
**Enabling Perceptions: The Views of Blind and
Partially-Sighted People of African Descent in the UK**

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“Being blind is not the end of the world... There is life to be lived and if you have an aspiration to do something then go and get more information and start digging into it. It takes time but you can get there. You can’t let people tell you that you can’t do it. You will find obstacles, but that is life – even sighted people come across obstacles.”

50 year old female participant

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Executive Summary

National minority populations represent about 6-7% of the overall UK population. In the attempt to broaden our collective understanding of the needs of blind and partially-sighted people in the UK, Guide Dogs undertook a qualitative study designed to gain an understanding of the attitudes of people from various communities toward their vision loss, including their perceptions of society's response to them. The study also served as a follow up to Guide Dogs'/Lewisham's 2003 study which was largely a service evaluation by users and non-users of Lewisham's and Guide Dogs' services in the area.

The sample for this study was drawn from the African descent community resident in London. The study was designed to document people's experiences and perceptions on a range of life issues, including their access to services, their social and economic circumstances as well as their hopes for the future. In the report we provide a detailed picture of people's experiences of sight loss within their own environment, focusing in particular on family/social relations, service delivery, employment and education, as well as perceptions of discrimination and prejudice. Also examined are the perceptions of blind and partially-sighted people – both of themselves and of society towards them.

Between February and April 2006, 37 blind or partially-sighted men and women of African descent took part in four focus group sessions at the offices of OBAC (the Organisation of Blind African Caribbeans).

We found an articulate, energetic and vibrant group of people from diverse educational and socioeconomic backgrounds who had, on the whole, received minimal support from the state in coping with the impact of sightloss. We also found a largely optimistic group of people who subscribed firmly to the notion of self-reliance as a means of surviving what they perceived to be a lack of support from the state and voluntary sector.

Too often the needs of minority populations in the UK are presented and discussed as if they differ significantly from "mainstream needs" – that is the needs of everyone else. In reality, the needs of members of minority communities are no different from everyone else's needs – they include the need for information that enables informed choice, the need for independent living, the

need for continuing employment, the need for dignity and respect in the face of what is often a major traumatic life event. What does differ in the case of minority populations is the response to these needs even when these needs are no different to those exhibited in “mainstream society”. Indeed, it is the method by which access to the requisite services is enabled for these population groups that has always been and remains the central issue. Facilitating this access is the challenge that requires innovative thought, flexibility, adaptation where called for, and commitment by all involved sectors.

Simply put, three primary issues identified in this study include:

1. A lack of access to comprehensive information, including but not limited to condition and rehabilitation-specific information in all its aspects – that is, preventative and rehabilitative as well as general information – in order to address the high levels of information exclusion currently experienced by many in this population group.
2. The paucity of essential service provision to this population group.
3. The need to identify potentially registrable people, often isolated and unknown to the “system” within their community.

Eight recommendations follow from these findings:

1. Improving access to information

Improving access to information about the services available to blind and partially-sighted people as well as local community-specific information emerged as one of the most important areas of support required. Access to information implies information presented in language that is easily comprehensible and fully inclusive. Inclusive language means that the “language” of service provision is couched in a framework of values to which the individual client/user subscribes. One of the major findings of this study was the degree to which participants were unaware of the services available. There was clearly a near total lack of awareness of the variety of services that could have been used to enhance their quality of life. Individuals had no idea whatsoever what to expect from Social Services in the way of service provision, and sadly did not entertain any expectations of SS

whatsoever. Yet, it was clear that people who had received services valued them and those who hadn't expressed an interest once these services were identified. A mechanism is required to enable service providers to seriously engage with and respond to the concerns of the communities they are mandated to serve.

2. Identifying registrable people within minority communities through widening the scope of outreach work

Many of the participants who attended the focus groups could readily identify people in their communities whose eye conditions were comparable or more serious than theirs. Yet, these individuals were not registered, nor were they in regular contact with ophthalmic or other services. It would appear, based on this evidence, that there could be a significant number of registrable people with little access to any support or help. The scope of this problem needs urgent investigation. Instituting outreach work, particularly targeting areas of community gathering, like churches, might begin to reveal the extent of need. Indeed the Guide Dogs/Lewisham project found that contact and interaction with the community was a fundamental prerequisite for building bridges of communication and co-operation with its service users. It is therefore essential that the scope of outreach work within Local Authorities be broadened to ensure on-going contact with the constituent groups within the community.

3. Active recruitment of staff from national minority populations

Responding effectively to the diverse populations that currently define local communities will require the participation of these communities – particularly through consultation with them on how best services can be provided to reach those most in need. Engagement will be most effective when both users and professionals from these communities are involved. This implies that Local Governments and charities in the sector should be reflective of the populations they serve, thereby incorporating the culture and relevant philosophical constructs of users into their entire approach to service delivery. Currently, very few establishments reflect these diverse staffing patterns. There is perhaps no greater way for the spread of information and advice within a community than to engage its members as staff in the delivery of the service.

4. Training for rehabilitation workers

It is clear that an institutional commitment to improve access for all groups requires the provision of continuous and improved training for its rehabilitation workers. Specifically, the training would include improving the capacities of rehabilitation workers to deliver services based entirely on the individual's identified needs (adopting the philosophy that the user is their own best expert) and avoiding often erroneous assumptions of some professionals about the impact of a person's race, culture, religion or other attributes on their capacity or desire to use rehabilitation services.

5. Conducting research

There is very little research on blind and partially-sighted people from minority populations in the UK. In virtually every vision-related sphere imaginable, the need for quality research is apparent. Two areas in particular are important to highlight. First, research is needed to determine how to best and through which channels vital information can be made more inclusive and readily accessible to minority groups. Second, research into the prevalence, of blindness/partial-sight, including condition-specific prevalence rates, are clearly needed to enable any real long-term planning for the provision of services to these and other population groups.

6. Employer-targeted education

Many people lost their employment as a result of their loss of sight. There is no doubt as to the devastating impact which the loss of employment created for these individuals and their families. People seemed able to cope better with the potential disability, if they could have been enabled to retain their employment. The need for employer-targeted education is clearly indicated in this study and supported by other national studies on the subject.

