



supporting blind and
partially sighted people



Edinburgh and Lothians Joint Sensory Partnership



Can You See Me, Can You Hear Me?

Ethnic Minorities – Sensory Impairment: The Journey

30th April 2014

While you're at your seat we invite you to tweet!

@Bemis_Scotland

#SeeHearEM

Ministerial Foreword

Michael Matheson, Minister for Public Health, said:

Nearly one in five people in Scotland experience some form of sensory impairment, and we know that they can still face a number of barriers when it comes to playing a full role in society. That is why the Scottish Government is determined that everyone with a sensory impairment should have access to the best quality health services, with early diagnosis and appropriate treatment when they need it. It goes without saying that we're also committed to stamping out discrimination against anyone with a sensory impairment wherever it still exists, regardless of their ethnic background.



This is an issue which goes way beyond the NHS, so we recently embarked on a wide ranging consultation to find out how we can improve services for people with a sensory impairment. The resulting strategy, 'See Hear', was launched last week.

See Hear is the first of dedicated sensory impairment strategy anywhere in the UK, and will guide our approach as we seek to improve the lives of people living with sensory impairment in Scotland. The strategy sets out seven recommendations, including basic sensory checks being offered to people when they reach a certain age, that employers are advised to review their compliance with the 2010 Equalities Act, and that we should raise awareness of sensory problems in training programmes, to make sure people do not miss out on professional qualifications.

I am delighted that the Scottish Government is able to fund today's conference. It is a valuable opportunity for you to learn from one another's experiences, and share ideas for how we can improve the landscape for sensory impaired people even further.

Can You See Me, Can You Hear Me?

Ethnic Minorities – Sensory Impairment: The Journey

BEMIS Scotland and our partners in the sensory impairment third sector, came together to raise awareness of, and advance, race equality within the setting of sensory impairment.

People with sensory loss experience varying levels of inaccessibility, disadvantage, and attitudinal prejudice and discrimination.

Many ethnic minority communities, at risk of, or experiencing, various degrees of sensory impairment, will not be aware of, access, or benefit from, mainstream support services.

How can frontline services and policymakers deliver and continue to improve outcomes for ethnic minorities with sensory impairment?

The purpose of this conference is to explore how we can ensure policy, practice and service delivery, is informed by a thorough understanding of the needs of ethnic minorities experiencing sensory impairment, and guarantees equality of access.

Today we will:

- Discuss child and adult experiences of sensory impairment.
- Explore the challenges and barriers faced by ethnic minorities experiencing sensory impairment.
- Share good practice on meeting the needs of ethnic minorities experiencing sensory impairment.
- Hear about the Scottish Government's Sensory Impairment Strategy.
- Share of a unique range of resources demonstrating practical, tested approaches to community engagement, accessible information and cultural awareness.
- Hear from service users sharing their journey.
- Network and discuss joint working solutions.

Conference Agenda

10:00	Registration & Refreshments
10:30	Opening Address - Dr Rami Ousta, BEMIS Scotland
10:40	Angela Bonomy, Scottish Government Lead (Sensory Impairment), National Audiology Manager
10:50	Tasneem Jameel: 'My Journey'
11:00-11:45	Workshops Session 1 – delegates will attend their first chosen workshop <ol style="list-style-type: none">1. Challenges and Barriers2. A Case for Prevention and Early Intervention3. Dual Sensory Loss – Just Try It4. Making a difference
11:45	10 Minute Break
11:55-12:40	Workshops Session 2 – delegates will attend their second chosen workshop <ol style="list-style-type: none">1. Challenges and Barriers2. A Case for Prevention and Early Intervention3. Dual Sensory Loss – Just Try It4. Making a difference
12:40	Panel Q&A – <ul style="list-style-type: none">• Jac Ross, Corporate Health Inequalities, NHS GG&C• Angela Bonomy, Scottish Government• Eddie Fraser, Director of Health and Social Care, East Ayrshire Council
12:55	Shanaz Razaq and Mohammad Rasheed Akhtar: 'My Journey'
13:00	Networking Lunch

Workshop 1 – Challenges and Barriers

With Annette West, Qurat Al-Ain & George Ajayi (Edinburgh & Lothians Joint Sensory Partnership)

"People from black and minority ethnic communities are at greater risk of some of the leading causes of sight loss."

