



South Birmingham  
Primary Care Trust



**SeeAbility and South Birmingham  
Primary Care Trust. Services for People  
with a Learning Disability**

**'eye2eye' Campaign. End of year three report  
Seeing beyond disability**

**September 30th 2008**

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SeeAbility and SBPCT supporting people in Birmingham.





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## **Introduction**

SeeAbility and South Birmingham Primary Care Trust have facilitated and delivered the **eye2eye** campaign within the city of Birmingham. The **eye2eye** campaign focused on doing everything possible to help those who are blind or partially-sighted and have learning disabilities, to overcome the challenges they meet in everyday life with the view to improving every individual's quality of life. The campaign also focused on access for all people with a learning disability with the promotion of quality care.

SeeAbility were originally known as the Royal School for the Blind and changed their title in 1994. SeeAbility is a charity that linked with SBPCT in order to promote quality care services for people with learning disabilities. The opportunity for promoting quality care stems from the belief that there are thousands of people in the United Kingdom who would benefit from services promoted by SeeAbility. The national campaign was launched at 10 Downing Street on 14<sup>th</sup> June 2005 called 'The **eye2eye** Campaign', with the view of expanding and promoting quality care to people with learning disabilities in different parts of the country.

The **eye2eye** campaign focused on promoting community projects across England with SeeAbility linking with partner organisations, including South Birmingham Primary Care Trust, in support of the campaign.

## **Aims of the national campaign**

The **eye2eye** campaign aimed to change individuals' lives through the vision of enabling those who are blind or partially-sighted, and have learning disabilities, to achieve their full potential. The SeeAbility campaign aimed to enable people to access better eye health care and improve quality of life through the launch of the community projects across the country. The objectives were to:

- a) Identify people in a locality with visual impairment and learning disability.
- b) To offer advice, support and access to specialist Health and Social Care services.
- c) To provide advice to local Health and Social Care and Health services on promoting effective methods of communication, mobility, environmental design and equipment.
- d) To engage with community stakeholders to improve access to local resources and activities.

The **eye2eye** campaign also looked to launch a National Advisory Service to provide a network of knowledge throughout the United Kingdom to produce and disseminate information on visual impairment and additional disabilities for people with learning disabilities, carers, and health and social care workers. The National Advisory Service also aimed to develop and promote the SeeAbility website as a portal for information. Furthermore, the National Advisory Service aimed to support the work of local projects. The National Advisory Service became the **LookUp** ([www.lookupinfo.org](http://www.lookupinfo.org)) Information and Advisory service which has supported positive change throughout the country.

The local **eye2eye** campaign started its three-year journey within Birmingham in October 2005. The SeeAbility and SBPCT team strived to ensure that a key ambition, as noted by David Scott Ralphs, Chief Executive of SeeAbility, was achieved.

“Our ambition is to keep improving and expanding to reach more people with combined sensory and other disabilities and to improve the quality of their lives.”

David Scott Ralphs, Chief Executive of SeeAbility.

## **The eye2eye campaign in Birmingham**

SeeAbility and South Birmingham Primary Care Trust ensured the promotion of quality care services for people with learning disabilities and visual impairments. The team focused on:

- a) Ensuring that people with learning disabilities accessed services in line with need.
- b) Social inclusion of people with multiple impairments by ensuring that their visual impairments were taken into account, in relation to individual plans and programmes.

The Birmingham team also looked to place hearing and transition as areas for development to support the person centred nature of the campaign. The Birmingham team worked with local ophthalmic services, low vision services, learning disability services and hospital eye and hearing care services to ensure access to services as needed. The team provided an open referral system and assessment and care management service to promote appropriate access to care. The team provided advice and support to adults with learning disabilities and carers on pathways to access specialist Health and Social Care services within the city. The team promoted methods of effective communication, mobility, activities, environmental design and advice on equipment. The team collaborated with other visual impairment related services in the city and provided training in order to build capacity within learning disability teams. The promotion of access to services and advocacy services was seen as paramount. The team aimed to ensure that links to the Valuing People document (UK Government 2001) were clear; notably that rights, choice, independence and inclusion were encouraged within a person-centred approach to planning, which meant that planning started with the individual. The team supported the concept of Health

Action Plans (DOH, 2003a), which aimed to promote health and indicate how the individual can get help in the strive for health promotion. The team also aimed to ensure that the Department of Health's (2003c) recognition of preventing illness and providing effective treatment and care was seen as important.