7. Support to blind or partially-sighted parents of sighted children and to children of blind or partially-sighted parents.

The need for support to blind and partially-sighted parents of sighted children with no disabilities and to the children themselves is clearly indicated in this study. Services, where they exist, are often directed at the person with the disability (adult or child) with little attention being given to the significant others in the individual's life. In the words of one parent, "children with VI should

be give special attention and so should the ones whose parents are visually impaired.”

8. Support to OBAC and similar organisations

OBAC and similar such organisations need to be supported to expand their capacities to deliver to an even greater number of users and to broaden the range of services to these users. The critical role of organisations such as OBAC cannot be overstated. Minimally, OBAC provides a humanising environment that enables therapeutic engagement. But it does so much more than that – it delivers practical solutions and reintroduces hope and purpose into many lives.

1 BACKGROUND AND CONTEXT

1.1 National Context

National minority populations represent about 6%-7% of the overall UK population. However in a number of boroughs (especially in London and the West Midlands), they can constitute up to a third or more of the local population. It is critical to highlight the enormous differences that exist within these collectively labelled and poorly-researched population groups – variations that stem from geography, history, culture, as well as certain disease prevalence rates. Overall however, these diverse groups have in common poorer health outcomes and quality of life indicators than the general population.¹ While there is a major deficit in the quantity and quality of eye/vision-related research within national minority populations, existing data highlights a number of facts. First, the age profile within minority populations is generally younger than the general population;² thus, we are likely to see lower prevalence rates of age-related blindness. It is important to note however that this may change for some of these communities in the next 10-20 years, given projected demographic trends. Second, the higher prevalence of certain eye conditions, such as glaucoma in African descent and cataracts in Asian descent peoples has implications for the incidence of visual impairment within these populations. Similarly the higher prevalence of certain health conditions such as hypertension (among African descent populations) and diabetes (among both African and Asian descent populations) also has implications for the incidence of visual impairment within these groups. Urgent research is required in all these areas. And third, evidence suggests serious under-registration and under-use of relevant visual impairment-related services among national minority groups - *significantly less than in the general population.*³ The low vision/VI sector suffers from a lack of critical information needed to determine the prevalence of visual impairment within these population groups as well as the true extent and nature of need within these groups.

¹ See Department of Health, *Health Survey for England – the Health of Minority Ethnic Groups '99* and Department of Health, *The General Household Survey: Living in Britain 1998*.

² Office for National Statistics, *Mid-2000 Population Estimates*.

³ Royal National Institute for the Blind, *Ophthalmological Conference: Ethnicity related eye conditions and relevant services* (proceedings), 9 November 1988 and Royal National Institute for the Blind, *Ophthalmological Conference: Ethnicity related eye conditions and relevant services* (proceedings), 1 May 1990.

1.2 The Study Context

In an attempt to broaden our collective understanding of the needs of blind and partially-sighted people in the UK, Guide Dogs undertook a qualitative study designed to gain an understanding of the attitudes of people from various communities toward their vision loss, including their perceptions of society's response to them. The study also served as a follow up to Guide Dogs'/Lewisham's 2003 study⁴ which was largely a service evaluation by users and non-users of Lewisham's and Guide Dogs' services in the area.

The sample for this study was drawn from the African descent community resident in London all of them members of the Organisation of Blind African Caribbeans (OBAC). The study was designed to document people's experiences and perceptions on a range of life issues, including their access to services, their social and economic circumstances as well as their hopes for the future. In the report we provide a detailed picture of people's experiences of sight loss within their own environment, focussing in particular on family/social relations, service delivery, employment and education. Also examined are the perceptions of blind and partially-sighted people both of themselves and of society towards them, including perceptions of discrimination and prejudice.

1.3 Objectives

Our objectives were threefold:

1. To explore the experiences and perceptions of blindness or partial-sight among African descent populations in London.
2. To identify barriers to accessing services for the population.
3. To make recommendations designed to enhance further inclusion and access for the population.

⁴ Melody Madge and Femi Nzegwu, **The Guide Dogs/Lewisham SSU Project: A Report on the Needs of People with a Sight Loss from National Minority Populations**, 2003.

2 Methods

Between February and April 2006, a total of 37 women and men of African descent, were interviewed in four focus groups. The sample was drawn from the membership or service users of the Organisation of Blind African Caribbeans (OBAC). OBAC contacted all its members explaining the purpose of the study and inviting their participation in the focus groups. All those who consented were then given a choice of dates to attend the meetings.

A semi-structured questionnaire was used to guide the discussion sessions which focused on four main parts:

- The impact of blindness/partial-sight on people's day to day lives
- Knowledge about and use of rehabilitation/social services
- What people felt they needed most when they found out they were losing their sight
- Hopes/prospects for the future

All interviews were taped and subsequently thematically analysed.

3. Demographics

3.1 Age/gender distribution and household situation

Participants attending these sessions came from diverse backgrounds. They ranged in age from 21– 74 years; 13 were women and 24 men. Most people were of working age as the age distribution below illustrates:

<u>Age</u>	<u>Number</u>
20s –	3
30s –	6
40s –	13
50s –	9
60s –	5
70s –	1

23 people lived with their families, 13 lived alone and 1 lived with friends.

3.2 Registration

23 of the 37 participants were registered – 3 as partially-sighted and the remainder as blind. One individual had tried to register but was told that his sight in one eye was “too good to register”.

3.3 Causes of blindness

30 of the 37 members present stated the main cause of their blindness as follows:

<u>Condition</u>	<u>Number</u>
Glaucoma	8
RP	6
Cataracts	3
Bleed in eyes	2
Macular Dystrophy	2
Macular degeneration	2
Accident	2
Optic Nerve damage	2
Diabetic Retinopathy	1
Retinal Detachment	1
Optic Atrophy	1

Two members of the group stated that they had never been told what their diagnosis was. Two were blind from birth, one as a result of meningitis. Most of the people present had become blind or partially-sighted as adults – only three of the members had been blind or partially-sighted in their early childhood.