- The Black population aged under sixty has a greater risk of developing age- related macular degeneration (AMD) compared to the White population of the same age.
- Asian people have a greater risk of developing Cataracts compared to the Black population and White population.
- Black and Asian populations have a greater risk of developing Diabetic Retinopathy eye disease compared to the White population.
- The risk of Glaucoma is much higher for the Black population compared to the White population.

(Source - Access Economics, 2009)

These statistics have major implications for health and social care resources given the increases in Scotland's ethnic minority population in the 2011 Census. When designing services organisations need to ensure they have consulted in detail with the communities / users they aim to support.

This workshop will offer:

- Explore some of the reason why ethnic minorities with sensory impairment are not currently accessing services.
- Challenge some possible assumptions they might have.
- Help participants to realise that 'one size doesn't fit all'.
- Examine the potential for developing tailored services.
- Provide insight on the work of the Edinburgh & Lothians Joint Sensory Partnership with ethnic minority communities.

Workshop 2 - A Case for Prevention and Early Intervention

With Gozie (RNIB) and Varshali (NDCS)

It is now widely evidenced that people from certain ethnic groups and have significantly higher prevalence of sensory loss compared to the White population.

- Diabetes – the primary cause of sight loss in working age people in Scotland – is up to 4 times more prevalent in south Asian compared to White people.
- Growing evidence exists that people of south Asian and African descent often contract diseases like diabetes and glaucoma at a younger age and that complications are often more aggressive.
- Other sources indicate the incidence of deafness to be 4:1 in every 1000 Asian children being born with a hearing loss.

These statistics have major implications for health and social care resources given the increases in Scotland's ethnic minority population in the 2011 Census. They create a strong case for prevention planning and early reach approaches that aim to improve regular access to screening, identify appropriate support and promote informed health choices for people, patients and carers from high risk groups.

This workshop will offer:

- A unique insight into the work of RNIB Scotland and NDCS on prevention of sight loss and early intervention with ethnic minority clients.
- A chance to consider practical solutions to community engagement and accessibility for ethnic minority clients and patients.
- An understanding of cultural perceptions of disability, especially in relation to age and gender.
- An opportunity to share learning and consider actions for your own localities or services.

Workshop 3 - Just Try It – Dual Sensory Loss

With Vijay and Suzanne (Deafblind Scotland)

Workshop Overview

"Persons are regarded as deafblind if they have a severe degree of combined visual and auditory impairment resulting in problems of communication, information and mobility."

Deafblind people can find it difficult to access service for a number of reasons, these can include:

- Information which is not accessible, housing application forms which cannot be produced in an alternative formats i.e. Large print, audio or Braille, large print in foreign languages, audio in foreign languages, Braille in foreign languages etc.
- Staff who cannot or do not understand how to communicate, or do not know how to go about getting appropriate communication support.
- A lack of sufficient time to ensure a person's needs are met – a standard 10 minute appointment slot for a person who has communication difficulties and complex health needs.
- Inaccessible buildings or environments, for example voice controlled entry systems at audiology departments.
- Inadequate information and services that meet the needs of people living with dual sensory loss.
- The lack of awareness and sensitivity to meet with religious and cultural needs, i.e. the need to have same sex staff – female G.P. to see women from certain cultures.

With all these barriers to contend with think about how does a person feels if they need to access information or services?

People who are Deafblind are often afraid to leave their homes - they cannot manage ramps or stairs; lifts and escalators can be frightening. If they are not familiar with the layout of a building going to an appointment for the first time can be very daunting - leaving them feeling very apprehensive while attending appointments. Family members and most professionals are not trained to provide specialist mobility support.