The SeeAbility and South Birmingham Primary Care Trust Team's annual work plans set a number of objectives to support the **eye2eye** campaign. The following objectives were paramount:

- 1) To establish the project and communicate its existence to relevant individuals and agencies.
- 2) To undertake a mapping exercise to identify needs within Birmingham.
- 3) To communicate the results of the mapping exercise and make recommendations and provide solutions where appropriate.
- 4) To raise awareness amongst people who have learning disabilities.
- 5) To raise awareness amongst those who support people with a learning disability.
- 6) To raise awareness amongst a wide range of eye care providers.
- 7) To form links and collaborate with other sensory impairment community groups.
- 8) To raise awareness amongst relevant health and social care staff.

The annual work plan objectives enabled the team to proactively plan how best to function, noting that the team was made up of two practitioners. The team initially focused on identifying the target population. The 'Valuing People' document (UK Parliament 2001) estimates the learning disability population to be made up of about 210,000 people with a severe learning disability; and 1.2 million people with a mild to moderate learning disability. The Foundation for

People with Learning Disabilities (2004) reports that there are no reliable official statistics concerning learning disabilities, but does go on to estimate that between 580,000 to 1.75 million people have a mild learning disability; with 230,000 to 350,000 people having a severe learning disability. Gates and Wilberforce (2004) note that calculating the correct incidence of learning disability can be problematic, which makes the targeting of resources difficult, while Whitaker (2004) argues that the bulk of people who could be classified as having a learning disability may not be known about. The Birmingham team focused on the population of the city. Birmingham's population has been estimated at 977,087 as noted by the Office for National Statistics (2001) while Birmingham City Council (2001) note that the true figure is higher and predicts year on year growth over the coming years taking the population size to well over a million residents. It could be estimated, if we use Whitaker's (2004) judgement of 1% to 3% of the population as having a learning disability, that the number of people within Birmingham who have a learning disability could be between 10,000 and 30,000 people. Birmingham's General Practitioners, through the Health Facilitation agenda, are being encouraged to record all individuals with a learning disability who use the G.P. practices, which should, as time progresses, give a clearer picture of the prevalence rates of learning disability within Birmingham. However, as the literature notes, prevalence rates can be problematic.

The extent of sensory care problems faced by people with a learning disability is clear (Evenhuis et al 2001, Carvill 2001, Carvill and Marston 2002), however access to services are possible (Woodhouse, Griffiths and Gedling 2000). The Birmingham team facilitated access to services from high street optometry services through to inpatient hospital care services. The team, through an open referral system, focused on addressing a variety of issues from signposting individuals and carers to services, facilitating access to services, practically supporting individuals and carers in the promotion of health, training and awareness raising, as well as embedding the **eye2eye** campaign within the

health facilitation service and community nursing service. The team completed a mapping exercise to gain the views of people with learning disabilities, carers, eye care professionals and other stakeholders, which formed a basis for identifying barriers faced by people with a learning disability within the city.

The **eye2eye** campaign aimed to support intervention such as that delivered to Jasmine (Case example: Service user confidentiality has been maintained in line with NMC (2002) guidelines).