3.4 Employment & studying

6 people were employed at the time of the interviews – 3 owned their own businesses, 1 was a part-time solicitor, 1 worked as a painter/decorator and 1 as a writer/musician. All others were either unemployed or had retired.

Three people were taking courses outside of OBAC - two were studying counselling and one was training to be a legal secretary – and one person was about to begin a PhD. Everyone was either currently or had previously been engaged in some sort of IT training by virtue of their association with OBAC.

There was evidence of a wide range of former careers and skills among those present, including an accountant, solicitor, an office manager, a number of registered nurses/midwives, someone who worked in the financial industry, a former member of HM Forces, a sales assistant, an industrial assembly worker and a cab driver. A number of people were currently involved in voluntary work in schools or other charitable organisations.

4 The Impact of sightloss on daily life

Four broad themes emerged from the discussions on the impact of sight loss on people's lives – economic, socio-cultural, information, and the interplay between race and disability.

4.1 Economic

Most of the people present at the focus groups were of working age, and many told stories of how they had lost their careers as they began losing their sight:

“I used to be a postman but when I was diagnosed with my sight problem they resigned me.”

64 year old male

“I had a very good life and a very good job. My job signed me off in 1992 after twenty-two years.”

46 year old male

“Before I lost my sight I was a secretary and I used short hand. I haven't been able to do that since I lost my sight, but my RW told me about OBAC... and now I'm retraining here.”

47 year old female

All agreed that the expectation of both society as a whole and blind and partially-sighted people themselves, was that one's employment would cease following sight loss. There was also an acknowledgement that both the employers and their blind or partially-sighted employees had little knowledge of the measures that could be put in place to prevent an unnecessary termination of employment. The following examples illustrate:

“I originally started studying medicine but I had to stop. I switched to physiotherapy and worked as a physiotherapist for a while. I then did a course in health and social care and worked with youth suffering from mental illness. I did that for about a year, then they [employers] said my eyesight was affecting my performance... They couldn't tell me exactly how...They got rid of me. Since then, I have tried to apply for jobs. I give the impression that I am fine but their computers don't have the facilities I need. When I look too closely at

the screen they can tell that I have problems. After a while I decided to stop applying for jobs because every time it is the same thing...

36 year old male.

“When employers see that you put down that you have a visual impairment, there is an immediate barrier to considering you to be a competent candidate. My experience was that it was really, really difficult to find employment even though I wasn’t totally blind.”

52 year old male

The importance of the continuation of employment in the face of sight loss was echoed by all those present. People spoke about how they felt their lives had been turned upside down and in effect brought to a standstill almost as much by the loss of their jobs immediately following the sight loss, as by the loss of the sight itself:

“My main issue was employment. It can be quite devastating especially when you have a family to take care of... It [unemployment] really set me back and it affected my whole life and my whole family structure... I think to a large extent it contributed to the breakdown of my then relationship. It was a major factor. People’s ability to cope is seriously brought into question [with the loss of employment].”

50 year old male

“I lost my job and I am trying to see how I can get it back and carry on with my life again...”

30 year old male

“The income structure of the family comes under massive strain – it is a major factor in how able you are to cope with the sight loss itself.”

54 year old male

For one professional man his greatest need at the time of going blind was:

“All I wanted was something that could help me go ahead with my career.”

41 year old male

People spoke about the fear of bringing to their employers notice, their worsening eye condition:

“I couldn’t bring myself to tell my employers at the initial stage. Even the colleagues that I worked with did not know it [eye condition] had got that bad.”

43 year old male

In this one case when his employers were eventually told, they acted, quite contrary to expectation, by putting in measures to support him:

“Surprisingly, when I told my boss, they got me a secretary... At that stage I felt confident that my job had not gone and I could still work...I have been surviving ever since.”

The experience of supportive employers was echoed by another participant:

“During the time that I took sick [first lost sight] I was at home and I didn’t feel that all my friends had deserted me. I had one friend who worked for a small insurance company and he spoke to his boss about what was happening to me. The company took me on and I worked for them for five years. They took me under their wing and I was with them for five years until my vision got worse and we had to part company. I would like to say that it is not all companies who have the idea that visually impaired people have no skills.”

74 year old male

Some of the unemployed participants spoke of spoke of measures they had either put in place or were putting in place to find employment.

“I was in the teaching profession. I retrained. I was a student here [OBAC] and I finished last year. I decided to enter voluntary work here with the intention that in the future I might be able to get some part-time work...”

31 year old male

“I was born with meningitis – it damaged my eyes and legs. I have always wanted to do something in the media and I decided I would like to do a TV show. I brought my ideas to a group of three university students and we got together and decorated a kitchen and put on a show. We found a lot of signed and unsigned acts and put together the show. We have also done a documentary and I have now established a recording studio and filming company. I wasn’t getting the encouragement to go out and do it because people think that you can’t accomplish it due to your situation... And this has been independently done on my own – I channel myself that way. If you think you can do something, then you will.”

25 year old male

“I am re-orientating and training myself afresh. If I can’t do that [work in the financial sector], maybe I can do something else. The general perception is that we are not capable of doing anything but people are forgetting that we already have skills. It’s just a matter of retraining so you can adapt.”

30 year old female

“I am trying to do counselling. I just finished the introductory course and I do volunteer work at OBAC.”

69 year old female

“I came here and got the energy and a lot of confidence to go out and do something.”

25 year old male

The individual’s own level of confidence as an important motivational factor in beginning to seek employment and persisting in doing so was discussed at length. Many people felt that a loss of confidence could be experienced by those seeking work, not so much because the individual could not do the job but rather because of their own perception that the outside world saw them as incapable - because of their sight loss. In the words of one person:

“I think the loss of confidence comes from people’s knowledge of how people in the external environment perceive them. They know they are up against a barrier

before they get there... That can even affect how they perform at an interview.” 33 year old male

Virtually everyone in the group had worked at some point in their lives, even those who were blind or partially-sighted at birth or in their childhood.

