

Good Practice Guide

Supporting deafblind people from BME communities



DEAFBLIND
·UK·

Contents

02	Introduction
03 → 04	What is Deafblindness?
05	What approaches worked? • What did not work?
06	What should you be aware of?
06 → 07	Project Management and Planning
07 → 08	Ethnic Groups • Single Sensory Groups
09	Combined Sight and Hearing Loss Groups
10 → 11	Thematic recommendations • How did we make a difference?
12	What Next
13	Top Ten Tips
14	Other Initiatives
15	Useful Organisations

Introduction & Background

These guidelines are the culmination of a project undertaken by Deafblind UK over the past 3 years. The Project was envisaged following an analysis of our membership and a realisation within the organisation that our membership was not representative of UK society as a whole. Deafblind UK is governed by deafblind people at Board level and it was apparent that Black Minority Ethnic (BME) deafblind people were also under-represented on our Board of Directors.

In 2003 having identified that we were not fully representative we set about developing two projects, one focused on London and the other with a national remit. The projects focused on identifying BME deafblind people, their carers and families as well as community organisations who work with BME people. This meant we could talk about the benefits and advantages people from a BME background could experience through joining Deafblind UK if they have a combined sight and hearing loss.

In parallel to working with BME communities we also worked with our staff and volunteers offering training and support for frontline staff. Ensuring that levels of awareness were appropriate and that we ensured a good standard of support to existing and future members from BME communities.

The purpose of this Good Practice Guide is to share the successes of the project, and for others seeking to undertake similar pieces of work to highlight activities which have worked well and led to positive and sustainable outcomes. Equally important we have highlighted areas of organisational learning where our approach did not work as well as we had hoped or where through evaluation we feel we could have improved our outcomes and benefits had we adopted a different approach. The purpose of outlining our learning is to help others to target resources in the best way to promote quality services to people with a combined sight and hearing loss from BME communities.

What is Deafblindness & Section 7 Guidance & how many people from BME Communities are deafblind?

In 2001 the Government launched guidance under Section 7 of the Local Authority Social Services Act 1970; which formally recognised that deafblind people required specialist services to meet their unique needs. The guidance provides the working definition of deafblindness, 'people are regarded as deafblind if their combined sight and hearing impairment causes difficulties with communication, access to information and mobility'. In 2006 the Section 7 guidance was cancelled and became recognised best practice, this is normal practice for legal guidance. 'The DH reviewed and reissued the guidance on 23rd June 2009, and now includes people with progressive sight and hearing loss. In essence the section 7 guidance places a responsibility on Local Authorities to:

- identify, make contact with and keep a record of deafblind people in their catchment area (including those who have multiple disabilities including dual sensory impairment);
- ensure that when an assessment is required or requested, it is carried out by a specifically trained person/team, equipped to assess the needs of a deafblind person – in particular assess the need for one-to-one human contact, assistive technology and rehabilitation;
- ensure that services provided to deafblind people are appropriate, recognising that they may not necessarily be able to benefit from

mainstream services or those services aimed primarily at blind people or deaf people who are able to rely on their other senses;

- ensure they are able to access specifically trained one-to-one support workers for those people they assess as requiring one;
- provide information about services in formats and methods that are accessible to deafblind people; and
- ensure that one member of the senior management team includes within his/her responsibilities, overall responsibility for deafblind services

There is a lack of data which accurately defines the numbers of deafblind people in the UK. However, Sense through reviewing previous research have estimated (Sense 2008) that there are 242,000 deafblind children and adults in the UK i.e. 400 per 100,000 population. The demographic composition of this group is as follows:

- The number of deafblind children under 18 is estimated as 4000
- The number of deafblind adults aged between 18 & 74 is estimated at 24,000
- The number of deafblind adults aged 75+ is estimated at 214,000

Whilst these figures are estimates they indicate with an ageing population in the UK that the numbers of people who are deafblind will increase year upon year.





The last census revealed that the percentage of BME communities in the UK was 9%. Using the estimates relating to the prevalence of deafblindness in the UK we can estimate that there are circa 22,000 people within BME communities that are deafblind or have a progressive sight and hearing loss.

It is well documented that BME communities are less likely to come forward to access services and information or report issues of concern. Those who justify this under-use, by making assumptions about the reliance of people from minority ethnic groups on family support and informal caring, ignore the evidence from potential service users: which describes prejudice, discrimination, distrust and a lack of appropriate services (Grewal and Lloyd, 2002; Mclean et al, 2003).

