Our better vision

Campaign report

What people need from low vision services in the UK

> "It is devastating when you find out that you can't even read the top line."

RNIB Helping you live with sight loss

Acknowledgements

We are extremely grateful to a large number of people for their help and support throughout the project:

The Advisory Group
Nigel Charles (Royal National Institute of the Blind)
Dr Christine Dickinson (UMIST, Manchester)
Carl Freeman (Royal National Institute of the Blind)
Dr Adrian Hill (Oxford Eye Hospital, Oxford)
Brian Jones.

Those who assisted with the data collection:

Ini Grewal, Stephen Chartres, Evelyn Russell and Jo Rideal for their help in planning and facilitating the focus groups

The staff at The College of Health, London, for their input to training focus group facilitators

Opinion Research Corporation International for its help and advice with the telephone questionnaire

To the many agencies and organisations who assisted in finding people for the telephone interviews and focus groups (see Appendices)

Also grateful thanks to the many people who took part in the focus groups and the telephone interviews

To Oxford Eye Hospital for seconding Dr. McCloughan to carry out this work

To Michelle Beaver and Dan Vale for their help in preparing the report.

This project was funded by a grant from the Royal National Institute of the Blind.

Contents

Report overview

How would you feel if you developed a condition that made it difficult to undertake the simplest of everyday tasks? For the first time you find it extremely hard to travel, shop, cook and clean effectively. Dealing with bills and correspondence is impossible and your independence is diminished. Pleasures that have enhanced your life such as reading a novel or watching a favourite television programme are no longer available.

Imagine then that there are a number of ways that these tasks could be made very much easier but that nobody tells you about them. Unfortunately, this is the situation for hundreds of thousands of people in the UK who have eye conditions that leave them with low vision.

Most people who experience low vision can be given equipment and training that will often dramatically improve the things that they can see and do. However, all too often these services are not provided by the NHS or by local authorities. The consequence for many people is isolation, social exclusion and frustration. In the majority of cases this could be prevented for less than the annual cost of a daily newspaper, restoring the independence and self-sufficiency of many otherwise able people.

The research

This is one of two reports published concurrently by the Royal National Institute of the Blind (RNIB) which show that the provision of low vision services in the UK is unacceptably poor in three fundamental areas – accessibility, distribution and delivery. This report “Our better vision”, produced in collaboration with Heriot-Watt University, is based on new qualitative and quantitative research into the experience and needs of service users with regards to low vision services. The companion report “Fragmented vision”, produced in collaboration with Moorfields Eye Hospital, presents major national quantitative research on the nature, extent and geographical distribution of low vision services in relation to prevalence and other factors.

The results presented in this report give an invaluable insight for service providers into the good and bad aspects of low vision services from the user's perspective.

The principle of user participation

An important way of finding out how easy and effective it is to get a service is to ask the service users. They are the people who know what it is like to have the condition. It is also widely acknowledged now that the success of service provision and take-up is enhanced by the involvement of service users at every level, from planning to evaluation. This is reflected in the greater emphasis on user participation that has been given by the current Government in recent papers on the future of the National Health Service (NHS).

Important principles for service delivery

Three important principles for the delivery of low vision services arose from focus group work and questionnaires.

Awareness: the vast majority of people with low vision want comprehensive information about what they need, what they are entitled to and what is available.

Timeliness: people do not want unnecessary delay in assessment, rehabilitation, training and follow-up.

Accessibility: people with low vision need every part of the service to be accessible; this includes the physical environment, the form in which the information is given and the communication skills of the health providers themselves.

Findings

The delivery of effective low vision services is a positive experience for the vast majority of people. The provision of appropriate low vision aids, training and support is generally seen as invaluable. The problem is that most people are not able to access and utilise these services with ease and confidence.

The research found that many people with low vision felt that they had received no information at all regarding what help was available to them after diagnosis. Furthermore, many who had been given information were unhappy that they had had to ask for it. Many people who would have benefited from low vision services had been either told, or led to believe, that nothing could be done to improve their sight.

It is widely felt that people have to wait too long for appointments. Seven out of ten people surveyed felt that they should be seen within two weeks of diagnosis. The buildings are often found to be difficult to move around for people with a serious sight problem. Getting to the appointment safely was regularly cited as a further source of difficulty.

The majority of people felt that they wanted to get help with sight loss in one place. In other respects people wanted greater choice, especially in the range of low vision aids offered.

Policy recommendations

As a result of the survey, RNIB is making recommendations aimed at government, statutory and voluntary sector service planners and providers.

Recommendation for central Government

To give increased priority to the improvement in the quality of low vision services throughout the U K.

Recommendations for professional bodies and voluntary organisations

To develop and distribute information about sight loss and low vision services in an appropriate format for low vision service users.

To provide information about older visually impaired people and low vision services to professionals such as ophthalmologists and general practitioners.

To develop training for ophthalmologists on rehabilitative strategies available to people with serious sight problems.

To provide information about good practice for assessing sight for people with low vision.

If services in the primary care sector expand to support secondary care services, they should ensure that the public and other services are made aware of the role of community optometrists.

Recommendations for those who commission low vision services

To ensure that low vision services are available and accessible to everyone that might require them.

To ascertain the needs of people locally from low vision services by focusing on: information provision, improving access to appointments, physical access to services (both transportation and architectural access), improvements in the way that the low vision assessment is carried out, the way that low vision equipment is displayed and the skills of all staff working within services.

To assist in reducing waiting times

To consider employment of information officers or extension of existing workers roles to provide information within the hospital setting.

Recommendations for those with responsibility for individual low vision services.

To further develop integrated multi-disciplinary services involving input from several different professionals and agencies.

To review methods of training people to use their low vision aids.

To stock a wide variety of different types of equipment or have information on local providers.