One participant's suggested employment solution for blind people was for more blind and partially-sighted people to set up and run their own businesses:

“I studied contract law when I went to university and I was active in the student union. I made visual impairment an issue within the student union. After university I went on to work and I became a training manager... three years ago I set up my own business. I think that in order for blind people to survive they must set up their own business.” 56 year old male

Employment emerged almost as an enabler of one's ability to cope with their sightloss. In most cases, people wanted to retrain and return either to previous or new professions. The barriers were in the perceptions of both groups – employers and themselves – but also in the simple lack of knowledge as to how people's working environments could be modified (often at minimal cost) to allow them to continue their careers. An important finding also was the positive experience of some participants of employers who do not respond to their employee's difficulties by terminating their employment.

4.2 Socio-cultural

Within the group, people's social experiences in the aftermath of their vision loss was, understandably, quite varied. The group discussed the impact of their sight loss on their family and friends, on their social pursuits, and the reactions from the communities in which they lived and interacted as well as the general public.

For some people, the experience of sight loss was as traumatic for their families as it was for themselves – especially as changes in the roles and responsibilities of family members occurred:

In the words of one participant:

“The people around me were unable to cope – emotionally or with the general care. As my needs changed I made more demands on my family and of course it generated some resentment.”

57 year old male

For others, the family responded by becoming extremely overprotective:

“The family can become overprotective and they won’t allow you to do things for yourself, even when you can... Sometimes they don’t even think you’re capable of making a cup of tea...Sometimes it’s annoying...”

74 year old male

“You take everyday tasks for granted and then [after sightloss] they become huge tasks for you. I had to fight for my independence because my family wanted to do everything for me, but I wasn’t comfortable with that. All I want is to be independent. I might be visually impaired but my brain is still working and I want to carry on with life.”

30 year old female

The impact on friendships and the loss of friends was noticeable for many.

“People feel uncomfortable around me, they shy away. I now don’t go out as much as I used to and I miss that. People are condescending to blind people... Some of my friends don’t visit as much any more because of my low vision.”

41 year old male

“A lot of my close friends disappeared when it happened to me. I have a very close family and they really rallied around me.”

53 year old female

One woman whose friends had all virtually disappeared referred to her social situation as being “completely wrecked.”

For others though, there was little impact on their network of friends. They had largely retained the same circle they had had

prior to their eye condition and even expanded on this through their networking at OBAC.

The perceptions of blindness within the African descent community as a whole clearly had an impact on many participants – both in terms of their own acceptance of their eye condition and their subsequent identification with “symbols” of blindness. There was a general agreement in the various group discussions that the perception of blindness or partial-sight within African descent communities was nothing short of “disastrous”:

“I think the community has a lot to learn about blind people. They tend to isolate them and treat them like lepers. I think you have to fight your way through and that can be disheartening.” 53 year old female

So, for one woman who had had mobility lessons, she never used her white cane because it was “not nice for her children.” People felt that the symbol of the cane was not known or was misunderstood by the public as a whole and members of their own communities in particular:

“When I first started using a cane one of my neighbours told me that her sister had seen me at the bus stop and she had been so shocked that she walked straight past me. Why?” 47 year old female

“I’ve tried to use the white cane, but for me I guess it is a little bit embarrassing to do that.” 39 year old female

“I know it [road crossing] is dangerous and I should be using it but I just don’t feel right.” 59 year old female

One woman felt very strongly about the potentially disabling impact of religious beliefs on blind people of African descent and their capacity to access and use services – in their words “to move on with their lives”:

“I haven’t accepted it [blindness]. I have just had to move on. If left to most black people you shouldn’t accept it anyway because as far as they are concerned God can create miracles. And the amount of people who try and drag you to church is just very annoying. They

should leave people alone because you can sit there in that suspense, in limbo waiting for this miracle to happen...” 47 year old female

Others, however, felt that their church had rallied around them and provided vital support when it was most needed.

The group’s general perception of the public was that it was largely unaware of visual impairment issues:

“I think there is a lack of empathy where the public is concerned. It is always like they are telling you to get out of the way or watch where you are going. They are not aware at all...” 57 year old male

This often had major implications in all spheres of life in which people interacted with the public. Many thought that even officials of councils, mandated to serve all sections of the public, lacked adequate awareness of VI issues and differed widely in the quality of their response to issues of visual impairment in their locale. The following quote illustrates one man’s experience of this lack of awareness on the part of council staff:

“I went to the job centre and I told the lady that I was blind and couldn’t see the full application form and they started taking the piss and saying that I couldn’t read or write...” 42 year old male

4.2.1 Impact on children

The impact of parental vision loss on the lives of their children – especially their young children – emerged as a very important finding in this study. Those who had young children clearly had major difficulties in just coping with the day to day support of their children’s educational and social needs.

“I used to do as much as I could with him [son] from what I remember about schools, but schools have changed so much. It was really difficult to keep up with him. My daughter was growing up behind him. They never used to play so when they see certain things at school they grab it by the hands... They play too much. It’s hard...They don’t mix very well...” 39 year old female

“My boy looks stupid because he brings his homework and I am the only one to help him but I can’t see it properly. Every year when he starts a new class I have to go and talk to the teacher...but it doesn’t make a lot of difference.”

46 year old female

For so many of these, mostly mothers, a lack of understanding on the part of the school about the child’s situation meant that many of these children were not getting the educational support that they needed, nor did they have the time to play and fully experience their childhood:

“I tell the school to ring me at any given time if my children are not keeping up with their homework. They failed my middle son for three years in school... A lot of the homework he couldn’t do because I couldn’t help him at all. At that particular point he was also doing a lot at home with me because Adult SS was not helping. The Children’s social worker wasn’t helping my children either... He is fourteen and he probably won’t be able to take exams and things like that because he has missed so much...”

39 year old female

“There needs to be some sort of system to help those who have children in school. Children with visual impairments should be given special attention and so should the ones whose parents are visually impaired.”

46 year old female

Equally evident was the role that some of these young children were playing as carers in support of their parents. In speaking of his sister who was also blind, one participant captured the seriousness of this issue:

“My sister has a fourteen year old son and that little boy is her guide dog. I know that it is a cruel thing to say and it takes a huge chunk out of his life. There are all these organisations that do nothing so that is why we have to rely on family and friends. If we don’t have family and friends where do we go?”