Jasmine was referred to the service for support with a sight test; she had glasses in the past but had lost them some years previously. Jasmine had not had a sight test for many years and was anxious about going for a sight test. Jasmine also had two main concerns: firstly that she could not afford the sight test or the new glasses. With support a full eye test was completed. Jasmine was prescribed new glasses, one pair for general use and the other for reading or looking at pictures. Jasmine was given advice which enabled her to access the sight test and glasses without cost. The glasses each had a different coloured frame which helped Jasmine know what each pair was for. The team role was to facilitate the eye test as well as ensuring appropriate information was provided to support the eye test through the pre eye test form (LookUp factsheet 'Telling the Optometrist about me' form).

The team established its base at Waterlinks House in the Nechells area of the city and immediately established appropriate management and supervision links with SeeAbility focusing on **eye2eye**. The team regularly met with Paula Spinks-Chamberlain, Deborah Hamlin and Martin Thomas from the SeeAbility **eye2eye** campaign and National Advisory Service as well as meeting SeeAbility **eye2eye** representatives from Bristol, Sheffield, Barnsley, London and Surrey. The team also gained from a positive link with Gill Levy from the SeeAbility LookUp information service. The Birmingham team introduced itself to the Multidisciplinary teams in the Heart of Birmingham, East and North and South

and West Birmingham areas. The team presented the campaign to the Birmingham Local Optical Committee and to Birmingham Focus on Blindness who fully supported the campaign through the formation of a steering group which focuses on encouraging relevant stakeholders to share good practice, identify barriers and promote effective working. The team has been supported with the campaign through liaison with City Colleges, training and educational placements and through the goodwill demonstrated from Anita Morrison-Fokken the Director of Low Vision Services from Birmingham Focus on Blindness.

Information was sought from people with learning disabilities to highlight both positive and negative experiences of accessing eye tests / eye care services. The aim of the exercise was to identify relevant factors which can promote quality eye test/care for people with learning disabilities. The service user interviews were completed in a number of establishments within the city of Birmingham that provide work, training or education.

Positively, the survey highlighted aspects of eye tests / care from the perspective of those who use the services, from high street opticians right through to hospital services. Secondly, the survey noted individuals' experiences of wearing prescribed glasses. Thirdly, the interviews identify some of the reasons why people are not accessing eye tests. Limitations of the exercise included the fact that service users who could not comprehend the questions would be excluded which, in reality, ruled out people with a severe learning disability. Secondly, service users interviewed volunteered for interview and, therefore, valuable information may have been lost because many service users choose not to be interviewed. Thirdly, the interviews were completed in day centres, training/work establishments and colleges and so were completed with a group engaged in some form of community activity and so did not gain the opinions of those not engaged in community activity.

The service users involved were interviewed on a one-to-one basis at the work, training or educational placement. The interviews followed a semi-structured interview format enabling the collection of quantitative and qualitative data, which looked to produce knowledge, or raise awareness, of the experiences of service users with a learning disability, within the City.

One hundred and eighty-one service users agreed to be interviewed. However, the information of forty-five of those individuals was not used because thirty-nine individuals could not or did not consent to sharing information, while six appeared not to have a learning disability. The total number of service users interviewed, therefore, who could agree to information for this report was one hundred and thirty-six (136). The information gained is only relevant for the population interviewed. Of those interviewed, 86 (63.24%) were male, while 50 (36.76%) were female. Of those interviewed, the ethnic origins described by the individuals themselves were as follows:

<b><u>ETHNIC ORIGIN</u></b>	<b>NUMBER OF INDIVIDUALS</b>	<b>%AGE</b>
British,UK or English	99	72.8%
Pakistani	12	8.8%
Indian	8	5.9%
Afro-Caribbean	7	5.2%
Irish	5	3.7%
African	3	2.2%
Other	1	0.7%
Other European	1	0.7%