To reconsider the way that low vision aids (LVA's) are presented within the low vision service, by having an open display which can been seen by service users either before or after attending the low vision assessment.

To stock information leaflets on local and national organisations dealing with sight loss, in appropriate formats and language.

To establish a re-referral procedure.

Recommendations for individual practitioners

To ensure that a low vision assessment covers non-reading tasks.

To ensure that the way sight testing is carried out in an appropriate way and is not distressing to the service user, by explaining the necessary techniques used for establishing acuity levels.

To inform those responsible about the types of architectural barriers that service users might face when visiting the low vision service.

Recommendations for researchers

To investigate the specific information needs of people whose first language is not English.

To find out whether older people would prefer low vision services to be provided by their local high street or community optician, centrally in the nearest big town or city, or both.

To establish the clinical effectiveness of training to use LVA's.

To establish the effectiveness of different models of low vision service.

Introduction

Many people, especially older people, find it hard to see even after they have had an eye test, are wearing the correct spectacles and have had all possible medical treatment. It is estimated that there are 1.7 million people in the UK who have a serious sight problem (OPCS 1989).

Over 95 per cent of people with serious sight problems have some sight. Nevertheless, they still face difficulties with everyday activities that most people take for granted. For example, reading ordinary sized print, preparing meals, dealing with personal finances, taking medications or travelling alone outside the home.

Almost 90 per cent of people with a serious sight problem are over the age of 60 (Evans, 1995). This means that many are also more likely to live on their own (ONS, 1996), and to suffer restrictions in everyday life accompanied by other age-related conditions such as hearing loss (Davis, 1995) and physical limitations (ONS, 1998). Sight problems can also place psychological stresses on the individual, sometimes causing depression, anxiety and loneliness (Dodds, 1991; Baker and Winyard, 1998). In essence, someone experiencing serious sight problems can be at risk of losing their autonomy unless rehabilitation services are initiated.

Low vision services are one type of rehabilitation service that exist to reduce the disabling impact that a visual impairment can have. They do this by helping people to make full use of the sight that they have. This help comes in many forms including: the issuing of magnifiers and other low vision aids, training in the use of low vision aids and vision, advice on the use of lighting, contrast and other environmental modifications. In some cases, people also receive help with the psychological and emotional problems associated with sight problems.

Most low vision services are based in hospital eye departments and a smaller number are provided by community (“high street”) optometrists or opticians' practices, social care professionals or multi-professional centres.

In the UK, low vision services have been described as “fragmented and patchy” (Dickinson, 1995). This view has been confirmed by a survey of

low vision services carried out by RNIB and Moorfields Eye Hospital NHS

Trust (Ryan and Culham, 1999). Where services do exist, other problems have been described such as too great an emphasis on helping people to read print, rather than with other activities of daily living (Leat et al, 1994) and a lack of training given to people in the use of equipment loaned (Lomas, 1997).

Problems with low vision services are likely to be compounded in the next few decades by the imminent increase of potential users of them. Most people with low vision are over the age of 65 and the number of people in this group is projected to increase by 29 per cent in the next 20 years (Shaw, 1996). With no immediate advance expected in the medical treatment for the main cause of blinding eye disease, age-related maculopathy (Chong and Bird, 1998), there will be an increase in the number of people needing visual rehabilitation or low vision services.

Using the views of people with low vision to help improve services

Professionals working in the area of low vision services have suggested a variety of approaches to overcome some of the problems described. These suggestions include: encouraging the provision of low vision services in the primary care sector (Rumney, 1997), the initiation of inter-disciplinary approaches to low vision services (Moore, 1994), or the placement of low vision services within regional resource centres (Lomas, 1993). In addition, an inter-organisational working group is establishing recommendations for future developments in low vision services (Low Vision Services Consensus Group, 1999).

Central to good practice in the research and planning of health services is the involvement of users of those services. Lovelock states that, “direct service users and their carers are now commonly acknowledged as having a right to choice and a right to take part in shaping services in partnership with professionals” (Lovelock, 1995). Such an approach is in line with recent Government publications encouraging service providers to find out the views of those using the services in order to assist in their development and improvement (NHS Executive and The Department of Health).

There have been “user-centred” needs surveys in the past (see Lovelock, 1995; Herbst, 1997 for reviews). However, these have either been specific to a particular health or local authority or, have concentrated on the general needs of people with a visual impairment.

To contribute to the process of including user-defined needs in the development of low vision services, RNIB, in collaboration with Heriot-Watt University, has carried out a study to highlight what people with serious sight problems feel that they need from the services. The intention is that local providers and purchasers can use this information to focus their efforts when conducting their own local “needs” surveys. This report briefly describes how the views about needs were obtained from people. This is followed by an analysis of the results concerning the range and type of expected need found in the study.

To initiate the process of including users' views in improving services, the report gives a series of recommendations for all bodies having an input into low vision services. This includes practitioners (those who meet people with serious sight problems face to face) as well as commissioners of low vision services (those who decide about the location and nature of services).

Aims and objectives of the study

The aim of this study was to influence the future structure of low vision services, by promoting the inclusion of user-defined needs in the development of services.

To achieve this aim, two main objectives were formulated. The first was to use focus groups ($n = 12$) to find out the range of perceived needs from people with low vision. This involved asking different groups of users to discuss three main topics:

- What was good about the services they receive?
- What was bad about the services they receive?
- What did they feel they needed to help them make the best use of the vision that they had?

The second objective was to replicate the objective of the focus groups using a questionnaire to assess whether these needs can be measured using quantitative methods. The methods used to carry out these objectives, including the constitution of focus groups are described in more detail in the Appendices (The focus groups’ methodology).

Results from the focus groups

Six main themes emerged from the focus groups which were applicable to the three topics covered during the discussions (good aspects, bad aspects and aspects needed from low vision services). These themes are summarised, and discussed in more detail below. It is important to note that these themes may not be representative of the views of all potential low vision service users: they reflect the main issues expressed during the focus groups. Quotations from the focus groups are intended to illustrate the themes but are not intended to summarise the diverse views of all the participants.