In addition it is also recognised that ethnic minorities across all ages, particularly South Asian communities are more likely to experience poorer general health (Department of Health, 1999). With a higher risk of particular conditions such as heart disease, stroke and diabetes caused by generally lower levels of physical activity, diet and lifestyle choices and a genetic predisposition. Some of these medical conditions have associated implications for sight and hearing loss. In general, life expectancy has

increased yet disparities still exist between some ethnic groups which experience poorer health, outcomes and access.

People from BME communities, are less likely to access services than other parts of society. This leads to a significant risk that deafblind people within these communities experience double discrimination, caused by their disability, ethnicity and cultural identity.

This guidance document seeks to begin to identify how these barriers can be overcome, and enhance the opportunities for deafblind people from BME communities to access services that are culturally and individually tailored and thus enabling people so they can live independent lives.

This guide identifies elements of good practice, which could be implemented in the voluntary sector, providing short cuts to beneficial approaches to ultimately develop improvements for BME people with a sight and hearing loss.

To recognise good practice we have found it useful to break the subject area into a number of strands:
- Overall Approaches, Project Management and Planning, Ethnic Groups, Single Sensory Groups and Combined Sight and Hearing Loss Groups.

Overall Approaches

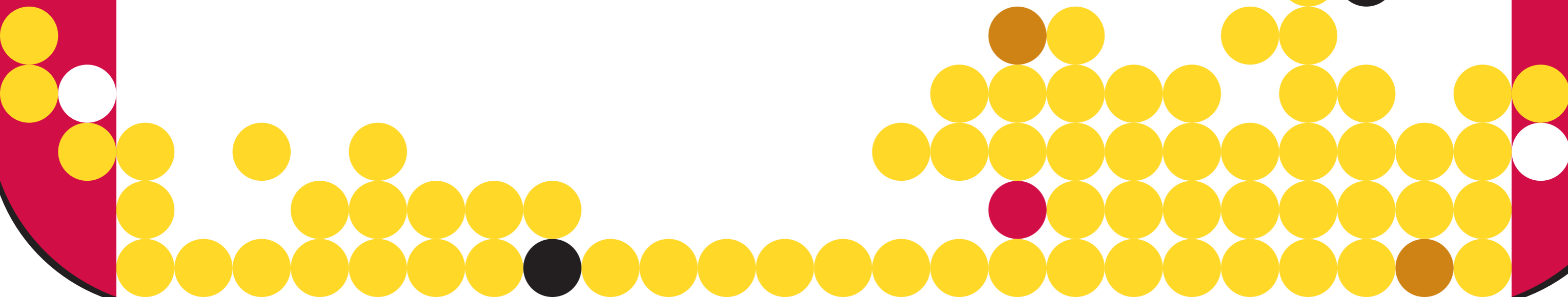
What approaches worked?

- Community outreach to develop links in the community and with voluntary groups
- Attendance at events, for example, the Global Peace and Unity event, presence at health awareness days alongside other voluntary organisations and information days at community venues. Raising the profile of Deafblind UK and the services we can provide to deafblind people and people with combined sight and hearing loss
- Producing basic information in community languages to reach an older audience whose first language is not English
- Providing free deafblind awareness training to the statutory sector and healthcare services which has been very well received
- Mainstreaming our learning and embedding it into our organisational practices - for example, including cultural awareness training for new staff and as part of the training provided for external organisations. We also record the ethnicity of members

- Identifying 'hidden' carers through our deafblind awareness talks, many have been family members who would not identify themselves as carers. They can then be offered support they are entitled to but would not have been previously accessing

What did not work?

- Assuming that community and voluntary groups will outreach for awareness sessions – the sessions need to be offered individually
- Offering free deafblind awareness training for volunteers – interest levels have been low despite advertising through volunteer bureaux and CVS
- Interest in formal volunteering opportunities at BME events – this has not generated a high level of interest
- Changes in project staff and management - although this has drawn in a variety of skills which has been very positive this has also meant that there have been different staff working on the project at different stages



What should you be aware of?