Deafblind people can experience psychological barriers caused by the communication difficulties they experience with the professionals .They rely on interpreters, there can be communication breakdowns, misinterpretation or a lack of interpretation support. This can leave the deafblind person feeling frustration, paranoid and let down. Professionals often lack awareness of the needs

of a person who has a dual sensory impairment which can lead to misdiagnosis. This is multiplied when English is not their first language. Consider how you would teach tactile communication i.e. deafblind manual (a form of English based finger spelling) to someone who knows no English.

This workshop will offer:

- Delegates an insight into how a person who lives with dual sensory loss experiences the world around them.
- A chance to reflect on what it feels like.
- Come up with some simple changes to take back to their work places to improve services for people with sensory impairments.

Learning outcomes:

- How would you identify a deafblind person?
- Consider access ability and deafblindness in information provided.
- Consider language simplification.
- Plan in advance; consider the environment and how you can adapt it.
- Get to know who your clients.

Workshop 4 – Making a difference

With Tasnim and John (Deaf Connections)

This workshop will offer:

- Help participants understand the needs of deaf ethnic minority people and the risk of mental health issues within this community.
- Give a brief background understanding of Deaf Connections services, who are we, and what do we do.
- Refer to the Asian Deaf Club and Ishara Project as examples of good practise for engaging with and empowering ethnic minorities experiencing sensory impairment.
- Explain why it was felt there was a need to establish a deaf club specifically for deaf members of ethnic minority communities.
- Introduce a member of the Asian Deaf Community who will give a real life account of the support she has received from both membership of the Asian Deaf Club and the Ishara Project.

Partner Organisations

BEMIS Scotland is the national Ethnic Minorities led umbrella body supporting the development of the Ethnic Minorities Voluntary Sector in Scotland.



BEMIS aims to represent and support the development of the ethnic minority voluntary sector across Scotland, and to support the diverse communities and individuals that this sector represents, especially those who are under-represented and disadvantaged. BEMIS aims to address inequalities by empowering communities, working towards an inclusive society by establishing structures, which recognise diversity and empowers ethnic minorities, and ensuring that they are fully recognised and supported as a valued part of the Scottish multicultural civic society.

For more information please visit: www.bemis.org.uk or contact: mail@bemis.org.uk



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partially sighted people**

The Royal National Institute of Blind People

(RNIB) Scotland is the country's leading charity working with blind and partially sighted people.

In 2013 RNIB Scotland reached 61,570 people

within Scotland. We provide a wide range of support services for children and adults across Scotland. These include: Education and Family Services, Youth services through Haggeye Youth Forum, Income Maximisation services, Employment and Learning Services, Parliamentary and Campaigning, RNIB Edinburgh and Lothians and Visual Impairment and Learning Disability (VILD) Service. We have a strong focus on prevention of avoidable sight loss and have recently concluded a series of pilots targeting ethnic minority and low income communities. In Edinburgh our work with ethnic minority communities is delivered in partnership with Deaf Action to raise awareness of support available for ethnic minority people living with sensory loss. In partnership with hearing loss organisations we are delivering joint sensory services in a number of areas in Scotland and also are leading in vision support services in eye clinics for the newly diagnosed. RNIB Scotland also has a unique radio station - Insight Radio - which develops programming of interest to blind and partially sighted people across the UK. As a membership organisation we are dedicated to delivering services our members need and campaigning for their rights.

National Deaf Children's Society

The National Deaf Children's Society is the leading charity dedicated to creating a world without barriers for deaf children and young people.



As part of our core services we manage a BME Family Support Volunteer Network. This is a group of parents of deaf children, trained by NDCS to provide informal emotional and communication support to families who don't have English as their first language. We work closely with statutory services to enable them to engage more effectively with these families. We also host information days, coffee mornings, family outings, workshops for children targeted at the hard to reach families.