Main themes emerging from the focus groups:

- information about services
- getting an appointment
- access to services (geographical and architectural)
- the low vision assessment
- equipment (optical and non-optical low vision devices)
- personnel involved in low vision.

Information about low vision services

This theme dominated most of the focus groups. A small number of people mentioned that the information received about services and gadgets was good. However, the majority of people provided numerous examples of situations where information was poor and many people felt that they received no information at all regarding what help was available.

Regarding the quality of information given, two main issues were discussed: the use of technical terminology and the fact that the differences between the various professionals (ophthalmologist, optician, optometrist, rehabilitation worker) involved were not explained. The group of people with Punjabi as a first language felt that there is an inequality between the information they receive and the information that English speakers receive. In all focus groups, many of those who were in possession of information were unhappy that they had to ask for it themselves. For example, a participant who cared for an older person with serious sight loss felt that information about the existence of low vision services should come automatically:

> **"From my point of view it is information. I feel it shouldn't be so hard to find things out ... I shouldn't be having to phone around hundreds of people."**

People felt they needed information on the existence of low vision services and different types of equipment. To overcome the problem of getting information a variety of solutions was suggested, the most common being the presence of someone at the eye hospital to give out information on relevant issues when a serious sight problem is diagnosed. Other suggestions regarding methods of information dissemination included: advertising low vision services in the local and national media, sending information to people's homes in non-print formats and having more information available at family doctors' surgeries.

Getting an appointment

Focus group discussions about getting an appointment were dominated by comments of dissatisfaction with waiting times for referral, which ranged from three months to a year. Other negative comments regarding appointments included the cancellation of appointments at short notice, being "taken off" low vision service lists after a certain period of time and long delays between follow-up appointments. One person felt that these delays led to a worsening of his condition:

> **"I would like early appointments for people like me, don't leave us for six months ... you have to wait too long to see the optician at the hospital, and you deteriorate in the mean time."**

There were no positive comments about getting an appointment for low vision services. When asked what they needed in terms of getting appointments, most people felt that any help should be given as soon as possible after the time of diagnosis. Many people stated that they would like to be seen again after an initial assessment and some expressed a need to re-refer themselves for a low vision assessment when the need arose. Where self-referral was not possible, a few participants thought that follow up appointments should be made every six months or 12 months.

Access to services

Many difficulties relating to access (getting to the low vision service) were described. Problem areas regarding transport included: waiting for ambulance services, long ambulance journeys and a lack of parking for those using private transport. Problems with access do not stop on arrival at the service base and there were criticisms of architectural barriers such as steps and difficulty finding the low vision service. This was a particular problem in large hospitals:

> **“It's at the back of the hospital, in the bowels of nowhere ... you'd never find your way from where you entered.”**

Two positive comments regarding access were recorded from two of the groups. The first was about a “shuttle” system that transferred people from a pick-up point to different departments within the hospital grounds. The second concerned the accessibility of a local optician's (optometrist's) practice for low vision care which was very important to one of the younger participants.

When focusing on what they felt they “needed” from low vision services in terms of access, many of the younger participants suggested that this could be achieved through architectural changes to the building where the low vision service is located, such as easy-to-see signs. Most of the older participants did not entertain the idea of visiting the low vision service on their own, so it was difficult to get ideas from them about how to improve building access to the low vision service.

In terms of the geographical location of the low vision service, there appeared to be a polarisation in views between those who thought that the service should be in the “centre of town”, and those who thought it should be "more local". However, the idea of low vision services beingprovided by a community optometrist did not seem to appeal to many of the older groups.

People in several groups felt that a “high street” optometrist was a commercial enterprise and not a health-care provider and consequently were concerned about charges for services and lenses. However, the few people who were receiving low vision services from high street optometrists appeared to be satisfied with their treatment.

The low vision assessment

The most positive comments were about the low vision assessment itself. Mostly the comments related to different procedures carried out during the participants' visits. These included getting an eye health check, having the chance to "talk things over" and getting help with tasks which were important to the participants. Many people felt that the overall help from the practitioner was very good:

"I got the magnifying glasses, I got television glasses, everything. They were really nice and kind and they did everything that they could."

Negative comments about the low vision assessment related mostly to the way that "vision tests" are conducted. Some people did not like having to do the letter reading tests when the chart was too high or when they could not see any letters on the chart at all. Being made to comply with forced choice testing and being encouraged to "guess" at answers to vision tests also caused distress to some participants.

The only comments regarding solutions relating to low vision assessments concerned the way that vision was tested. For example, many people felt that the lighting conditions in the clinics were unrealistic and would like to be tested under domestic lighting conditions. Some people felt that the tests should be made easier, or that they should be allowed to sit closer to the test stimulus. For example, one person described how upsetting the process of sight testing in this context can be:

"It is devastating when you find out that you can't even read the top line. And you come out and you find that you're drained and you feel a lump in your throat."

Equipment (optical and non-optical low vision aids)

Experiences with optical low vision aids (such as magnifiers) were polarised, with people finding them either very good or very poor. When asked about the reasons for not liking their magnifier, most comments related to the reduction in field of vision, as well as eye strain which was attributed to using magnifiers. Regarding the way in which magnifiers are issued, many participants felt that the range of magnifiers on offer was too limited.

Most of the comments regarding non-optical devices were positive. ″Bump-ons″ (Self-adhesive, brightly coloured raised bumps for labelling items such as cooker dials) were particularly liked. Localised lighting and black felt-tip pens were described favourably in most focus group sessions, as were sight-substitution devices such as talking books.