- Some deafblind people may also be living with additional complex conditions, especially those more prevalent amongst BME groups e.g. diabetes, stroke and heart disease. These need to be recognised and considered when providing accessible services and support
- There are examples of single sensory initiatives with deaf or blind people, these could be adapted to address the needs of deafblind people
- The needs of deafblind people and BME deafblind people are very similar, but sometimes a culturally specific approach is needed to respond appropriately as demonstrated in our case studies
- BME groups are not homogenous, there is often diversity within diverse groups, and this needs to be acknowledged
- Project staff need to be culturally aware, and understand the cultural or religious issues which may affect their clients
- Collect examples of good practice from similar ethnic groups to make people from the community aware of the benefits of accessing support. Raising awareness of what is possible within their cultural group can promote the uptake of support and services
- BME groups are poorer at accessing services and support that they are entitled to, and quite often face double discrimination if they also have a disability
- Be aware of the stereotypes and preconceived ideas that you may hold about BME communities, these could hinder appropriate service development

Project Management and Planning

Although not directly part of the project work focus, management of any project and its initial planning is an essential element to ensure success. We therefore list, as a reminder, some of the key factors you will need to consider on any project you may instigate. These are by no means exhaustive and you are advised to consult with your planning experts for further advice:-

- Develop a clear project plan with defined aims and objectives
- All outcomes/deliverables and success criteria, should be identified
- Potential risks should be identified and mitigating solutions agreed
- The plan should have a realistic

time scale, with review points and milestones

- Outcomes should be measurable and agreed by stakeholders
- Set realistic goals
- Aim for a lasting legacy, therefore incorporate sustainability at the beginning of the project rather than as an afterthought
- Ensure clear budget responsibility and regular actual versus planned budget reporting
- Each project should have a defined spend profile. Track all over and under spend
- Revisit the aims and objectives

Ethnic Groups

- Ethnic groups are not homogeneous there is diversity within diversity, this needs to be recognised when planning initiatives and setting up projects
- Be aware of the stereotypes and preconceived ideas that you may hold about ethnic groups. Work to understand what their needs are, rather than imposing ideas, in particular be aware of cultural issues, customs and beliefs
- Be open minded and strive for agreement between all parties
- Identify and build relationships with community leaders/ champions/advocates and work

frequently to ensure you are meeting the desired criteria and objectives

- Set up effective ways of recording data e.g. databases, tables, spreadsheets to facilitate reporting, bear in mind any requirement to report to funders
- Be clear about what data you are collecting, why you are collecting it and what you will do with it
- Schedule regular supervision meetings and record actions to be taken with timescales
- Do not work in isolation, establish at the outset to whom, how and when you will report progress

with them to raise awareness and build relationships within their community, they already have a rapport with that community

- Involve community groups through consultation and identify who you are reaching out to and groups you are not
- Translating materials into community languages for BME deafblind people may not always be a successful method of communicating information. This is a complex area, and you may need to communicate using a variety of methods, to meet communication preferences

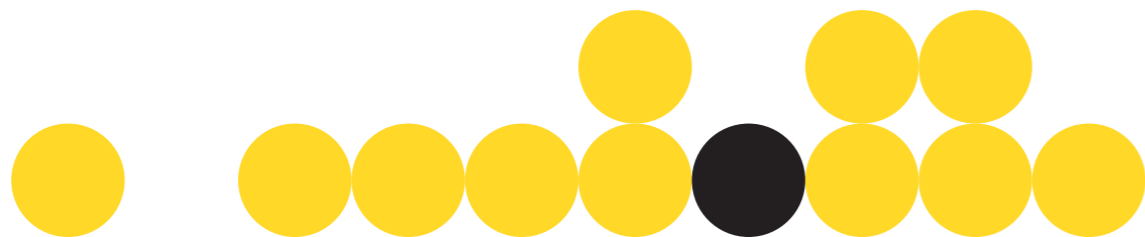




- Reach out to people in their own environments rather than expect them to come to you, for example places of worship, lunch clubs, deaf clubs, GP surgeries, libraries, residential homes
- Try advertising in a wide variety of media to reach a diverse audience, such as:
 - Local community radio** - Club Asia, Sunrise Radio, Punjab Radio
 - TV** - Sony TV, TV Asia, Community Channel, Zee TV
 - Text** - newsletters, free local
 - Press** - Pink Press, Asian Voice, Irish Times, Urdu Times
- Some BME communities may be unfamiliar about referral processes which can mean that self-referral is less likely to happen
- Social exclusion, geographical isolation and transport difficulties