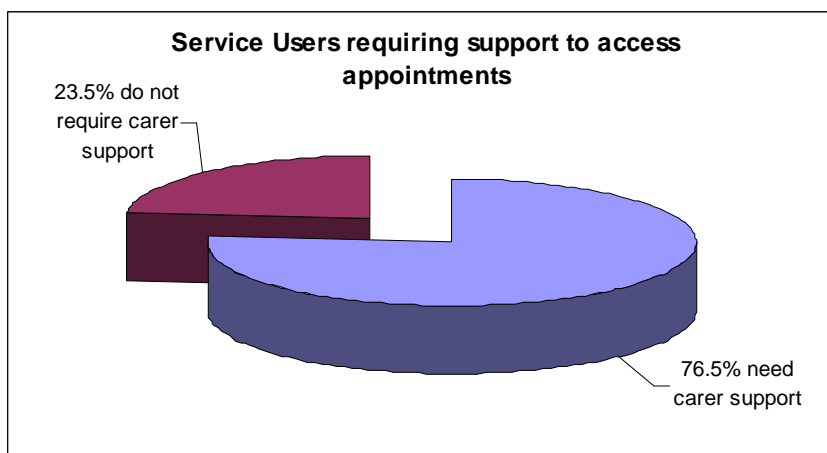
77 (56.6%) individuals reported living with their family. 49 (36. %) lived in residential care. 7 (5.1%) lived on their own with support workers visiting to

provide limited support. 3 (2.2%) individuals reported living in warden controlled flats (1 person 0.7%) or in hostels (2 people 1.5%).

The age ranges of those interviewed were as follows:-

<b><u>AGE BETWEEN</u></b>	<b>NUMBER OF INDIVIDUALS</b>	<b>%AGE</b>
18 – 30	34	25%
31 – 40	36	26.5%
41 – 50	25	18.4%
51 – 60	30	22.1%
61 – 70	10	7.3%
70+	1	0.7%

Of those interviewed, 104 (76.5%) reported that they required a carer to support and accompany them to appointments such as an optician or hospital service. 32 (23.5%) individuals noted that they do not need support.



The number of individuals who reported having had an eye test was 102 (75%), while 34 (25%) reported they had never had an eye test. Of the 34 (25%) individuals who had never had an eye test, 26 (19.1%) did not know where to go to receive an eye test. 5 (3.7%) disliked/feared appointments in general, while 17 (12.5%) felt that their sight was not a problem and so did not need a test.

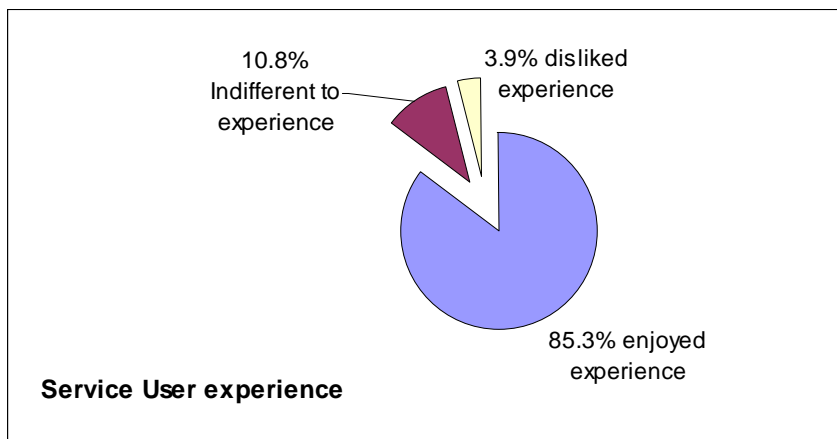
Looking at the 102, as a 100% total of individuals who had an eye test, produced the following results- 34 (33.3%) individuals had an eye test in the last twelve months; 17 (16.6%) had an eye test within the last one or two years; 14 (13.7%) had an eye test more than two years ago; while 37 (36.3%) were not sure how long it had been since they last had their eyes tested.

36 (35.3%) individuals reported that they paid for eye tests and / or glasses, with prices varying from £5 up to £120. 66 (64.7%) individuals reported that they received free eye tests, and glasses (for those who needed them).