When discussing what they needed in terms of equipment from low vision services, comments mostly fell into three categories:

1) The need to be able to get a wide variety of different types of equipment. These ranged from thick black marker pens and "a better magnifier" to a closed circuit television (CCTV), the chance to learn braille and "getting a guide dog".

2) The need to get more information and instruction on how to use magnifiers and non-optical devices.

3) The need to be more informed about what low vision aids are available. Many participants suggested that some type of "open display" of magnifiers was needed, so that the full range of magnifiers could be seen and tried out by the user on their own, either before or after seeing the practitioner.

One of the participants described this solution to the small range of LVA's on offer as follows:

> **"There should be a big range of all the visual aids on the market for people like us to try ... because everybody is different."**

Personnel involved in low vision services

Most of the negative comments regarding encounters with professionals related to experiences which had occurred before getting low vision help. In almost every focus group, people had been told that nothing could be done for them; this was described as being particularly upsetting or misleading. Other negative comments included: not seeing the same person each time the low vision service was visited, poor communication from staff, poor inter-professional communication, encountering negative attitudes towards older people and nurses not being “eye trained”.

When discussing the type of personnel needed, many people mentioned needing someone to talk to about negative feelings or coping with sight loss. For example, one person felt that he would have been helped by an additional staff member:

> **“I think the most important thing would be to have somebody ... a social worker of sorts, with some knowledge of eye sight at the clinic. That to me would be most useful. And to be told what is the matter with you, you could go and sit quietly somewhere, have a chat and maybe given some advice.”**

The term “social worker” was mentioned in relation to training in magnifier use, although others felt that a rehabilitation worker should do this. Finally, in many of the focus groups there was some confusion about the label “optometrist” and how this person is similar to or different from an ophthalmologist or an optician. Quite often, part of the focus group discussion was devoted to discussing the meaning of these terms.

The questionnaire study

Overall, the focus groups helped to establish the problems experienced and needs expressed. This may be particularly useful for those who do not have everyday direct contact with people with serious sight loss. A second, quantitative study was also carried out to ensure that the needs expressed during the focus groups were not just the ideas of a vocal minority within the focus group environment. It is hoped that this quantitative approach will serve as a basis for inclusion of users' views in future service developments.

The survey carried out by RNIB and Moorfields Eye Hospital NHS Trust (Ryan and Culham, 1999) shows that services vary dramatically throughout the country. This suggests that "user-needs" will be most usefully assessed at a local level. The questionnaire for the second study was developed to serve as a starting point for measuring such local needs. It is suggested that such a quantitative tool would be useful when gathering the type of prevalence data needed for reassessing the priorities of resource allocation.

Developing and administering the questionnaire

The questionnaire was based entirely on issues raised in the focus groups. Most of the questions were based on what participants felt their needs were. Each item on the questionnaire related to a particular issue such as "to get information in another language", and participants were asked if they needed it "a lot", "a little" or "not at all". The questionnaire was administered via 10-minute telephone interviews to a UK-wide sample of 90 people who had serious sight problems.

The emphasis of the discussion in the focus groups was sometimes different between the younger and older groups. As the majority of people with low vision are over the age of 60, the questionnaire study was restricted to that age group. The interviewees were recruited from 10 different local societies or resource centres from throughout England, Scotland, Wales and Northern Ireland.

Questionnaire results

Most interviewees were women (64.4 per cent) and the ages ranged from 60 to 98, with a mean age of 75.75 years. Most interviewees (76.7 per cent) had received low vision services before but 23.3 per cent had not. No statistically significant differences on responses to the survey were found between those who had and those who had not received services.

Table 1 Information about services

Information	don't need (per cent)	need a little (per cent)	need a lot (per cent)
On sight loss	41.1	24.5	34.4
On new magnifiers	46.7	20.0	33.3
On low vision help from eye doctor	52.2	20.2	26.7
Existence of low vision help	58.9	14.4	6.7
On relevant groups or societies	70.8	11.2	7.8
Information in another language	98.9	1.1	0.0

Table 2 Getting an appointment

Information	don't need (per cent)	need a little (per cent)	need a lot (per cent)
To be able to self refer	50.0	15.5	34.4
To get a follow up appointment	51.1	21.1	27.8

Table 2a How soon after diagnosis do you think you should be seen?

Time after diagnosis	response (per cent)
Same day as diagnosis	30.0
Greater than 1 day, less than 2 weeks after	40.0
Greater than 2 weeks, less than 2 months after	16.7
Greater than 2 months, less than 6 months after	4.4
Greater than 6 months, less than 1 year after	5.6
Don't know	3.3

Table 2b How often do you think you should be seen?

How often	response (per cent)
Every 0–3 months	43.3
Every 4–6 months	37.8
Every 7–12 months	10.0
More than a year	2.2
Whenever you request	6.7

Table 3 Access to services

Need	don’t need (per cent)	need a little (per cent)	need a lot (per cent)
To get help with sight loss all in one place	36.7	13.3	50.0
To get low vision help locally	48.9	16.7	34.4
To get low vision help in town centre	50.0	16.7	33.3
Low vision help to be near public transport	55.6	11.1	33.3

Table 4 The low vision assessment

Need	don’t need (per cent)	need a little (per cent)	need a lot (per cent)
To get eye health checked	50.0	24.4	25.6
To get help with non-reading tasks	54.4	24.4	21.1
To get advice on lighting	56.7	15.5	27.8
To get help with sight substitution	67.8	14.4	17.8

Table 5 Equipment (optical and non-optical low vision aids)

Need	don’t need (per cent)	need a little (per cent)	need a lot (per cent)
To be able to see full range magnifiers at same time	42.2	12.2	5.6
To get gadgets such as LVA's	68.9	8.9	22.2
Training to use LVA's	68.9	10.0	21.1

Table 6 Personnel involved in low vision services

Need	don’t need (per cent)	need a little (per cent)	need a lot (per cent)
To get help from same person each time	43.3	10.0	46.7
To have person to help with negative feelings	63.3	12.1	24.4
To be able to talk to someone else with low vision	66.7	12.2	21.1
Someone to visit you at home	70.0	11.1	18.9

Discussion

The results from these two nation-wide studies show that people with serious sight problems can participate in the process of suggesting solutions that could overcome some of the problems with the way that low vision services are provided. The studies serve to give a general indication of the type of problems experienced and the type of solutions that people find acceptable for overcoming them.