Single Sensory Groups

- Provide clear information in a range of formats (Braille, large print, tape, audio cd's and email). Information and Advice helplines and interpreters are also important
- Respect and record each person's preferred method of communication (lip reading, British Sign Language, etc). Then communicate with them using their preferred method
- Disseminating information through community TV channels - Sony TV, TV Asia, the Community Channel, Zee TV which are widely accessed can increase awareness of vision or hearing loss issues
- Frequently used documents should be made available in large print and relevant local community languages if appropriate, for example healthcare appointment letters and information sheets
- Link into single sensory organisations such as the Royal National Institute for the Blind and the Royal National Institute for the Deaf and other associated organisations and support networks
- Link into single sensory groups depending on the nature of the project



can make access difficult

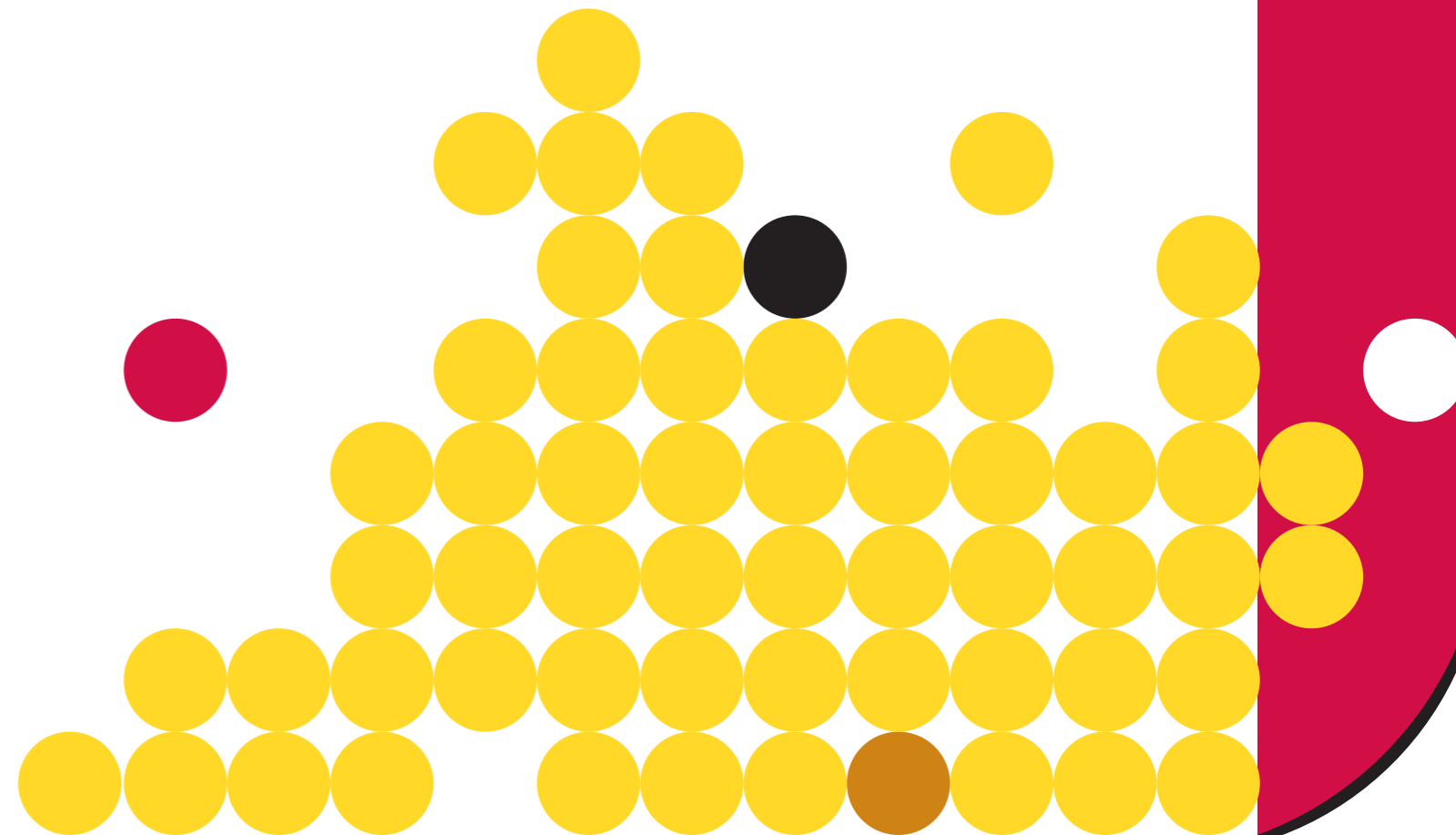
- When planning events, meetings, community activities or awareness raising sessions, be mindful of religious festivals as they can be a great way of the community coming together, enabling you to reach a wider audience, but it can also be a time where the community are observing religious rituals and intervention may not be appropriate. A SHAP calendar can provide you with a list of religious events
- Carry out adequate research before the project takes place, for example face to face interviews, or communication with focus groups which can guide you to achieve good service delivery and make you present to what the community wants