82 (80.4%) individuals had been prescribed glasses, with 18 (17.6%) of these individuals reporting that they do not wear their glasses. 1 (.98%) individual would not wear glasses because she reported that she would fall over when wearing them and said she disliked wearing them because of the falls. 2 (1.96%) individuals reported that they break their glasses when upset while 5 (4.9%) individuals reported that they do not need the glasses. 10 (9.8%) individuals did not identify reasons why they do not wear their glasses.

Positively 87 (85.3%) individuals reported that they enjoyed visiting optometry services with 11 (10.8%) indifferent to the experience. Frequent positive comments include: a) staff were nice to talk to; b) people were friendly; c) we could pick our own glasses. 4 (3.9%) individuals reported that they disliked the

experience. Reasons for not liking the experience of going for an eye test were: a) dislike of eye drops; b) a service user reports a dislike of the optometrists face being so close to his face during examination; c) dislike of the dark room; d) 1 (.98%) service user was not sure why he disliked the experience.



Of those who received vision tests 12 (11.8%) individuals reported that they are seen regularly at a Birmingham hospital because of vision problems. Of the 136 individuals interviewed, 15 (11%) reported that they had heard of Health Action Plans, while 11 (8.1%) individuals reported they have a Health Action Plan.

The clinical work focused on direct referrals strictly looking to address the reason for referral. Throughout the campaign the team supported over two hundred sight tests of which more than 80 people were prescribed glasses. 26 cases of hospital treatment or assessment were supported with awareness-raising, advice, information being circulated to more than 1800 people with a learning disability. The work clearly indicated that the pre eye test form is essential in enabling people to access eye care as it provides appropriate information to support care; secondly the work indicated that we have a large group of people with learning disabilities who can access high street or hospital care services with advice, information and carer support without difficulty if planned appropriately. The second group of people with learning disabilities do require additional support, such as additional visits to services in preparation for intervention,

desensitisation, and domiciliary support. Many individuals deemed challenging by services were supported through the campaign to access services, but success was not always gained as a small number of individuals have remained difficult to engage in services which can promote better health. A concern continues for a small group of people with learning disabilities in relation to access to diabetic retinopathy screening.

The team's direct link into the Health Facilitation service enabled the clinical work to become embedded within the Health Facilitation culture around the areas of inclusion in annual health checks so that sensory care is raised at the annual review. The Health Facilitation link with the **eye2eye** team through transition has also facilitated access to services for those leaving school. On top of the clinical work, the team has presented to many groups such as service user groups, carer groups, social care and health groups, national conferences, including the National Network of Learning Disability Nurses conference which focused on the skills of the learning disability nurse in supporting the **eye2eye** campaign now and in the future.

Optometry services were also approached for their views with one hundred and three questionnaires being sent out to Optometrists within the city of Birmingham. The aim of this exercise was to elicit the views and experiences of Optometrists in relation to the provision of services for people with learning disabilities. The response from the exercise resulted in twenty-seven questionnaires being returned. The responses produced the following information, which is only relevant to the services involved. Seven (7) optometrists reported seeing between 1 – 10 service users with a learning disability each year; six (6) saw between 11 – 20 per year; two (2) saw between 21 – 30 per year; and five (5) saw 30+ service users each year. Seven (7) produced no figures, with one noting a lack of awareness of learning disability and so was not sure which group of service users has a learning disability.

When asked to self-rate their service performance related to eye tests for people with a learning disability the following results were noted:

NO. OF OPTOMETRISTS	RATE OF SERVICE PERFORMANCE
7	Very Good
15	Good
1	Poor
4	Not sure or no response

The measurement between very good, good and poor is ordinal and subjective.

