



## **West Sussex eye 2 eye project**

### **“Eye care and vision for people with learning difficulties”**

#### **Evaluation and Feedback from Questionnaires**

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#### **Accessible summary**

- Lots of people with learning difficulties have eye problems.
- We asked people what they think about eye care for people with learning difficulties.
- This report explains what people told us.
- People need to have regular eye tests.
- They like optometrists who are friendly and talk to them.
- They want to feel included in the eye test.

#### **1. Introduction**

Department of Health statistics estimate that around 1 in 3 people with learning difficulties have some difficulty seeing. Yet many adults with learning difficulties rarely, if ever, have an eye test. This fact puts people at risk of preventable sight loss from conditions including cataracts and glaucoma. Those that do have an eye test often find that this process is far more complicated than for the wider population.

As a result of this information, SeeAbility entered into a partnership with West Sussex County Council to establish an eye 2 eye project in that catchment area. The aim of the project is to provide support to enable adults with learning difficulties to access regular and effective eye care and vision services.

A mapping exercise was carried out as part of the project to gather information about current eye care practices. This exercise commenced in 2007 and ended in 2008. The findings can be used to identify what needs to be done to improve eye care for people with learning difficulties in West Sussex.

Questionnaires were distributed among the following five groups with the numbers of respondents in brackets –

- Adults with learning difficulties (95)
- Health and social care professionals
  - Managers (17)
  - Support Workers (10)
- Family carers (20)
- Optometrists (14)

The questions asked varied slightly between the different groups to reflect their different perspectives on the eye care process.

## **1.1 Methodology**

- The questionnaires used are the same as those used by eye 2 eye colleagues in other parts of the country. This is so that comparisons may be made between the different areas.
- Questionnaires for people with learning difficulties were carried out face to face, usually with myself. Respondents tended to have mild learning difficulties as this group were more able to understand and answer questions than those with more severe learning difficulties. This means that the views of people with more severe learning difficulties are not directly represented in these findings although some of their experiences will be expressed indirectly by other respondents.
- Questionnaires for health and social care professionals and family carers were given to people whom I met through my work. This includes staff from residential, supported living and day services.
- Questionnaires for optometrists were sent out twice during 2007. They were sent out to every optometry practice in West Sussex but were not addressed to individual optometrists as this information was not available to us.

## **1.2 Limitations to the exercise**

- a) The sample was not scientifically chosen. It is not representative of age, area, ethnicity or other factors. The results are based on responses of people I contacted who were happy to participate in the survey.
- b) For this reason, and as some questions were not answered, my report mainly uses general descriptions of trends and findings, as opposed to precise percentage figures.

## **2. Main findings of the mapping exercise**

In this section, I have considered the replies from all five sets of questionnaires. I have linked responses between the different sets of questionnaires in order to identify common themes or conflicting findings. The results are presented under four headings – awareness of eye care, the eye test, awareness of visual impairment and bringing about change.

### **2.1 Awareness of eye care**

#### **2.1.1 Most recent eye test**

Optometrists recommend that every adult should have an eye test at least every two years. We wanted to find out how often adults with learning difficulties had an eye test. Three questionnaires (people with learning difficulties, managers and family carers) reported that although the majority of people had undertaken an eye test in the last two years, there were some people who had not had an eye test during that time.

#### **2.1.2 Health Action Plans**

A Health Action Plan (HAP) is a process aimed at improving the health of people with learning difficulties. A Plan should cover all aspects of a person's health and should enable the individual to have more control over their health choices. Survey responses indicated that lots of people do have a HAP where eye care is addressed to some degree. However, responses from people with learning difficulties, family carers and support staff show that many people –

- do not have a HAP
- have a Plan but eye care is not mentioned
- do not talk to anyone who supports them about their sight.

### **2.1.3 Problems with glasses**

Many people with learning difficulties happily wear prescribed spectacles as directed by their optometrist. However, we have already seen that some people have not had an eye test in the last two years and may now require spectacles or a change in their existing prescription. Responses from people with learning difficulties, support staff and managers and family carers show that many people with learning difficulties have glasses but do not wear them. Reasons given include –

- Person feels the spectacles do not look good (cosmetic).
- Person is ridiculed for wearing glasses.
- Poorly-fitting spectacles which are uncomfortable or slip off the person's face.
- The person forgets to wear the glasses.
- The person refuses to wear the glasses because they do not fully comprehend the benefits due to their level of understanding.
- The spectacles are lost.
- The spectacles have been accidentally broken.
- The spectacles have been deliberately broken because the person does not want to wear them.
- The person has more than one pair and there is confusion about when each pair should be worn.
- Support staff do not know that the person wears glasses or do not know when they should be wearing them.
- The person prefers their old glasses.

This is a wide range of reasons, many of which may be overcome with the correct intervention.

## **2.2 The eye test**

### **2.2.1 Having a choice**

People with learning difficulties and family carers were asked if they wanted a choice about where the person had their eye test. In both cases, a sizeable majority did want a choice. The reasons identified for this included –

- To be able to go to an optometrist's if recommended by a friend.

- To see an optometrist they feel comfortable with.
- To go to an optometrist close to the person's home.

For the minority who did not want a choice, the main reason given was that they were happy with their current optometrist and did not feel that they needed any other choices.