Combined Sight and Hearing Loss Groups

- Voluntary and community organisations can offer a range of support including communicator guides, interpreters, practical help, benefits advice, advocacy, befriending, housing advice and independent living teams (ILTs)
- Health and Care organisations should actively seek information about what support voluntary and community organisations provide in their local area. Then identify how they can support people with both vision and hearing loss
- Empowering people with combined sight and hearing loss will enable them to access support that they are entitled to, and help maintain independence
- Promoting the services that voluntary and community organisations can provide will enable local authorities, social services and members of sensory

teams to have a clearer idea of what they can offer to clients that are referred to them with dual sensory loss. This will enhance better cross working partnerships. However, you need to be clear about what services are being offered for them to be promoted

- Having a named contact to work with, within the voluntary sector, enhances a better working relationship when referring clients from local authorities who have dual sensory loss. This helps promote awareness of legislation and obligations, and also determines focus
- Consider what other organisations are doing and look at ways of working together, for example volunteer training, and recognise that it may not always be appropriate to be the 'lead' partner



Thematic Recommendations

Planning and development

- All planning and development for services must engage BME people who are deafblind and their carers. This will ensure their views are reflected in the planning process throughout

Needs assessment and record keeping

- Needs assessment at a macro level should be done using available statistics to ascertain the size and location of BME people who are deafblind to enable effective targeting
- Mechanisms for keeping up-to-date with the changing nature of communities and their needs must be developed and exploited. Needs surveys should record and analyse ethnicity and disability

Information dissemination

- While accessible information may mean producing leaflets in different ethnic languages to target BME communities as whole, at a personal level, it is more about providing workers and advocates with the necessary community and sign language skills to engage BME deafblind people
- Examples of better or good practice and innovative strategies in making information accessible should be shared within and across organisations

Cultural competence

- All staff involved in assessing needs should be provided with guidance and training on how to accurately identify them and come

to a shared understanding of the support needs of BME deafblind people. This should ensure that assessment is holistic, needs-led, timely, appropriate to the level of need, engages BME deafblind people and their carers and takes into consideration cultural and religious issues that may prevent access

Access to and provision of services

- Competent sign language and community language interpreting services need to be provided in a systematic fashion to help access services at all levels
- Keeping abreast of technical advances in techniques and equipment, relevant to hearing and sight loss, will encourage access and promote greater independence of deafblind people and those with combined sight and hearing loss
- Best practice in the development and delivery of advocacy services needs to be implemented. A priority is ensuring that supporting BME disabled and D/deaf people is seen as a requirement for all advocacy providers
- Consistency of services must be maintained at all times to gain the confidence of BME deafblind people and their carers
- If cross referrals to other agencies are required, care needs to be taken to ensure BME deafblind people move seamlessly from one service to another with consistent levels of support and empowerment

Partnerships with Voluntary/ independent sector

- Statutory sector organisations should work with voluntary/ independent sector specialists who are often more flexible in providing a range of support for BME deafblind people. These can range from:- English as a second language (ESL) and sign language classes for carers, social and emotional support through volunteers and peers, and translated information and interpreting services

- Statutory sector organisations should consider offering direct financial support to volunteer/ independent sector specialists or direct payment to clients per se
- Partnerships should be fully defined and service standards agreed by all partners so that there is a clear understanding of what services are to be provided and by whom

How did we make a difference?

The following case study examples demonstrate how this work has provided support to individual deafblind or combined sight and hearing loss BME people to access much needed information and services.

Case 1

R.G. a young woman from Pakistan has Usher Syndrome Type 1. R.G. loves socialising and attends a local Deaf Project where she gets support and help in a signing environment. Whilst R.G. travels independently, her balance is unstable and she becomes anxious in the evenings as she suffers with night blindness, resulting in a number of injuries. She refuses to use a cane as she is embarrassed to do so. She has established a link to a deafblind subculture who

embrace her as being a Deaf BSL user as opposed to a deafblind Asian woman.

Resolution: the Project Officer needed to understand and respect this 'culture' which the member valued, and was then able to advocate on behalf of R.G. so that she had the necessary mobility training in place and could be referred for services from a communicator guide.



Case 2

S.A. is a 34 year old woman, English born with family from Kashmir, and has Usher type 2. This means she has a very limited visual field and a hearing loss. Through religious and custom practice her family ignored her deafblindness and support needs, perceiving her disability as a curse due to a sinful act that someone

in her family may have committed generations ago.

Resolution: Working with the Project Officer has enabled S.A. to feel sufficiently confident to identify and access services and equipment herself. She now wears a hearing aid consistently.