At a very general level, the results from the questionnaire study confirm that the issues raised as important during the focus groups are shared by between a third and two thirds of the questionnaire respondents.

The initial work described in this report draws attention to some of the areas that warrant further attention at a local level. It would be inappropriate to interpret these results as indicating that the problems reported are encountered in every part of the UK, or that the solutions suggested would be applicable in every region. The results indicate that people with serious sight loss have mixed experiences of the way that low vision services are provided. The variability of services around the country (Ryan and Culham, 1999) is likely to be a contributing factor in this.

The finding that nearly 23 per cent of people interviewed in the telephone survey had not received low vision services is of concern. Although there were no differences in responses between those who had received services and those who had not. This was not surprising as most of the questions were designed so that people who had not received services could answer them. That is, most questions did not assess the in-depth detail about the low vision assessments.

The six types of need which emerged from both studies are described here in further detail, both in terms of how they fit with the broader framework of improving low vision services, and the ways in which they can be implemented in regions where they are found to be relevant.

Information

The emphasis on the need for information, found in both studies, supports a number of previous studies related to serious sight loss. Information provision has been described as a way to empower people using the services, helping them to take greater responsibility for their own welfare (Brading and Yerassimou, 1998) by giving them access to a range of services, reducing stress and helping positive adjustment to sight loss (Department of Health,1989).

An option for information dissemination, which was particularly popular among the questionnaire respondents, was to have someone to give information about sight loss and low vision services. This reflects calls made in two other reports (Department of Health, 1989; Lomas, 1997) that workers providing information are necessary at the point of diagnosis and at the point of registration. The results from this study indicate that such an information officer would also have a useful role in low vision rehabilitation.

In the focus group discussions, one solution suggested for information dissemination was the advertising of low vision services through local and national media. This might raise the profile of low vision services in general and reduce the expectation that “nothing can be done”. However, at a local level, it might be more cost effective to specifically target information at those in need of services.

One of the suggestions made during the focus groups was for people to be contacted directly at home. However, lists of people with a serious sight problem often do not exist or are inadequate. Also, medical confidentiality and the Data Protection Act (1998) mean that lists that are available may not be available to organisations, even for the purposes of circulating information.

A number of professional bodies and voluntary organisations provide information leaflets in places which might be attended by those with serious sight problems, such as eye hospitals, GP’s surgeries and optometry/optician practices. However, information about topics highlighted in these studies as important, such as low vision help and magnifiers, is not generally available. Inclusion of information relating to low vision services in the range currently offered would seem a useful first step to providing information to people who need it.

Almost half of the respondents in the questionnaire study stated that they needed information about low vision services from the ophthalmologist. The ophthalmologist is likely to be the first person that informs someone about their serious sight problem, so it is particularly important that information about other sources of help is given at this point. The lack of information being passed on about low vision services might be due to "idiosyncratic attitudes of various professionals regarding the role and value of other professionals" (Lomas, 1993), or a lack of knowledge of the role of other professionals (Moore, 1994). Greater inter-disciplinary working, the raising of awareness of their own profession by low vision practitioners (Keeffe et al 1994), or more formal training in the rehabilitative strategies available to people with serious sight problems might be ways of facilitating this solution.

The only issue raised about information that was not rated as a need by many people was "information in another language". It is highly likely that this result is an artefact of the method used for gathering opinions in the questionnaire study; those people who do not have English as their first language may not have wished to be involved in a telephone survey. This is an area that warrants further investigation using alternative methods of data collection.

Getting an appointment

The need for getting low vision help as soon as possible after diagnosis was highlighted during the focus groups. This was borne out by the questionnaire study with 70 per cent of people stating that they would like to have been seen within two weeks of diagnosis. The problem of waiting times is an issue for every field within health care. However, given the negative impact of serious sight loss upon all aspects of the individual's wellbeing, from being able to make a hot meal, to mobility, to emotional wellbeing, the initiation of low vision rehabilitation at the earliest possible stage, is needed by many people. Also, once a person has been identified as having a sight problem he or she has to wait a considerable time for an appointment with an ophthalmologist before being referred to a low vision service (Department of Health NHS Executive, 1998). Such long waits might result in people losing essential life skills and therefore their autonomy.

The vast majority of people with serious sight problems will need to continue to revisit low vision services because of changes in their eye condition or circumstances. Half of the questionnaire respondents indicated a need to refer themselves to low vision services. This method of accessing services may be useful to those people who feel assertive enough and who are aware enough of changes in their own circumstances to do this. Eighty-one per cent of people stated that they would like to be seen every six months or sooner. To ensure that people who are not assertive also have access to services, it would also be useful to establish a "safety-net" follow-up procedure for those who would not self-refer. Staff in social care and voluntary sectors who may maintain contact with a person in the community might have a useful role to play in this follow-up procedure.

Access to services

The issue of access is particularly important for people with serious sight problems who in many cases do not have access to private transport, do not go out alone, and who encounter difficulties in using public transport (Baker and Winyard, 1998).

The problem of access is one reason for offering services away from city-centre based services in the local high street. No clear cut conclusions about what people prefer can be drawn from the questionnaire study, because 50 per cent of people stated that they wanted services in the town centre, while 51 per cent stated that they wanted services more locally.