42 year old male

Parents spoke of their children being bullied because of their (i.e. the parent's) disability; and of not being sufficiently supported in class by teachers or through Social Services. They also spoke about ways in which they tried to equip their children to deal with this trauma:

“Whenever a classmate says something about me being blind to my children, they tell them that I do their hair and iron their clothes just like anyone else’s mum.”

39 year old woman

Also amongst the sample interviewed were a few young people in their 20s who had experienced school as blind or partially-sighted African children. Once again, a lack of access to information about the options available – in this case for the child – was a recurring theme. What also emerged was the great need for parental support – both by the school and all other relevant support structures. Clearly some of these parents did not know how to negotiate the formal Special Education Needs (SEN) structures to access the necessary help for their children. One young man’s experience:

“I started to lose my sight when I was at comprehensive school and when that happened, the other kids started to change. I started to get teased and bullied a lot. My school life was suffering because I didn’t want to go to school any more. I tried to tell my mum but she kept telling me that I would be fine... It was so hard and she couldn’t understand it...”

40 year old male

As Guide Dogs current study on the needs of blind and partially-sighted children also reveals, parental education and support is of the utmost importance in responding effectively to children and young people’s needs.⁵ One participant who was himself blind as a child and had an impressive career aptly captured this very important issue:

“When it comes to education you have to have a strong family background. You need to have parents who take an interest in how you are educated”

⁵ Tom Pey, Femi Nzegwu, Gary Dooley, **Functionality and the Needs of Blind and Partially-Sighted People in the UK**, Guide Dogs: Reading, 2007.

4.3 Information

The critical need for information – particularly information about eye condition and rehabilitation – is cogently captured in the words of one participant:

“There is a poverty of information that pervades our community... and this poverty restricts our access to education, to the right services, in fact to our own overall health.”

56 year old male

The “poverty of information” referred to above is illustrated in a number of areas. In the area of prevention/vision health education, this respondent’s reflections demonstrate the point:

“They [hospital] asked me if I had heard of glaucoma and when I said I hadn’t I was given a booklet to take home and read. I have had 8 operations on my eyes to try and correct them but they have not done any good... I was too late.”

70 year old male

Many participants spoke of not having the information to recognise that there was something seriously wrong with their eyes, thus delaying critical and timely action:

“The signs were there but I didn’t know it...Didn’t know my glaucoma was getting worse...”

50 year old male

“It was a depressing story back when my eyes started to get bad. All I wanted to know was what was wrong with my eyes. I kept being told I had all sorts of problems with my eyes. I finally went to a private hospital and they told me I had Retinitis Pigmentosa”

46 year old male

The non-communication of vital information even after a diagnosis had been established was also an issue for a number of people:

“I had problems with my diagnosis. It was done in a very casual way. To date nobody has written me from the

hospital. I came across the diagnosis from the disability assessment officer ...what struck me was the lack of respect...”
41 year old male

One participant's reflections capture the importance of accessing information at the right time:

“It would have helped me to have someone to talk to, to explain my condition and the things that I would still be able to do with the right equipment. It would have helped me face the future. The total lack of information was really an issue for me. I was in total darkness at that stage. I wasn't aware that there were computers that could read for me and things like that. I was looking at it from a perspective that if I can't read or write then I can't work. That was depressing in itself.”

41 year old male

This lack of access to timely information, especially about where to get services and support was evident in every aspect of discussion in all four focus groups. The following reflections illustrate this issue. The first quote is that of a young blind man in his 40s speaking about his older blind sister:

“We are talking about somebody who is not having anybody ring her up to see how she is doing. We are talking about somebody who can just about make out how to get to her phone so that she can make a call. It is easy to say that there is so much out there. When I am registered on a national grid of some kind that I am a blind person then everything that is available to blind people should be made available to me. What would happen if I wasn't capable of getting up and looking for it myself? Where would it come from? This is the situation my sister is in at the moment. If she is not told what she is capable of getting she doesn't get it. What happens to people like her? She could be left in a corner until she dies.”
42 year old male

“When I was registered blind I had to be on the waiting list for about 6 months before I could get someone to visit me from the Council. Those six months were very

hard for me. I couldn't go out and everything just crumbled around me. I lost my independence and everything. There was no contact or information on where to get help. Everything just stood still."

44 year old female

"Accessing information about services is very difficult. Add to that the issue of language differences, lack of access to social workers and you see how huge this problem is.

46 year old female

A member of the group spoke about the need also to access other types of information besides rehabilitation or condition-related information such as local issues and events. Just being able to access and keep up with local issues was seen as very difficult:

"I live in Dagenham and I go to my local library. They have seventeen computers for public use, but not one of them has any screen readers. I don't know where to go to get help to put pressure on them so that I can access one of the computers."

41 year old male

Many people spoke about the social consequences of this type of information exclusion. There was a consensus that the lack of information and consequently lack of opportunity to interact with people of similar backgrounds generated and reinforced the worst perceptions about living with low vision:

"When I was registered blind, I thought I was the only black lady who was registered blind. When you meet people who have the same problem as you, then you can move with them – move on with life."

44 year old female

Equally, people were in no doubt about the benefits of having the appropriate information as this young man's comments demonstrate:

"When I learnt about the technologies that were available, it opened my eyes and made me think that I could do whatever I wanted to do if I had the access."

25 year old male

Apart from a few very knowledgeable individuals on the management committee of the organisation, there was widespread limited knowledge within the group about the scope of available services. For example, very few people knew how to go about getting an assessment of one's needs, how to access low vision clinics, equipment, training, or reading materials. Likewise people did not know the types of support available from SS. Knowing where to access support groups (particularly culture-specific groups expressed by one person as "clubs/places to go where there are shared cultural experiences") was also a problem for a number of people. It is important to bear in mind that many people in this group were educated to a very high standard. The vast majority spoke English as a first or fluent second language. It is possible, therefore, to grasp how potentially serious the situation is for those people who don't speak English or have the wherewithal to go out and find this information.

