
- Partnerships between health, care and housing organisations are particularly important because people with visual impairment from BME communities frequently experience multiple needs that cross different services.⁶⁸
- Low vision committees bring relevant organisations together and can drive forward change in local services.

⁶⁸ Johnson and Morjaria-Keval 2005.

Planning future services with BME communities

Key issues

- Experience shows that good ideas are often introduced for a limited time, with inadequate evaluation and without provision for long-term sustainability.
- There is a history of racism within white organisations and discrimination against people with disabilities within BME organisations.⁶⁹
- BME service users aspire to more choice and control in their lives and are positive about being involved in the design and delivery of the services they require.⁷⁰
- Involving BME communities at an early stage of service development is essential to ensure it responds to needs. Too often consultation is too late and may then be seen as ‘rubber stamping’ decisions that have already been taken.⁷¹

What can be done?

- Organisations should embed good practice in the services routinely offered to people from BME communities with visual impairments. In Bradford the disability strategy has involved and included the local BME population for more than 10 years.
- Involving BME communities in planning and developing services requires attention to practicalities: good physical access, a comfortable venue, language support, transport.
- A lead person with responsibility for ensuring that services for BME people with sight loss are coordinated, appropriate and used by those who need them can work across services, monitor and report on progress.
- Many organisations have found that employing a ‘development worker’ to start the process of developing appropriate services and make links with the communities is a valuable first step. Sustainability is essential – either by embedding services and practices or by continuing local multi-purpose support for minority communities.
- This guide may be a stimulus to bring together local commissioners and service providers across statutory, voluntary and community organisations to plan how local services may be made more accessible and appropriate and to determine the roles that different organisations may play in that.

⁶⁹ Evans and Banton 2001.

⁷⁰ Butt and Dhaliwal 2005.

⁷¹ National Black Carers and Carers’ Workers Network with the Afiya Trust.

Useful Resources

Equality and Human Rights Commission

<http://www.equalityhumanrights.com>

The Commission has taken over responsibility from the Commission for Racial Equality (CRE), the Disability Rights Commission (DRC) and the Equal Opportunities Commission (EOC) for promoting racial, disability and sex equality in Britain. It defines and promotes good practice and makes available guidance and statutory codes of practice.

Ethnicity and Health Specialist Library

www.library.nhs.uk/ethnicity

This resource aims to make accessible good, currently available electronic evidence relating to health care for minority ethnic groups in Britain.

Health for asylum seekers and refugees portal

<http://www.harpweb.org.uk/>

This web-based resource offers resources for work with asylum seekers and refugees. It provides basic information about different cultures that can facilitate culturally sensitive practice with communities regardless of their immigration status.

The Race Equality Foundation

www.raceequalityfoundation.org.uk

The Foundation promotes race equality in social support and social care. It disseminates good practice through training, conferences and useful briefing papers including: *Effective Communication with service users*.

<http://www.raceequalityfoundation.org.uk/hsc/files/health-brief2.pdf>

Race Equality in Health and Social Care – Good Practice Guide – Equality Commission for Northern Ireland

<http://www.dhsspsni.gov.uk/eq-raceeqhealth>

This guide addresses the issues facing communities in Northern Ireland and also contains a great deal of information that is generally applicable.

Multi-Kulti

<http://www.multikulti.org.uk>

This web-based resource provides culturally appropriate and accurately translated information on housing, debt, employment, welfare benefits and immigration. An English version indicates what is available in other languages.

Network of Ethnicity in Health Care

www.jiscmail.ac.uk/ethnicity-health

This is a discussion list where over 400 practitioners and active researchers working on ethnicity and healthcare issues exchange ideas and suggestions for effective practice.

A Practical Guide to Ethnic Monitoring in the NHS and Social Care

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4116843.pdf
(or via the Ethnicity and Health Specialist Library)

This guide shows good practice examples throughout health and social care to help organisations meet their responsibilities under the Race Relations (Amendment) Act 2000.

UK Centre for Evidence in Ethnicity, Health and Diversity (CEEHD)

<http://www.ethnic-health.org.uk/>

The Centre undertakes new research and also identifies, assesses and disseminates evidence in the multidisciplinary field of ethnicity and health, providing research findings which can help user organisations in health, social care and other sectors to develop ethnically sensitive, appropriate and cost-effective services and policies.

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Notes

Notes

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In this publication, the terms 'visually impaired people', 'blind and partially sighted people' and 'people with sight loss' all refer to people who are blind or who have partial sight.



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Registered Charity No. 1113729

Company Registered No. 5359336

Published by Thomas Pocklington Trust

ISBN 978-1-906464-03-5



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