This is not a division of agreement, as a statistical analysis revealed that the two responses were highly correlated (P less than 0.01). That is, the people who wanted services more locally also wanted them in the town centre. This anomaly may have arisen due to differences in perceptions regarding what constitutes "local" between the researchers and the participants. However, it is also possible that people would like a variety of options. Future questionnaires assessing this issue will need to carefully define what constitutes "local".

The concern raised in the focus groups regarding the commercial image of "high street" optometrists' and opticians' practices also highlighted the need for further research in this area, as there is an increasing move towards providing low vision services in the community. It is suggested that at local levels, if the need for the extension of low vision service provision into high street optometrists and opticians is demonstrated, a public awareness campaign might be carried out first. Professional bodies could assist at a national level, in order to ensure that potential users understand the role of community optometrists in providing low vision services.

During the focus groups, several people mentioned that they would like to receive their sight loss-related care “all in one place”. This issue was also rated as a need by almost two-thirds of the questionnaire respondents. This result may lend some support to the suggestions that services should be provided through “one door” in an attempt to reduce the gap between the health, social and voluntary agencies involved in serious sight loss (Lomas, 1993). The implications of this will need to be weighed against the need for “local” services and the results of studies of the effectiveness of different models (Russell et al, 1997). In the meantime, an improvement in communication between services for people with serious sight problems (Ryan and Culham,1999) might increase the likelihood that a person received all of the appropriate services.

Other issues relating to access difficulty concerned entering and moving around the building. However, the older participants in the focus groups have not offered solutions to these problems. Where services are provided in hospitals, the responsibility for architectural access will formally reside with building estates managers and facilities managers. However, it is suggested that there may be a role for low vision practitioners in using their knowledge about overcoming problems with visibility (by the use of lighting, size and contrast) to influence those responsible for universal access to health services.

The low vision assessment

Low vision assessments received the most positive comments from the focus groups and, for those who receive services, assessments are perceived as very useful.

Some people felt that the procedures for sight testing caused some distress. Where problems like this are found, they might be overcome by the use of a number of techniques. Firstly, charts can be used which are especially developed for use with people with low vision (LogMar charts such as the Bailey-Lovie system, 1976). This might be added to with an explanation to the patient about why tests are difficult (ie to find the threshold at which the test stimulus can no longer be seen). Finally, ensuring the tests are carried out at a distance where the individual being tested can see the test stimulus is a technique well described in texts of low vision practice (Bailey and Lovie, 1976; Rosenthal, 1996; Dickinson, 1998).

The other results from the questionnaire study indicate that to meet many users′ needs, the low vision assessment should focus on more than optical LVA's and reading. Over 40 per cent of respondents need help with lighting and non-reading tasks and almost a third of people require sight substitution devices.

Equipment

A third of the questionnaire respondents indicated that they needed help with getting LVA′s, and a subsequent statistical analysis revealed that there was no significant difference in this rated need between those who were in receipt of services and those who were not (Mann-Whitney U test, P less than 0.12). This gives support to the idea that many people need to be re-assessed from time to time, or at least be informed if and when new devices come onto the market.

A third of questionnaire respondents felt that they also require training to use LVA′s, supporting previous research carried out in the UK by Shuttleworth et al (1995) and in other countries (Nilson 1990). Furthermore, focus group participants suggested that social workers or rehabilitation workers are the appropriate professionals to provide this service. Rehabilitation workers are usually employed by social services departments to provide practical assistance to people with a serious sight problem in the areas of lighting, communication, daily living and mobility skills in their own environment. An extension of their role to provide training with low vision aids would seem appropriate. The finding in a recent survey that they are part of many low vision teams (Ryan and Culham, 1999) may indicate that is happening already.

Many people expressed a need to see all LVA′s available at the same time. This question was developed from the focus groups where many people described a type of ″open display″ where the full range of LVA′s could be seen either before or after the low vision assessment. This issue may not only inform how LVA′s are presented, but may also have implications for how overall services are provided. If this type of display is found to be needed by a lot of people at a local level, it may need to be centrally based because it would be expensive for service bases serving small populations or for peripatetic practitioners to provide cost effectively.

Personnel

During the focus groups, the main criticism of staff involved with aspects of help for people with serious sight problems was the perceived misinformation given by ophthalmologists about further care possibilities, that is by being told that "nothing can be done". This suggests a need for greater awareness among ophthalmologists about training in the rehabilitative strategies available to those with people with serious sight problems and their importance.

Other problems raised included poor communication skills and negative attitudes towards older people. This suggests the need for training all staff involved with people with serious sight problems, as well as optometrists (Rumsey, 1993) in the needs of older people.

One need which was expressed during the focus groups and was also shared by 30 per cent of the questionnaire respondents involved the inclusion of "someone to talk to about negative feelings". It is proposed that the relatively low number of people needing this may be due to the fact that questionnaire respondents were recruited mostly from voluntary societies or social services. These people may be more adjusted to their condition than people who are not in contact with a local society. While many practitioners may be aware of the emotional impact of serious sight loss, they are not trained to deal with it, so there appears to be a real gap in the staffing provision for these issues. This perceived need reflects calls for workers to be available for "reassurance" and counselling at the point of diagnosis or certification of blindness and partial sight (Department of Health, 1989; Lomas, 1997). The fact that this need is still apparent in a group of people who are in receipt of voluntary or social services (as in the current questionnaire sample) suggests that the availability of such a worker may need to extend beyond the stage where sight loss is first encountered and into the rehabilitative setting.

Other needs relating to personnel concerned the way that the staff-patient interaction is organised. One of the issues which was rated as a need by most respondents was to be “seen by the same person each time”. Increasingly, low vision services are being provided by groups of professionals and agencies (Ryan and Culham,1999). Therefore this need brings a new challenge to low vision service providers regarding how to organise an integrated service involving numerous professional groups and agencies while satisfying the needs of the people using the service to see the same person each time.