For more information please contact: Varshali Swadi 0141 3547855 (v) or 07966341021 (v/t) or Email: varshali.swadi@ndcs.org.uk

You can also contact our FREE Phone Helpline on 0808 800 8880 (v/t).



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Edinburgh and Lothians Joint Sensory Partnership (ELJSP)

With two-year funding from the Scottish Government, RNIB Scotland and Deaf Action have launched the Edinburgh and Lothians Joint Sensory Partnership

(ELJSP). The partnership will deliver better services for ethnic minority people with hearing or sight loss by:

- Maximising existing resources and networks
- Introducing sustainable support services
- Raising awareness of sensory loss issues throughout the region.

For more information please contact: Tariq Mahmood, Project Development Officer (Ethnic Minorities) – Telephone: 0131 652 3140 or Email: tariq.mahmood@rnib.org.uk

Deafblind Scotland works with adults who are dual sensory impaired, many of them having become dual sensory impaired later in life - this is called acquired deafblindness.

Deafblind Scotland has 8 members from ethnic minority communities in April 2014; this has increased from 2 in the last 12 months an increase of 300%. This increase has been directly attributed to awareness raising and training sessions funded by a Greater Glasgow and Clyde Health Board equal access project. The aims of these sessions have been to connect with and engage people living with dual sensory loss and support them to access to services. The demand for support has been overwhelming.

Contact us on: Telephone: 0141 777 6111 Fax: 0141 775 3311
Mobile: 07715 421 377 Email: servicesadmin@deafblindscotland.org.uk



Deaf Connections is the leading voluntary organisation delivering specialist services to adult deaf people across Scotland. We are committed to enabling deaf people to participate fully in the community to make equality and fairness a normal feature of their everyday lives.

The Asian Deaf Club, established in 1998, welcomes Deaf people from all minority ethnic backgrounds. The project has provides a confidential service and members understand and respect different cultures. The Club meets weekly; arranging trips, social activities, information sessions, and celebrating cultural events from different ethnic minority cultures.

Deaf Connection's Ishara Project provides support to Deaf ethnic minority people in the West of Scotland in the following ways:



- Information and advice on accessing employment, health services, housing, benefits, etc.
- Communication guidance for ethnic minority families and community agencies. For example, deaf awareness training and BSL Taster classes in a culturally sensitive manner.
- Information, advice and arranging sessions for Deaf ethnic minority people to find out more about their own cultures and beliefs.

Making a Difference

'I am a mother of three children and live with my in laws, the job of looking after everyone whilst having sight loss is quite challenging, days go by when I break dishes, burn or bruise myself, trip over objects left by family members, although very frustrating, I have to keep my patience and carry on.'

I didn't have anyone to talk to regarding my anxieties and frustrations, I personally felt the less the community knew about me, the more normal I could be, I found people had a tendency to pity you than support you and I am not comfortable with pity.'

Before getting in contact with the ethnic minorities development officer with the Edinburgh & Lothians Joint Sensory Partnership I hadn't accessed any services. I am personally discreet about my condition and keep my company to a small circle of friends and family however through the peer support group of ethnic minority women I have started engaging with RNIB Scotland a lot more and have accessed a range of services. I am also championing support to other ethnic minority women with sight loss through the peer support group which I am proud to be a part of.'

Pakistani Woman

'Since S was diagnosed you have been a great support to us. You helped with his nursery placement and organised the taxi which we didn't know we could get. The translated information you send to us is invaluable. My English is not so good, so the translated leaflets help me to get information in a language I understand. If there are any issues with the school we contact your volunteer, T, who is able to sort things out for us. You have arranged for the sign language tutor to come to our home since my wife is unwell and cannot walk properly. This has been so beneficial to us. We can communicate with S and he is happier. I am really enjoying leaning to sign. I also take S to the Saturday club where he meets other deaf children. Events like the information days you host give us the opportunity to meet Deaf Role models and it reassures us that S can also grow up and get a job, get married and live a life like anyone else.'