Access to information **of all types** was a critical need identified in this study. Consequently, while there was a discussion on the lack of availability of appropriate services in all the group discussions (see section 4.4), it was clear that the emphasis was resoundingly on the lack of access to existing information. The group unanimously endorsed the need for the availability of timely, appropriate and accessible information to enable people make informed and empowering choices in their lives.

4.4 Access to services

The experience of access to services differed across the group of people interviewed. 62% (23) of the people present were registered blind or partially-sighted, nevertheless only 69% (16) of these had received services of some sort from their local authority.

Many service recipients spoke about having mobility or independent living skills (ILS) training. Some had been given equipment such as liquid level indicators and magnifiers for their PC. Most of these people spoke positively of their rehabilitation/ social workers and the services they had received. The following are typical:

"I had mobility. The services were very fine. I had a very supportive social worker who introduced me to OBAC."
69 year old female

“I saw a social worker 3 months after I lost my sight in 2002 and I still see one when I need to.”

30 year old female

“I got training on the white cane – it was quite useful. I can go out most times, sometimes I take a taxi.”

40 year old male

“I had someone to the house and they put two stickers on the cooker by the burners. Taught me how to use the cane, how to go up and down stairs and how to cross streets...”

42 year old male

A significant part of the discussions was about mobility. Given the important findings of Guide Dogs functionality study on the important role of a guide dog in facilitating mobility⁶, the community’s perception of the guide dog as mobility aid warrants some discussion. There was one guide dog owner present and one whose sister was on a waiting list for a guide dog. What was clear from the discussions was that very few people had any real understanding of the potential benefits of a guide dog. Many people discussed the limitations of long cane training in facilitating “total, unrestricted mobility” – long cane training often involves learning certain routes and there are obvious limitations to the number of routes that can be learned. The guide dog owner, however, presented an alternative view on mobility – one which suggested the possibility of “free and unfettered mobility”. This was both enlightening and surprising to the group:

“I can do it [go anywhere] with my dog. We don’t have mobility training for everywhere in Britain but I can get anywhere I want as long as I have my dog. I used to be petrified of dogs. When my husband died, I thought I could either have a cane, a dog or stay sat indoors. I didn’t want a cane because I didn’t feel comfortable with one, so I decided I’d have to get used to dogs. I contacted Guide Dogs and because they knew about my fear they used to come and take me to the centre every so often so I could get used to being around different

⁶ Ibid.

sorts of dogs. It took about 2 or 3 years... it was the best decision that I have ever made.” 37 year old female

Amongst many of the assumptions and stereotypes that exist towards many African and Asian descent communities is the belief that dogs, in particular guide dogs, are unacceptable in these communities. The presence of a guide dog owner and one potential GDO on a waiting list challenges this assumption. It further challenges the relevant organisation and professionals to provide these communities with inclusive and accessible information on the huge benefits of guide dog ownership.

A couple of the participants had received counselling services. One member's recollection of the experience was most uplifting for the group:

“Social Services contacted me and talked about counselling. I said I was fine but they told me there was a blind lady who could do the counselling. I opted to meet her. I was very inspired by her. She was partly responsible for giving me the courage to go back to school. That was the first time that I had close contact with someone who was blind and could still work. She could do thing for herself. I became very positive after that.” 41 year old male

And the impact of this service on his life was explained as follows:

“Each time I walked out of the office I felt different and I knew I had someone who understood me. She would sit and chat to me and ask about my personal life. By the time I had talked out my frustrations with her we had achieved something. By the time the session ended I had an action plan to put in place.”

44 year old male

For some people though, the wait to be seen by a social worker was unacceptably long:

“I sat in the house for a year with no rehabilitation or support. The Council provided me with a bleeper for my cups and a cane... [The Charity] showed me how to use

the cane. No regrets about using it because it helped me accept my blindness and stopped me bumping into things.”
69 year old female

Some even reported having undergone registration and yet not having any contact from SS for a decade or more.

Many members of the discussion group spoke about the large numbers of people in their communities without access to any service. These were people who did not have a consultant or were not registered. Non-registration was sometimes out of choice (mostly uninformed) or as a result of a lack of information – they simply did not know why or how to register. As one person put it, “if you don’t have the information, you don’t and won’t know what is possible”.

The lack of access to services for this group of people, whatever their size, was seen as a significant problem by the group.

Great anger was expressed by some people at what they perceived to be the non-responsiveness of Social Services to their needs. The first quote is by a man who had been registered for 9 years but had never been contacted by SS in the entire time.

“I doubt if Social Services knows if I am alive or dead. Social Services are not going to tell you what you are entitled to and what you can get. No one comes to check on us... There are these other charities which also do nothing for us...”
42 year old male

“It takes time, it takes time... but all the discomfort that we have while we wait for things to take place is only felt by us. It is not felt by anyone else. When we bring these issues forward they are talked about by lots of people for years and years. We are suffering discomfort for the entire time that it is being talked about. Where is the evidence of them putting it right?”

38 year old male

“[People] have been talking about these issues for a while so how come we are still here talking about them?”

Nothing is going to get done about them unless we do it ourselves.”

41 year old male

Or from another member:

“We’ve all had a lot of problems with Social Services. I didn’t see a social worker until about a year after I was registered in 1998...If I hadn’t got up and started phoning around to see what I could access I would have been stuck, sitting there feeling sorry for myself. I know that Social Services aren’t helping. You are not the only one. They don’t help you and you have to get up and do it yourself. We have all had to go through the hell of Social Services not being there. Thank goodness for an organisation like OBAC.”

52 year old female

It is clear that while there was a lot of anger expressed by some members of the group, many people who had received services were positive about the experience. Most of the services received were mobility or ILS training, the provision of some equipment and occasionally counselling. What was clear from the discussion was that only a minority of the population receive services even when they are registered. Equally worrying, the views of participants suggest that significant numbers within their communities may not even be known to SS or other service providers.

5 Race and disability

In Guide Dogs' earlier 2003 Lewisham project⁷, the importance of a person-centred approach in providing rehabilitation services for people was highlighted. This was because all the evidence suggested that it is the person rather than their cultural group which is the single most significant factor in delivering services of any kind. While this may appear to be an obvious statement, its application is not always as obvious.