Case 3

F.A. a 20 year old young English woman, with a mother from Iran and a father from India, suffered a brain haemorrhage at a young age leaving her with loss in her left visual field and partial hearing. She experienced a range of problems whilst trying to undertake a University course, including difficulties with accommodation and theft of specialised cooking equipment. These experiences had a negative impact on her wellbeing; she lost weight and felt both physically and emotionally ill,

to the extent that she was unable to continue with her studies.

Resolution: The Project Officer provided F.A. with information and advice on how she could move to private accommodation and she put her in touch with Social Services to ensure she was able to access the appropriate benefits, as her status changed from student to job seeker. Now F.A. continues to receive support from the Local Authority and the Project Officer.

What next?

There is an immense amount of initiative and inspiring work, demonstrating good practice but we have found a lack of integration of single projects into mainstream work. We have also identified a significant amount of re-invention particularly when it comes to identification of barriers for BME people. In our view if real progress and improvements are to be gained then we will need to move onto "higher ground" and establish principles of good practice and integrate them into our mainstream

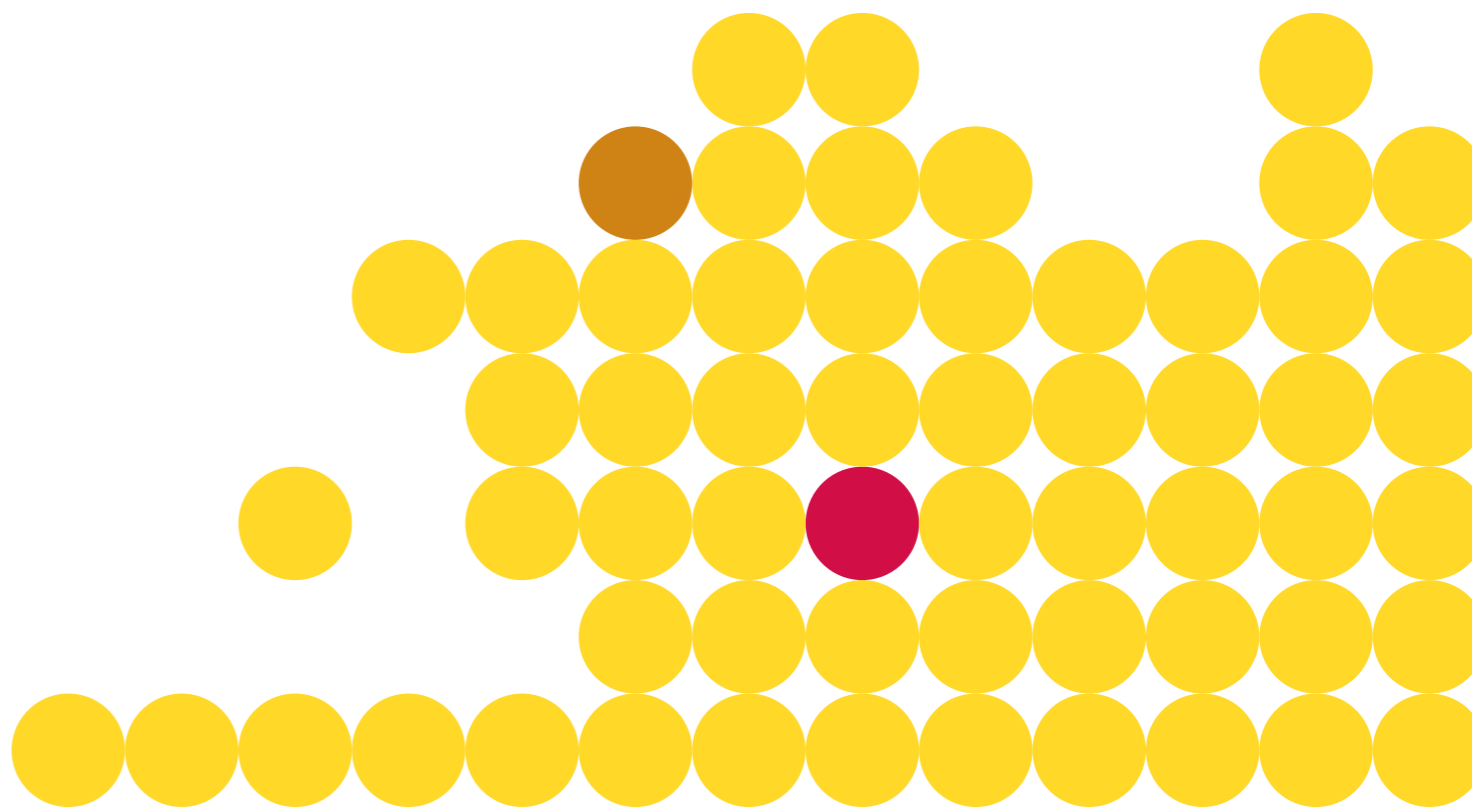
work as well as our thinking.