### **2.2.2 Eye test experiences (positive and negative)**

We wanted to find out more about people's experiences of having an eye test. We received responses from people with learning difficulties, family carers and support staff. The factor which had the greatest bearing on how the person felt about the eye test was whether they felt relaxed and comfortable during their visit. The greatest contributory factor to this was the interaction between the optometrist and the individual. This included whether the optometrist's staff were friendly, patient, good at explaining what was happening and easy to understand. Other important factors included the use of alternative eye tests (such as pictures or symbols instead of letters), sight being improved and eye problems being identified and treated. An important element for people with learning difficulties was being valued as part of the process – being able to participate well with the test, choosing their own frames or even being able to go by themselves to the appointment! Responses from support staff also indicated that some optometry staff could benefit from training to increase their understanding of people with learning difficulties and that results of the eye test were not always properly explained.

Optometrists felt that the following factors contributed to a successful eye test –

- Level of experience of the optometrist and previous relevant training.
- Allowing extra time for the appointment.
- The optometrist to adapt their approach (e.g. extra patience) and tailor the eye test to the needs of the person.

Optometrists also identified factors which hindered the completion of a successful eye test, including –

- Subjective tests which rely on patient responses can be difficult.
- Challenges with co-operation and communication.

- Lack of medical information provided to the optometrists.

Optometrists were asked, on average, how successful were the eye tests they carried out with people with learning difficulties. All responded that the tests went either well or very well, none answered poor or very poor. Nearly half of the optometrists expressed an interest in receiving further information on working with people with learning difficulties.

## **2.3 Awareness of visual impairment**

### **2.3.1 Detecting problems**

We asked family carers, support staff and managers how they might detect a deterioration in someone's vision. People responded with a long list of possible indicators which broadly fall into two groups –

- Changes in functional ability such as difficulties in seeing objects or people's faces at near or far distances and bumping into things.
- How this affects the person, including withdrawing from activities, becoming less confident or displaying behaviour which can be challenging.

Very little mention was made of changes in the appearance of the person's eyes (for example cataracts can give the eye a cloudy appearance) or eye infections.

### **2.3.2 Working with people who have a visual impairment**

Managers and support staff were asked whether anyone with a visual impairment used their service. The majority of people answered that they do.

### **2.3.3 Awareness of sources of support**

The same two groups were asked who they would contact if they felt someone had a problem with their sight. The only answers common to both groups were the GP and the Community Team for People with Learning Difficulties (CTPLD). Both of these are obviously not specific sight-related services. Some support staff mentioned optometrists and some managers suggested the Sensory Services Team, Royal National Institute for Blind People

(RNIB) and the hospital eye clinic. Nobody mentioned 4sight, the local voluntary society for people with a visual impairment.

### **2.3.4 Visual impairment awareness training for support staff**

Despite the fact that support staff will work with people with a visual impairment, only a minority of staff have actually received any training in eye care or visual impairment awareness.

### **2.3.5 Equipment**

Managers and support staff were asked whether anyone who used their service had any specialist visual impairment equipment. This refers to items such as mobility canes, talking clocks and magnifying glasses. There was a difference in responses between managers and support staff to this question. Support staff identified only three items of equipment with quite low numbers. Managers identified six items of equipment in significantly higher numbers. However, managers and support staff agreed that there were usually no guidelines or training available for staff about how the equipment should be used.

## **2.4 Bringing About Change**

Managers, family carers and optometrists were asked what needs to be better for eye care and low vision services for people with learning difficulties in West Sussex.

Responses common to all groups –

- To have specialist services particularly for people with more severe learning difficulties.
- For eye care professionals to undertake training to increase their awareness of the needs of people with learning difficulties.
- To ensure that people with learning difficulties have regular eye tests (at least every two years).

Other responses –

- To work to improve awareness of the importance of eye care among parents and carers, GP surgeries, Day Services and so on.
- Publicise a list of optometrists who specialise in eye care for people with learning difficulties.
- Managers wanted there to be more information sharing between residential services and hospital Eye Clinics.

- Family carers wanted greater access to alternative eye testing methods, more home or Day Service visits for eye tests, continued Eye Clinic access for children when they become adults and more physically accessible optometry practices.
- Optometrists requested a higher testing fee which would facilitate a longer eye test for people with learning difficulties as well as increased opportunity for optometrists to provide Low Vision assessments as an alternative to the hospital setting.

### **3. RECOMMENDATIONS**

The work of the eye 2 eye project will continue at least until November 2009. The mapping process has revealed fresh and honest feedback that has consequently informed the work for the next 18 months. The results from the mapping exercise indicate that the priorities for the project are as follows –

1. Circulate the report widely in West Sussex and share the findings.
2. Continue to work to raise awareness about the importance of eye care including the benefits of wearing prescribed spectacles.
3. Encourage the use of the Eye Test Form which provides quality information to the optometrist before the eye test.
4. Encourage optometrists to complete the Eye Test Report Form which explains clearly the outcome of the eye test so that this information may also be used in Health Action Plans and other relevant documents.
5. Encourage more optometrists to add their details to the register on the Look Up website and encourage people to take advantage of this facility when arranging an eye test.
6. Promote awareness and use of alternative eye testing kits.
7. Encourage optometrists and their staff to attend training to enhance their awareness of the needs of people with learning difficulties.
8. To provide training to support staff to raise their awareness about visual impairment including specialist equipment.
9. Continue to promote visual impairment services such as the Sensory Services Team, 4Sight and Worthing Society for the Blind to people with learning difficulties and their carers.

The responses people have provided have shown that there is much to do to improve the experiences of people with learning difficulties in West Sussex. I will continue to work with all

appropriate groups to ensure that improvements in eye care are made. The launch of the UK Vision Strategy may support this work as the eye care and vision sector starts to review how services can best be provided.

## **Acknowledgements**

I would like to thank everyone who completed a questionnaire, as well as Trish and Christine at SeeAbility for their administrative support.

July 2008