Dad of a 9 year old profoundly deaf boy whose first language is BSL

'I've been happy with the way things were explained to me and what was going to happen. I've had a number of laser treatments in my eyes. I have had no complaints.'

Mr Mohammed Nazim

'..From a very early age I've had sight loss problems. I've never had my eye condition explained me; no one could understand what was going on with my sight. I visited the Southern General where an Urdu speaking doctor suggested I should register Blind. I did not fully understand what this meant and was afraid and had no one to talk to. If there was someone who could explain what it means to register and the benefits, this may have eased my mind...'

Bashiran Tayub on how services could have made a difference

'The second time I was hospitalised with a severe infection that took me to surgery, the first doctor after reading on my file that I am blind offered to send a taxi to my home to get me. Right after we finished talking another doctor called and asked me very harshly: "Can't you take a taxi yourself?!!" I told him that I had not asked for a taxi to go to the hospital that it had been offered to me by the first doctor. I said: "I beg you to forgive me. I will go to the hospital". He then told me to go to the outpatient clinic which I did and upon arriving there, with my legs all swollen and with high fever, they asked me: Why didn't you ask for us to send you a taxi or ambulance? My bad experiences were with the doctors on the telephone.'

Wanda, who is now supported by RNIB

Mrs S recently became a member of Deafblind Scotland. It was discovered that she had been in hospital five times with broken bones in her chest, shoulder, leg, foot and burns sustained whilst cooking. She has had a heart by-pass; she has cancer, high blood pressure, diabetes and arthritis. The GP was giving her various different eye drops. With specialist support she was seen by an ophthalmologist and registered blind. Intervention from social work and the falls prevention team were also arranged to ensure she can access services, regain her confidence and live more independently. She has now joined English, computing and exercise classes, all supported by Deafblind Scotland.

Client Case Study, Deafblind Scotland

'To be honest everything I have managed to learn, experience about F's deafness is because of NDCS. The audiology department at X is only there to give us a clinical view on things where as NDCS does the real life communication and practical, emotional support, how to deal with challenges, issues that deaf children will have to face as they grow up.. NDCS is the network and bridge between families of deaf children which helps us to share and learn from other people's experiences and find solutions to deal with day to day issues with your deaf child'.

Dad of a 12 year old deaf girl and a volunteer with NDCS

'Since I joined the Asian deaf club in 1998, where I was very quiet and no confidence. I know nothing about myself who I am and what I am. I never had independence all my life and feel so isolated as my parents taught me nothing at all. I started to learn slow signing with other deaf, just like me and learned lot of things like our cultural, how to communicate support and many things to do. Years and years later on, I became confident and can do what I want on my own outside from my home and able to get on with everything like how to travel, meeting friends/socialise and going to deaf club for activity that how help me improving my confidence build up. Without them, I would have nothing to gain my confidence and would be more isolated.

Ishara Project had been provided and support to Asian Deaf Club to give us good benefits and learn a lot from them, like e.g. Health/Fitness, Employment/Job skills, Counselling/Need to talk, Islam cultural/Religion, Training/Class Courses, Confidence/Independence, Benefits and so many activities things to do and it gives us good opportunities for the future.

I'm glad to join the deaf community is very important of communication and understanding and helping each other to improve our lives more better.'

Deaf Connections, Service User

Mr M is 83 years old. When he was in good health he enjoyed jogging and swimming, he also lectured at university in physics. Life was perfect till he started losing his vision and 2 years later his hearing. His wife left him and he is estranged from his children. He approached Deafblind Scotland for support after awareness raising session at an Asian Day centre. We now support him to attend health appointments, going out for walks and exercise classes. We are also supporting him to deal with his housing needs through Glasgow Housing association. Once he had severe headache and GP refused to give him an appointment. With the intervention of our specialist services he was seen by a GP and was admitted to A&E, where he was supported by a bilingual guide/communicator and was treated for high blood pressure, this he was told could have been fatal. He has now been referred to his local social work department.

Client Case Study, Deafblind Scotland

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