The other issue concerning organisation was the need to be visited at home. While this was rated as a need by relatively few people, the fact that many older visually impaired people who have to rely on others for transport means that implementation may make the difference between receiving services, or not.

References

Baker, M. and Winyard, S. (1998) **Lost Vision. Older Visually Impaired People in the UK.** London, Royal National Institute of the Blind.

Bailey, I.L. and Lovie, J.E. (1976) **"New design principles for visual acuity letter charts". American Journal of Optometry and Physiological Optics 53(11)**, 740-745.

Brading, J. and Yerassimou, N. (1998) **Ill informed: the provision of accessible healthcare and medical information.** London, Royal National Institute of the Blind.

Bruce, I., McKennell, A. and Walker, E. (1991) **Blind and Partially Sighted Adults in Britain: The RNIB Survey.** London, HMSO.

Chong, N.H.V. and Bird, A.C.B. (1998) "Alternative therapies in exudative age related macular degeneration". **British Journal of Ophthalmology 82,** 1441-1443.

Davis, A. (1995) **Hearing in Adults. The prevalence and distribution of hearing impairment and reported Hearing disability in the MRC Institute of hearing Research's National Study of Hearing.** London, Whurr Publishers Ltd.

Department of Health (1989) **Caring for People.** London, HMSO.

Department of Health (1998) **Waiting times for first outpatient appointments in England: Detailed statistics quarter ending 31 December 1998.** Prepared by the Government Statistical Service.

Department of Health (1989) **Co-ordinating Services for Visually Handicapped People.** Report to the Minister for the Disabled. London, Her Majesty's Stationary Office.

Dickinson, C. (1998) **Low Vision: Principles and practice.** Oxford, Butterworth-Heinemann.

Dickinson, C. (1995) **"Low Vision: a parochial view". British Journal of Ophthalmology 79,** 715-716.

Dodds, A.G. (1991) **"The psychology of rehabilitation". The British Journal of Visual Impairment 9(2)**, 38-40.

Evans, J. (1995) **Causes of blindness and partial sight in England and Wales, 1990-1991. Office of Population Censuses and Surveys. Studies on medical and population subjects.** London, HMSO.

Great Britain (1998). **The Data Protection Act.** London, HMSO.

Herbst, K. (1997) **Lifestyle and Needs of Visually Impaired Adults. A Literature Review for the RNIB.** Unpublished Internal Report for Royal National Institute of the Blind (available from RNIB Research Library).

Keeffe, J.E., Lovie-Kitchin, J.E. and Taylor, H.R. (1996) "Referral to low vision services by ophthalmologists". **Australian and New Zealand Journal of Ophthalmology 24(3)** 207-214.

Leat, S., Fryer, A. and Rumney, N. (1994) "Outcome of low vision aid provision: The effectiveness of a low vision clinic". **Optometry and Vision Science 71(3)**, 199-206.

Lomas, G. (1993) **A New Deal for Blind and Partially Sighted People. Joint Action on Resource Centres to Develop Care in the Community.** London, Royal National Institute of the Blind.

Lomas, G. (1997) **Closing the Gap. Linking health and social care for visually impaired people. A discussion paper by the visual handicap group on good practice supporting people who become blind or partially sighted.** London, Royal National Institute of the Blind.

Lovelock, R. (1995) **Visual Impairment: Social Support.** Aldershot, Avebury.

Low Vision Consensus Group. (1999) **Low Vision Services in the UK: Recommendations for future provision.** Draft March 1999.

Moore, M. (1994) "Multidisciplinary low vision care". **Optician 208 (5481)**, 24-27.

NHS Management Executive (1992) **Local voices: the views of local people in purchasing health.** London, NHS Management Executive.

Nilsson, U.L. (1990) "Visual rehabilitation with and without educational training in the use of optical aids and residual vision. A prospective study of patients with advanced age-related macular degeneration". **Clinical Vision Sciences 6**, 3-10.

ONS (1996) **Living in Britain. General Household Survey.** Office for National Statistics. London, HMSO.

OPCS Survey of Disabilities in Great Britain, Report 1-7 1988/9. Office Population Census and Surveys Social Survey Division. London, HMSO.

Robinson, J. and Elkan, R. (1996) **Health Needs and Assessment. Theory and Practice.** Edinburgh, Churchill Livingstone.

Rumney, N. (1992) **"An optometric approach to low vision services". The British Journal of Visual Impairment 10(3)**, 89-92.

Rumney, N. (1998) "Community spirit". **Optician 215 (5657)**, 23-26.

Rumsey, K.E. (1993) "Increasing knowledge about the older population: the role of the geriatric curriculum in optometry". **Optometry and Vision Science** 70(8), 684-688.

Russell, W.B., Harper, R.A., Reeves, B.C., Waterman, H.A., Mcleod, D. and Henson, D.B. (1997) "Randomised controlled design of an integrated versus an optometric low vision rehabilitation service for patients with age related macular degeneration". **Optometry and Vision Science 74 (12S)**.

Shaw C. (1998) "1996-based national population projections for the United Kingdom and constituent countries". **Population Trends 91**, 43-49.

Shuttleworth, G.N., Dunlop, A., Collins, J.K. and James, C.R.H. (1995) "How effective is an integrated approach to low vision rehabilitation? Two year follow up results from South Devon". **British Journal of Ophthalmology 79**, 719-723.

Appendices

Definitions

A person with low vision

A person with low vision is someone who has an impairment of visual function for whom full remediation is not possible by conventional spectacles, contact lenses or medical intervention and which causes restriction in that person's everyday life (Low vision consensus group, 1999).

Such a person's level of functioning may be improved by providing low vision services including the use of low vision aids, environmental modification and/or training techniques.

This definition includes, but is not limited to those who are registered as blind and partially sighted.