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**When asked if tests were difficult to perform for people with a learning disability. Sixteen (16) optometrists reported that the tests could be difficult to perform. Reasons noted from respondents:**

- Service users not concentrating on tests.
- Service users not co-operating with tests.
- Poor communication.
- Physical problems / postural problems making tests difficult.
- Service users frightened of the experience of the eye test.
- Lack of appropriate tests / equipment.
- Optometrists not knowing how to approach the Service user.
- Carers accompanying Service users having a lack of knowledge about the Service User (i.e. no medical or medication information, no awareness of service user's visual needs)

- Problems with stinging eye drops.
- Not enough time to complete a test.
- No training or awareness of learning disability.

Six (6) optometry practices reported that they do provide low vision services.

Three (3) optometrists reported that they or their staff have had training in learning disability awareness, with two (2) reporting the training at a pre-registration stage.

Twenty-five (25) optometrists reported that they would like further information on how to work effectively with people with a learning disability.

Twenty (20) optometrists reported that eye care and low vision services could be improved for people with a learning disability. They noted the following issues:

- Training for all staff within practices.
- Training on how to deliver tailored eye exams.
- A dedicated centre for low vision services.
- More community based services.
- Greater awareness of low vision services and how to access them.
- Improved services to address language barriers.
- Extra tests, i.e. pictures. (Specific tests).
- Sharing of available equipment.
- Carers assisting service users having knowledge of the service user.
- For carers and service users to be aware of the need for regular health checks.
- For funding for both eye care and specialist spectacles to be addressed.
- More funding for eye tests.

- Improving access for physical disability / postural problems.
- Annual eye examination for all children at Special Schools.
- All parents should be aware of optometry services and eye care services in the local areas.
- Improved communication and alternative methods of communication i.e. sign language, makaton.
- Recalls should be responded to.

Eleven (11) optometrists reported that they would like to become involved in SeeAbility's **eye2eye** campaign. Positively the team presented a workshop at the College of Optometry conference in April 2008 and it is notable that the national work of SeeAbility supported by the local steering groups and the positive work of the College of Optometry has resulted in the inclusion of guidance in the College of Optometry Handbook advising on supporting the adult with learning disabilities to receive a sight test.

## **Conclusion**

The campaign has raised many issues about the nature of services provided to support people with learning disabilities and the need for both person centred care and specialist provision to ensure people's needs are being met. The campaign has raised many barriers to care which highlight the need for integrated working between all services rather than parallel approaches to providing care. The knowledge, skills and attitudes gained by those involved with the campaign will ensure that positive practice remains embedded within the health facilitation and community nursing culture within the city, but also recognises the importance of keeping the national links so that national barriers, problems and concerns can be raised with a unified voice. The **eye2eye** campaign, planned for three years, will continue in Birmingham for one further year with a band 5 nurse working in the role of SeeAbility Development Officer

with a number of new objectives identified. The open referral system will change because the health facilitation service and community nursing service have the background and understanding of the **eye2eye** campaign so that the work will target the hospital eye and hearing care services to support progress within inpatient services in relation to people with learning disabilities.

The final year objectives fit in with the Healthcare for All report (Chaired by Jonathan Michael 2008) which was an independent inquiry into access to healthcare for people with learning disabilities, which supports the principles of both the Human Rights Act (UK Parliament 1998) and the Disability Discrimination Act (UK Parliament 1995). The final year plan has a number of objectives which follow on from the embedding of the **eye2eye** process within Birmingham services for people with learning disabilities, and these objectives include:

- Facilitating people with learning disabilities to access hospital services when necessary.
- Facilitating Functional Visual Assessments in line with need.
- Facilitating the inclusion of eye and hearing care within the Health Action Planning process.
- Providing a transition Clinic to signpost young adults/carers to eye/hearing care services.

The final year of the campaign will continue to flourish under the SeeAbility and Health Facilitation agenda of quality and access to care services. SeeAbility, in their five year plan, note how their quality work needs to become accessible across the country and the joint working between the trust and the charity has certainly proved beneficial as a means of supporting people directly, improving and sharing knowledge, changing clinical behaviour and changing attitude, but more needs to be done. A positive activity, post campaign, would be to review an area, such as the transition clinic, in order to see if **eye2eye** influence has

resulted in positive change. This summary report concludes by noting that the research in relation to sensory care is clear in that people with learning disabilities are at a greater risk of developing a sensory care problem as compared to the general population. Positively overt direct discrimination hasn't been a factor from the Birmingham project's perspective but systemic, institutional barriers remain which need to be focused on in order to promote access and quality for all.