From the work Deafblind UK has undertaken in this field we have identified essential elements of good practice and within this set of essential elements there are in our view two fundamental issues that cannot be ignored; sustainability and integration. These issues should be the watch words of any project that purports to create a lasting impression on any field of work and within any organisation.

Top ten tips

We have put together the following tips as a guide and hope you will find them useful when setting up your own projects

1. Consider and put in place how you will monitor, evaluate and collect data at the outset of the Project
2. Define who is responsible for the care of the client, particularly if they have complex needs, as this can be unclear and should be defined at the outset
3. Be aware that although the needs of BME deafblind people and deafblind people may be the same, the solutions to address such needs may be different
4. Be clear about the reporting requirements of the funder. Plan and record in advance to maintain continued funding
5. Forecast the activities and estimated expenditure on a regular basis, this ensures that there is sufficient funding in the budget allocation
6. Revisit the aims/objectives of the project periodically to ensure you are achieving your set outcomes and goals
7. Identify any gaps in the training needs of staff/volunteers/support people and carers
8. Ethnic minorities are not a homogenous group, be aware of ethnic differences, for example religion, language and customs
9. When applying for funding be clear that there will be overlap between the project objectives and organisational objectives
10. Research what already exists in terms of good practice, which could be adapted to target groups you are trying to reach, and then build on it. Don't try to reinvent the wheel!



What other initiatives have supported people with vision and hearing loss?

The following are examples of some of the initiatives that we came across during our research. Some have now completed their work but demonstrate the kind of initiatives that could be adapted to support people with vision and hearing loss.

National Deaf Children's Society, Glasgow

A two year project supporting BME families with deaf children. Volunteers who are parents of deaf children themselves support parents by providing them with advocacy, emotional support and accompanying them to initial audiology appointments and school reviews. The volunteers are multilingual and can therefore provide communication support. Parents are offered English as a second language (ESOL) alongside sign language classes. They can attend coffee mornings, where they can access information about speech and language therapy or have opportunities to network with other parents and go on trips and outings.

Varshali.swadi@ndcs.org.uk

Dekhtay Chai

Based in Tower Hamlets, Dekhtay Chai is a voluntary organisation that largely supports the Bengali community by providing information and support for BME people with visual impairments. It offers a wide range of information assisting people to take up services to which they are entitled such as, Freedom Passes, benefits advice and TV licences. This initiative has helped to increase the take up of services.

m.anam@btinternet.com
0207 790 1980

Deafblind UK BME Project

This project is specifically targeting people from BME communities

with combined sight and hearing loss, Deafblindness and older people because Deafblindness is more prevalent in old age. Our project has successfully worked to identify hidden people through our outreach activities and our presence at cultural events. Our work has also created greater levels of deafblind awareness amongst BME communities and groups. People have benefited from greater access to healthcare services, and referrals to other agencies providing support. We have also produced some basic information leaflets and bookmarks in six BME languages (Bengali, Gujarati, Cantonese, Hindi, Urdu and Punjabi).

Manveet.patel@deafblind.org.uk
07940 872 789

Directory of services for people with visual impairment

This directory has been put together by the London Borough of Tower Hamlets Low Vision Services Committee to provide health care professionals with information about the services available across the borough for people with vision loss, and encourages them to access them. The directory lists local services, employment services, transport, voluntary organisations, NHS and local authority services that the visually impaired person may find useful.

Barbara.disney@towerhamlets.gov.uk
0207 364 2025

Champion volunteers in Derbyshire Association for the Blind (DAB)

Four 'champion volunteers' from the BME community were recruited and trained to become expert volunteers. They have delivered talks, disseminated information and

supported people to understand vision services and conditions of the eye. The volunteers have also worked with DAB to further improve its work with BME communities.

vip@dab.org.uk
01332 292 262

Useful Organisations

Deafblind UK

The National Centre for Deafblindness
John and Lucille van Geest Place
Cygnet road, Hampton,
Peterborough, PE7 8FD
info@deafblind.org.uk
Voice/text: 01733 358 100
Free Helpline 0800 132 320