The authors of the report stated that:

“The evidence from this project makes abundantly clear how crucial a person-centred holistic assessment is to an accurate assessment, and subsequently the provision of services wholly appropriate to the individual’s needs. It is the individual and not a presumed ‘cultural group membership’ that should be the focus of a needs assessment. Thus the provision of services must be flexible enough to accommodate individuals whose needs (cultural or otherwise) require some adaptation to the available service.”

This study re-affirms that position. Across the board, participants felt that their blindness or partial-sight rather than their race or cultural group was the more immediate cause of any form of discrimination they had encountered since losing their sight. This was not to negate the very real experience of discrimination based on race, which the group felt they were still subject to. As one participant put it, “racial discrimination is a fact of life.” Rather, the group wanted to focus the minds of policy makers on the fact that services should be made **universally accessible** and targeted at everyone, taking into consideration their particular circumstances, rather than targeting a group of people based on a set of assumptions about the “need of the group”. Consequently, promoting inclusive, accessible and appropriate services should be the focus of any policy designed to improve access.

⁷ Madge and Nzegwu, *The Guide Dogs/Lewisham SSU Project*

6. What people felt they needed most when they found out they were losing their sight

“Support”, in a multiplicity of ways, was the recurring theme when people were asked what they felt they needed most when they began to lose their sight. This support was in the form of information, “a listening ear”, reassurance that life could continue to be accessed and lived fully, and support for family members.

“There was nobody to support me after having my operations. If I had had support before any operations or treatments it might have helped me to take the first steps towards accepting it.” 65 year old female

“Help and support” 59 year old female

“Shared experiences can be very helpful. Sometimes I go to the RNIB website and I read a lot of things. It’s important to access information...” 39 year old male

It is in the articulation of the need for such vital support that the crucial role of organisations such as OBAC to people’s lives becomes apparent.

6.1 The Role of support organisations such as OBAC

It is important to emphasise the critical role of support organisations such as OBAC. This study would be incomplete if we did not mention the spontaneous praise for the organisation which we observed during the interviews and the natural camaraderie that existed amongst the members. Repeatedly throughout the discussions, it was clear that OBAC had played an important role in the “rehabilitation”, and in the “movement forward” of the lives of so many of those present. Typical of the comments made were:

“Bless OBAC because it brings me out. I was really under but then I came here and I was taught how to use the computer and other little things. From then on my feet were set on the path to overcome situations.”
69 year old female

“OBAC has been very, very supportive. The organisation is very good and they are behind me 100%. I am grateful for that.”

59 year old female

“It has taken me nearly two and a half years to come to OBAC. Coming to OBAC has helped me a lot and I am learning that you have to get on and do things.”

46 year old female

“I don’t cope with being blind very well, but when I come to OBAC I see my own black people who have visual impairments and that is not something you see very often. I have learnt about others and to accept that sometimes you have to move on from just being angry and blind.”

39 year old female

“Coming to OBAC helps a lot because you meet other people like yourself. It helps me a lot...”

55 year old male

But while interaction in a culture-friendly environment was obviously important to all participants, the types of services and activities available within that environment were as important. The following experience illustrates:

“My social worker took me to a day centre on my birthday. The youngest person there was eighty six. I tried to talk to them but some of them were prejudiced because I was black. I felt frustrated with that... when I told them that I wasn’t going back to the day centre because it was depressing, I got another place where there were more black elders. I found there was nothing really going on. Some of them were my age or younger but they had no stimulation...Thankfully, I eventually managed to get to OBAC.”

69 year old female

In addition to the therapeutic and safe environment provided by OBAC, it also plays a very practical and empowering role, such as assisting in the procurement of equipment or services for people, or just in giving people a place to go “on their own” – in other words facilitating independent mobility and individual space. For

many people OBAC was a vital connection point to other critical services when it was needed.

“OBAC connected me to Guide Dogs who gave me training. It was arranged with my social workers.

53 year old male

“Before OBAC I was lost and I just didn’t know where to go. When I came here they helped me get a computer and CCTV.”

55 year old female

“I started coming to OBAC and learning IT and I really enjoyed it. Everyone was nice and friendly. Sometimes I would have down days in the computer classes but then I would perk up and go on.”

60 year old male

“My daughter found out about this place [OBAC] for me. I am very fortunate because it gives me a chance to get out of the house and do things for myself.”

74 year old male

“Before I came for my training [at OBAC] my life was hell...”

49 year old female

The important role of organisations such as OBAC that provide vitally needed services or referrals to these services within a culturally supportive and comfortable environment cannot be sufficiently emphasised. For so many people, finding OBAC was tantamount to being thrown a lifeline. Not only did they find the information they needed to access the services required, they also found supportive and empowering friends. The combination constitutes a powerful addition to any package of rehabilitation services aimed at any group of people.

7 Hopes and prospects for the future

Across the four focus groups and for the vast majority of the people present there was a pervading air of optimism about their future, expressed by one participant as follows:

“I don’t see any reason why you should give up on life because it [blindness or partial-sight] is not the end of the world.”

69 year old female

This optimism was clearly predicated on a sense of self-reliance that was evident in so many of the participants. The majority of people present at the discussion groups felt it was ultimately, largely, up to them to cope with the impact of their blindness on their lives as best as they could. That there were so few support structures – statutory or charitable – responding to their needs made this self-reliance all the more urgent. The quotes below capture this sentiment succinctly:

“I have developed no expectations from people. You have to make an effort yourself.”

36 year old male

“The only thing I can say to people is that you have to help yourself... In the whole area of disability you are more or less left to fend for yourself. I always try to encourage members to strive and do stuff for themselves. At the end of the day, your ability to cope is down to you...”

55 year old male

People wanted “simple things” like their independence and access to basic services to enable them continue their lives:

“My main hope is to be independent and to be able to do things for myself. I want to be able to go around the streets and not look like I am afraid.”

74 year old male

“All I want is to be independent. I might be visually impaired but the brain is still working and I want to carry on with life.”

30 year old female

One young man's reflections on what could be accomplished with energy and effort were inspirational for other members, especially the younger members of the group:

“I came to OBAC and got the energy to go out and do something... I have gained back a lot of my confidence. I believe that hard work will get you what you need to get. But there's a big fight when it comes to visually impaired people... I believe it comes from inside. If you believe that you can do it then you can.”