The leading causes of low vision are macular degeneration (53.2 per cent), glaucoma (10.6 per cent), cataract (7.6 per cent) and diabetic retinopathy (2.2 per cent). Most of these are age-related and it has been estimated that 88 per cent of all people with severe sight problems are over the age of 60 and 66 per cent are over the age of 75.

A low vision service

A low vision service is a rehabilitative or habilitative process, which provides a range of services for people with low vision to enable them to make use of their eyesight to achieve maximum potential (Low Vision Consensus Group, 1999).

Need

In this study “need” is defined as a self-assessment (by the user) of what they feel that they need from the low vision service.

The term “need” was employed as a verb rather than as a noun. This was done to facilitate research that could establish what people needed to solve problems, rather than whether problems exist.

The focus groups’ methodology

Determining the range of needs

A focus group is a discussion group that is focused around an issue that is common to all participants. It is a research method that is used to elicit spontaneous responses about issues which are important to participants and for identifying the reasons why people find those issues important. Focus groups were used in this study to determine the range and type of needs people had.

The focus group participants

People with low vision are not a homogeneous group and this was reflected in the recruitment procedure for the focus groups; each session was different according to the characteristics of the people participating in it. In addition, as the level of low vision service varies throughout the country, the participants for the focus groups were recruited from different parts of the UK. All recruitment was carried out by local contacts at either voluntary organisations, social services or schools. The location and type of each focus group is shown below in Table 7 and the organisation/agency who identified focus group participants in Table 8.

Table 7 The location of each focus group and description of participants

Location of each focus group	Description of participants (number of people)
Birmingham	People with Punjabi as their first language (3)
London	People of African or Caribbean origin (4)
Newtownards	Women aged over 60 (6)
Barrow-in-Furness	Men aged over 60 (6)
Kirkcaldy	Men and women aged over 60 with hearing loss (6)
Norwich	Men and women aged over 60 with recent sight loss (6)
Aberdeen	Men and women aged over 75 (6)
Cardiff	Children aged between 4 and 11 years (7)
Leatherhead	People aged between 11 and 18 years (3)
Bristol	People aged between 18 and 21 years (3)
Newcastle	People of working age (5)
Truro	Carers of older people with low vision (4)

Table 8 Local organisations providing access to participants for the focus groups

Organisation	Location
RNIB, Birmingham	**Birmingham**
Organisation of Blind Afro-Caribbeans	**London**
Ulster Community and Hospital Trust	**Newtownards**
Barrow and Districts Society for the Blind Ltd	**Cumbria**
Fife Society for the Blind	**Kirkcaldy**
Norfolk and Norwich Association for the Blind	**Norwich**
Grampian Society for the Blind	**Aberdeen**
RNIB Education Centre: Wales	**Cardiff**
Surrey Voluntary Society for the Blind	**Fetcham near Leatherhead**
RNIB Employment and Student Support Network: Wales and West	**Bristol**
Northumbria Sight Service	**Newcastle**
Cornwall County Association for the Blind	**Cornwall**

The focus group questions

During each of the hour-long focus groups, the following issues were discussed:

- good experiences when receiving help to make use of vision
- bad experiences when receiving help to make use of vision
- views on what participants felt that they needed from low vision
- services to help them make the best use of the vision that they have.

Where participants had no experiences of low vision services, they were asked to concentrate on the last of these sections.

Analysis of the focus groups

The transcriptions from the focus groups were "content analysed". This involved identifying and categorising the issues that arose during each section of each focus group.

Questionnaire methodology

Question content

The actual content of each question was entirely informed by the results from the focus groups. Most of the items were taken from the part of the focus group where participants were explicitly asked what they felt their needs were. These were added to by a very small number of issues which were raised as either very good or very bad aspects of current services but which were not necessarily mentioned as "needs".

The sections within the questionnaire (such as equipment, access) were not imposed during the focus groups but emerged during the analysis of the data.

Eliciting responses

The choice of scale used (categories: a lot, a little, none) in the questionnaire was made after an extensive review of other "needs" surveys in the literature. The scale ultimately decided upon was influenced by that used in the "Survey of the Needs and Lifestyles of Visually Impaired People" being conducted by The Office for National Statistics on behalf of the RNIB. The scale used was preferred as it is short (ie a three point rather than a five point scale) which may be easier to use in a questionnaire administered over the telephone. It also allows the respondent to respond that he or she already has a service/feature being asked about. That way, one can tell the difference between not needing something because it is already being provided and not needing something because it is genuinely not needed.

Recruitment

Recruitment of participants was made through social services departments in Northern Ireland, and through local voluntary societies for blind and partially sighted people in the rest of the UK. Each participating centre is listed below. Prospective interviewees were sent an information sheet and consent form by a local contact at each society or social service department. If the prospective interviewee consented to taking part in the study, he or she returned the form (containing the telephone number) to the researcher.

Participating centres

1) Fife Society for the Blind (Kirkcaldy).

2) Grampian Society for the Blind (Aberdeen).

3) Dundee Society for Visually Impaired People.

4) Moy Resource Centre, Co. Armagh.

5) Wilson House Resource Centre, Ballymena, Co. Antrim.

6) Teesside and District Society for the Blind, Middlesbrough.

7) East Sussex Society for the Blind (Herstmonceux).

8) Cambridgeshire Society for the Blind and Partially Sighted (Peterborough).

9) North Wales Society for the Blind (Bangor).

10) RNIB Cymru (Cardiff).

Questionnaire administration

The questionnaire was administered via telephone interviews. These were carried out by interviewers from Opinion Research Corporation International. This is a specialist telephone interviewing company whose interviewers were specially trained for this project.

Our better vision

Campaign report

What people need from low vision services in the UK

First published 1999

ISBN 1 85878 240 6

RNIB

105 Judd Street
London
WC1H 9NE

Telephone: 020 7391 2304
Fax: 020 7383 7613

www.rnib.org.uk