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## **Appendix 2 Work plan targets included in year 4 plan.**

- People with learning disabilities are facilitated to access hospital services by the **eye2eye** Development Worker. Functional Visual Assessments and Health Action Plans encouraged.
- Awareness raising activities take place with people who have a learning disability across the city of Birmingham with Information/resources being shared with people with a learning disability.
- Awareness of open referral system for hospital services to be shared via the MDTs in each geographical area of Birmingham, noting both sight and hearing as areas where support can be delivered.
- Updated information/resources to be shared with health and social care professionals and family/carers
- Transition Clinic held to signpost young adults/carers to eye/hearing care services by the development worker.
- BLOC and Steering group to be updated on any developments within the LookUp service and how Optometry services can use the service.
- Barriers, obstacles and solutions are identified in bi-monthly reports.
- For the steering group to champion the improvement of sight and hearing services for people with learning disabilities.



### Appendix 3 SeeAbility Core Messages

**SeeAbility is a growing charity which enables blind and partially sighted people with additional disabilities to achieve more from life and encourages others to see beyond the disability.**

**SeeAbility is here to enable blind and partially sighted people with other disabilities to:**

- develop and maintain their life skills which increase the ability to make personal choices and retain independence
- have access to good quality housing and support
- receive appropriate information and access to better eye health care and other support services
- raise awareness about being included in their local community.

**Over the next 5 year, SeeAbility aims to:**

- provide our specialist services to support more people with multiple disabilities
- provide more individual and personalised direct services across a wider geographical area
- expand the information and support we provide on eye and general health
- raise more income so we can help many more people.

**SeeAbility will achieve these aims by ensuring that:**

- people with disabilities are at the heart of everything we do
- we value and respect each person's role and contribution
- we work as one organisation, helping each other to do our jobs better
- we encourage new ideas and ways of working

## **Appendix 4 Optometry Tomorrow 2008**

### **Full inclusion, supporting people with learning disabilities to access eye care**

This workshop focussed on the historical nature of the treatment of people with learning disabilities, examining the barriers faced by people with a learning disability.

The workshop reviewed initiatives aimed at overcoming these barriers.

#### **Learning objectives:**

- To enhance awareness of initiatives to support people with a learning disability
- To develop a greater awareness of the problems faced by people with a learning disability
- An understanding of why it is so important for people with a learning disability to access eye care

**Presented by Martin Thomas and Michael Loftus. SeeAbility. CET Credit**

*Points: 1*

## **Appendix 5 Equality Impact Assessment - Full Impact Assessment**

The team contributed to the public consultation feedback for a consultant-led community-based outpatient ophthalmology service proposal looking at *'The Future of Outpatient Services for people with Eye Conditions in South Birmingham'*. A full impact assessment was undertaken on 26<sup>th</sup> November 2007 at Moseley Hall Hospital. The assessment was undertaken by the chair of the Patient Involvement Action Group, representative from Learning Disability / SeeAbility, Patient & Public Involvement Manager, Optometrist from Birmingham Focus on Blindness, South Birmingham PCT Equality & Diversity manager and a commissioning manager.

Areas which were identified for action included:

- Collection of gender, age, ethnicity and disability.
- Use of interpreters and accessible literature

- Need for individual preferences to be accommodated whenever possible e.g. gender of healthcare provider.
- Prevalence of eye disease in Black, Minority and Ethnic population within South Birmingham PCT.
- Review of the transport service contract.
- To promote access for groups who normally do not access services.
- Ensure prescriptions and medication are available.

The impact assessment process was viewed as being a very positive and helpful process by all involved.