Research findings
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Our Vision Too: Improving the access of ethnic minority visually impaired people to appropriate services; building a supported community referral system.

This publication summarises findings from research conducted by Dr Asesha Morjaria-Keval and Professor Mark R D Johnson, De Montfort University. The project was funded by Thomas Pocklington Trust and the Housing Corporation.

The aim of the project was to examine and develop means of ensuring that services are more effectively delivered to people from black and minority ethnic communities with visual impairment.

This study found that:

- there is still a lack of knowledge about the prevalence of sight loss in different ethnic groups
- potential service users in minority communities have a poor knowledge of eye conditions and of services
- completed projects have not fed into general service provision
- cost needs expressed by people with sight loss from ethnic minorities are in common with those from majority ‘white’ communities
- common themes between various minority ethnic groups may be better addressed if the initial response was ‘community specific’
- the primary need is for information
- people experience ‘learned helplessness’
- stigma, shame or pride have a disproportionate impact on minority communities
- information and outreach should be delivered through trusted routes.
Aims
This study sought to raise awareness of sight loss issues and services in black and minority ethnic communities and voluntary sector groups working in those communities. An additional aim was to raise the capacity of specialist visual impairment (VI) service providers to recognise the specific needs of people from black and minority ethnic (BME) groups, and establish the best ways of meeting these.

Methods
The full project report contains the findings from a review of literature and current research, and describes the process undertaken in the project. Community fieldworkers were trained and conducted ‘focus group’ discussions in their communities, giving information to group members. An action research model was adopted, leading to a series of ‘Sight Loss Information Fairs’. An evaluation study followed up these activities.

Evidence base
The literature review noted the poor evidence base generally in relation to minority groups and sight loss. There has been a recent growth of information through secondary analysis of Visual Impairment registers. Whilst the prevalence of age-related sight loss appears to be lower in minority ethnic groups, this may be attributed to their younger age profile.

High levels of diabetes lead to an expectation of worse eye health. There are more cases of juvenile inherited eye conditions, raised levels of glaucoma in African Caribbean populations, and more experience of cataract among people of South Asian origin.

The ‘visual impairment’ research literature tends to ignore issues of race and ethnicity. Similarly the literature relating to ‘race relations and ethnic diversity’ largely excludes attention to sight loss.

There is consensus that there is apparent under-use of services by minority groups, and possibly under-registration. This is linked to low levels of knowledge and failure to recognise needs that can be addressed.
Some service providers have been concerned about this but there is little evidence of strenuous effort to raise uptake. Improvement in service uptake requires assertive outreach, cultural competence, and partnership with voluntary organisations run by minority ethnic groups.

Many attempts have been made to improve the situation but problems have arisen from short-term funding and closure of projects. New or recent research and development projects have so far been poorly reported on in accessible literature and there were few reports of evaluations. All studies tend to underline previous findings, largely referring to low awareness.

More recent research has shown some specific housing needs from BME people with visual impairments, notably a greater level of housing need than comparable white users, and stronger family ties.

**Views of people from ethnic minorities**

Focus group discussions were able to locate people within specific minority communities with VI sight loss, with VI relatives, but not all those eligible were registered. The impact of sight loss on social and religious life was considerable and major problems were encountered through the lack of social and family understanding and support.

Most VI people had ‘drifted’ into their present state with little support although all praised the help given by family members, and expressed resignation and relative satisfaction, often in religious terms. Although low expectations were apparent, this was because sight loss was seen as an inevitable element of ageing, with little expectation of a maintained quality of life. Few people said they met stigma or were ashamed, but this was a frequent explanation of why ‘others’ did not seek help.

There were, as expected, very low levels of knowledge about a range of sight loss conditions, causes or solutions, and much frustrated help-seeking had led to a lower level of expectations, or ‘learned helplessness’. This was often worsened by the vulnerable state of people in marginalised or socially excluded communities. Those in the best position to help were culturally competent staff in BME community...
voluntary organisations but they lacked both the specific skills and knowledge, and resources to meet need – and were also exposed, vulnerable, or over-worked. Overall, the focus groups showed many similarities between minority ethnic groups - but also made it clear that to be effective, responses would have to be community-specific.

The good practice model for community involvement

The model adopted through this project appears to have worked. Fieldwork interviewers who are recruited from community-based organisations, and given training about visual impairment, can disseminate information and raise awareness, and influence those organisations. These are effective ways of reaching out to members of minority ethnic and religious communities, and there is a considerable demand for ‘information fairs’ which enable members to experience and try out relevant information and equipment.

More needs to be done to create translated and culturally competent information and support. The importance of ‘role models’ and professional workers from the specific communities was emphasised. A liaison group of stakeholders from service providers and potential user communities was formed to organise the ‘sight loss’ or ‘eye health’ Information Fairs, and this could be an ongoing outcome of the project.

The project developed a proposed ‘good practice model’ from the learning in this project together with checklists for service providers and community organisations to conduct organisational audits of their Visual Impairment and Ethnicity competences.

**Main findings:**

- There is still a low level of knowledge about the prevalence of sight loss in different ethnic groups and it is difficult to establish levels of service take-up.

- Potential service users in the minority communities have a poor knowledge of eye conditions and of services, and find it difficult to state needs or expectations.
Completed projects which intended to improve the knowledge base and develop new services have failed to lead to accessible published work and feed into general service provision.

The majority of needs expressed by people with sight loss from ethnic minorities are held in common with those from majority ‘white’ communities.

There are many common themes between the various minority ethnic groups who took part: however, it was felt these would be better addressed and with more confidence by service users, if the initial response at least was ‘community specific’.

The primary need is for information giving.

People experience ‘learned helplessness’.

Issues of stigma, shame or pride have a disproportionate impact on minority communities. There are also concerns that some faiths appear to suggest that impaired sight may be a ‘gift from God’.

Information and outreach needs to be delivered through trusted routes.

**Key recommendations**

- Sight Loss support services need to recruit staff from within minority communities.
- Information must be translated into minority languages.
- Information needs to be actively promoted through community organisations.
- Sustained effort may be needed to overcome suspicion based on past experiences.
- Previous initiatives have foundered because of a lack of continuity – a longer-term perspective is required to bring change and create better relationships.
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How to get further information
A short report, in the form of an ‘Occasional Paper’ entitled Our Vision Too: improving the access of ethnic minority visually impaired people to appropriate services will shortly be available from Thomas Pocklington Trust.

The full report, entitled Our Vision Too: improving the access of ethnic minority visually impaired people to appropriate services is available from De Montfort University, Mary Seacole Centre, Charles Frears Campus, 266 London Road, Leicester LE2 1RQ.
**Background on Pocklington**

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 £300,000 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 focusing 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.