Sense

101 Pentonville Road
London, N1 9LG
info@sense.org.uk
Tel: 0845 127 0060
Text: 0845 127 0062

Royal National Institute of Blind People

105 Judd Street
London
WC1H 9NE
0207 388 1266
www.rnib.org.uk

Royal National Institute of Deaf People

19-23 Featherstone Street
London, EC1Y 8SL
Tel: 0207 296 8000
Text: 0207 296 8001
www.rnid.org.uk

Jewish Deaf Association

Julius Newman House

Woodside Park Road
Off High Road
North Finchley
London N12 8RP
0208 446 0502 (voice)
0208 446 4037 (text)
mail@jda.dircon.co.uk

London Ethnic Minorities Deaf Association

Stratford Advice Arcade
107-109 The Grove
Stratford
London
E15 1HP
0208 522 1842
lemda@lemda.org.uk

Waltham Forest Blind Association

30 Zenith House
210 Church Street
Leyton
London
E10 7JQ
0208 558 0355
walthamforest_ba@yahoo.co.uk

Organisation of Blind African Caribbean's

1st Floor, Gloucester House
Camberwell New Road
London
SE5 0TA
Tel: 0207 735 3400
Web: www.obac.org.uk

About Deafblind UK

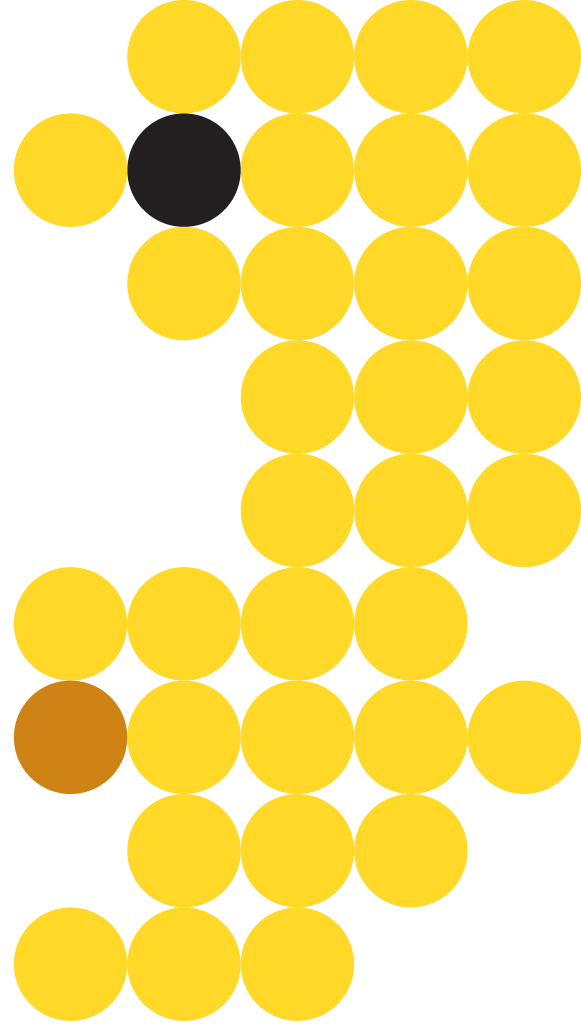
Who we are

Deafblind UK is a national charity offering specialist services and human support to deafblind people and those who have progressive sight and hearing loss acquired throughout their lives.

Our aim is to enable people living with this unique disability to maintain their independence, quality of life and reduce the isolation Deafblindness creates.

What we do

We achieve this through campaigning, education, the provision of practical and emotional support via independent living teams and a free Information and Advice Line.



References

- Department of Health (1999) Saving Lives: Our Healthier Nation. White Paper
- Grewal, I. and Lloyd, K (2002) 'Use of services' in O'Connor, W. and Nazroo, J. (eds) Ethnic Differences in Context and Experience of Psychiatric Illness: A qualitative study, London: The Stationary Office.
- Mclean, C., Campbell, C. and Cornish, F. (2003) 'African- Caribbean interactions with mental health services in the UK: experiences and expectations of exclusion as (re)productive of health inequalities', Social Science and Medicine, 56, pp. 657-69.
- www.sense.org.uk/about_us/five_year_strategy/deafblind_population.htm

Contact us

Deafblind UK, National Centre for Deafblindness,
John and Lucille van Geest Place, Cygnet Road,
Hampton, Peterborough, PE7 8FD

Tel/Textphone: 01733 358 100
Fax: 01733 358 356
email: info@deafblind.org.uk
www.deafblind.org.uk

Registered Charity No: 802976
Company Reg No: 2426281