25 year old male

While it is important and indeed gratifying to identify so many people who are actively pursuing their own rehabilitation in spite of limited services available to them, it is undoubtedly unacceptable that so many individuals are left without the support or services to which they are entitled.

8 Conclusions and recommendations

Too often the needs of minority populations in the UK are presented and discussed as if they differ significantly from “mainstream needs” – that is the needs of everyone else. In reality the needs of members of minority communities are no different from everyone else’s needs – they include the need for information that enables informed choice, the need for independent living, the need for continuing employment, the need for dignity and respect in the face of what is often a major traumatic life event. Rather, it is the response to these needs which differ from what is available to “mainstream society”. Indeed it is the method by which access to the requisite services is enabled for these population groups that has always been and remains the central issue. Facilitating this access is the challenge that requires innovative thought, flexibility, adaptation where called for and commitment.

Simply put, the main issues of this African descent population include their lack of information – in all aspects, including preventative, rehabilitative and general information; the paucity of essential services to this population group; and the need to identify potentially registrable, probably isolated people unknown to the “system”.

The groups unanimously rejected the development of policies “for” or “on behalf of them”. They called for consultation and full involvement in any initiative designed to bring about greater inclusion for blind and partially-sighted people from minority populations.

Eight recommendations follow from these findings:

1. Improving access to information

Improving access to information about the services available to blind and partially-sighted people as well as local community-specific information emerged as one of the most important areas of support required. Access to information implies information presented in language that is easily comprehensible and fully inclusive. Inclusive language means that the “language” of service provision is couched in a framework of values to which the individual client/user subscribes. One of the major findings of this study was the degree to which participants were unaware of the services available. There was clearly a near total lack of awareness of the variety of services that could have been used to

enhance their quality of life. Individuals had no idea whatsoever what to expect from Social Services in the way of service provision, and sadly did not entertain any expectations of SS whatsoever. Yet, it was clear that people who had received services valued them and those who hadn't expressed an interest once these services were identified. A mechanism is required to enable service providers to seriously engage with and respond to the concerns of the communities they are mandated to serve.

2. Identifying registrable people within minority communities through widening the scope of outreach work

Many of the participants who attended the focus groups could readily identify people in their communities whose eye conditions were comparable or more serious than theirs. Yet, these individuals were not registered, nor were they in regular contact with ophthalmic or other services. It would appear, based on this evidence, that there could be a significant number of registrable people with little access to any support or help. The scope of this problem needs urgent investigation. Instituting outreach work, particularly targeting areas of community gathering, like churches, might begin to reveal the extent of need. Indeed the Guide Dogs/Lewisham project found that contact and interaction with the community was a fundamental prerequisite for building bridges of communication and co-operation with its service users. It is therefore essential that the scope of outreach work within Local Authorities be broadened to ensure on-going contact with the constituent groups within the community.

3. Active recruitment of staff from national minority populations

Responding effectively to the diverse populations that currently define local communities will require the participation of these communities – particularly through consultation with them on how best services can be provided to reach those most in need. Engagement will be most effective when both users and professionals from these communities are involved. This implies that Local Governments and charities in the sector should be reflective of the populations they serve, thereby incorporating the culture and relevant philosophical constructs of users into their entire approach to service delivery. Currently, very few establishments reflect these diverse staffing patterns. There is perhaps no greater way for the spread of information and advice

within a community than to engage its members as staff in the delivery of the service.

4. Training for rehabilitation workers

It is clear that an institutional commitment to improve access for all groups requires the provision of continuous and improved training for its rehabilitation workers. Specifically, the training would include improving the capacities of rehabilitation workers to deliver services based entirely on the individual's identified needs (adopting the philosophy that the user is their own best expert) and avoiding often erroneous assumptions of some professionals about the impact of a person's race, culture, religion or other attributes on their capacity or desire to use rehabilitation services.

5. Conducting research

There is very little research on blind and partially-sighted people from minority populations in the UK. In virtually every vision-related sphere imaginable, the need for quality research is apparent. Two areas in particular are important to highlight. First, research is needed to determine how to best and through which channels vital information can be made more inclusive and readily accessible to minority groups. Second, research into the prevalence, of blindness/partial-sight, including condition-specific prevalence rates, are clearly needed to enable any real long-term planning for the provision of services to these and other population groups.

6. Employer-targeted education

Many people lost their employment as a result of their loss of sight. There is no doubt as to the devastating impact which the loss of employment created for these individuals and their families. People seemed able to cope better with the potential disability, if they could have been enabled to retain their employment. The need for employer-targeted education is clearly indicated in this study and supported by other national studies on the subject.

7. Support to blind or partially-sighted parents of sighted children and to children of blind or partially-sighted parents.

The need for support to blind and partially-sighted parents of sighted children with no disabilities and to the children themselves is clearly indicated in this study. Services, where they exist, are

often directed at the person with the disability (adult or child) with little attention being given to the significant others in the individual's life. In the words of one parent, "children with VI should be give special attention and so should the ones whose parents are visually impaired."

8. Support to OBAC and similar organisations

OBAC and similar such organisations need to be supported to expand their capacities to deliver to an even greater number of users and to broaden the range of services to these users. The critical role of organisations such as OBAC cannot be overstated. Minimally, OBAC provides a humanising environment that enables therapeutic engagement. But it does so much more than that – it delivers practical solutions and reintroduces hope and purpose into many lives.

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Too often the needs of minority populations in the UK are presented and discussed as if they differ significantly from “mainstream needs” – that is the needs of everyone else. In reality, the needs of members of minority communities are no different from everyone else’s needs – they include the need for information that enables informed choice, the need for independent living, the need for continuing employment, the need for dignity and respect in the face of what is often a major traumatic life event. What does differ in the case of minority populations is the response to these needs even when they are no different to those exhibited in “mainstream society”. Indeed, it is the method by which access to the requisite services is enabled for these population groups that has always been and remains the central issue. This is the important finding of this study.



Guide Dogs