

# **Factors which Influence the use of Low Vision Aids**



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Author: Shelagh Palmer

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2 Queens Crescent  
Glasgow G4 9BW

Distributed by: Visibility  
2 Queens Crescent  
Glasgow G4 9BW  
0141 332 4632

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## Foreword

Low vision aids provided as part of a comprehensive low vision service enhance residual vision and can improve the quality of life of people with a visual impairment.

This study examines the experiences of people who have recently been provided with a low vision aid. It explores some of the individual factors such as confidence, attitude, knowledge and choice that influence the use of low vision aids and examines some of the complexities of defining successful usage.

The study highlights that people do try to use their low vision aids but that they need to know about low vision services, and be encouraged, supported and trained to maximise their usable vision. It demonstrates that for people living with low vision, that confidence or rather lack of confidence and loss of independence and skills has a major impact on quality of life. It reinforces the call for integrated and comprehensive model of service delivery, which provides easy local access, with the facility for review of progress.

Recently, low vision services have received much attention. In England, a new care pathway for low vision services and several models of service delivery are being piloted. In Scotland, the Eye Care Review is currently underway and the interim report is about to be published for consultation. This study can make a valuable contribution to this process and can inform the development of new services. It provides an insight into the experiences of service users and a voice for their views. These views illustrate, very graphically, the need for services to be provided in a comprehensive, holistic, person centred way.

Thanks must go to all those who were involved in this project. Special thanks must go to the participants who gave their time and shared their stories in such an open and honest way, in anticipation that their experiences will be used to shape service provision.

By the end of 2005, recommendations will be in place, which will drive national, and local developments and it is hoped that the reality for people with low vision will change.

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## 1. Introduction

Low vision is a major problem with many people experiencing a diminished quality of life because of their visual impairment.<sup>1,2</sup> Estimates of just how many people are affected vary, depending on the definition of low vision used. The figure most commonly quoted is that there are about 1.7 million people in the UK with serious sight loss. Of these, 90% will be over the age of 60, and many have other disabilities or frailties that add to their difficulties in coping with everyday tasks<sup>3</sup>.

About 95% of those with serious sight loss, have some useful vision and with appropriate low vision support, can be helped to use their remaining vision. There is strong evidence that the provision of low vision services, which include equipment, training and rehabilitation skills, can make a positive difference to lives of visually impaired people.<sup>4,8-12</sup> However a study conducted by the RNIB<sup>5</sup> showed that the provision of low vision services in the UK is unacceptably poor in terms of accessibility, distribution and delivery, with around two thirds of those who would benefit from a low vision aid, not possessing one.

### 1.1 Background

In 2002, Visibility was commissioned by Greater Glasgow NHS Board to review the provision of services for visually impaired people within a defined geographical area. Within the review, there was evidence that whilst many are satisfied with the hospital based low vision service, both staff and patients would like more time and support to be given. Views were articulated that many of the people attending the low vision service didn't know why they had been sent or what to expect, once there.

There was informal feedback that magnifiers / optical devices are not being used and that they lie redundant in the homes of visually impaired people. This anecdotal evidence supports the findings of several studies which show that many people derive little benefit from low vision aids. In 1991, McIlwaine<sup>6</sup> et al reported that nearly one third of patients they studied never used their low vision aid and Humphery and Thomson<sup>7</sup> found that only 23 % of their sample found the low vision aid useful. On the other hand, there are many studies<sup>8-15</sup> which show the success of low vision aids. For example in a study by Biscoff<sup>12</sup>, 80 % of patients were still able to read newsprint five years after being prescribed a low vision aid. However, it is worth noting that this model of low vision therapy provides a comprehensive

package of equipment, rehabilitation, support and training. Similar models are in operation in the UK, although they are not very common. A recent evaluation<sup>13</sup> of such a service in Devon concludes that this integrated approach leads to higher low vision aid usage and higher patient satisfaction.

So what is happening locally? Do people use their low vision aids? What is meant by use? What are the factors in a visually impaired person's life which promote and prevent the use of a low vision aid?

### **1.2 Proposed study**

To explore these issues, a small-scale qualitative study was conducted, supported by a hospital low vision aid clinic and jointly funded by Greater Glasgow NHS Board and Visibility. This study did not set out to evaluate optometric parameters, or demonstrate quantitative changes in functional task performance. It was set up to explore people's experiences of low vision aids, how the aids fit into their lives, what they consider success and what factors influence usage of aids.

This report describes the findings of this study and sets it within the wider context of the Eye Care Review in Scotland, current service delivery and models of good practice. Whilst a small study cannot give a definitive picture across the population of low vision aid users, it can give an indication of the issues which need further consideration, provide an insight into the needs of people with low vision within the Greater Glasgow Health Board area and inform the emerging agenda for the future of eye care services.

## **2. Low vision, aids and services**

Low Vision is a term most often used by professionals and is a generic term for those with a significant visual impairment irrespective of registration status. It is a term which is seldom used by visually impaired people to describe their level of vision. In a study by Pollard<sup>19</sup>, many people did not identify themselves as having low vision, didn't really understand the term low vision and did not understand what low vision rehabilitation might provide. The participants in Pollard's study referred to their vision loss as "poor eyesight", "poor vision" "blindness" and it was only the workers who used the term low vision.

## 2.1 Definitions

In 1999, the Low Vision Services Consensus group produced a framework and recommendations<sup>20</sup> for the provision of low vision services and put forward the following definitions: -

### ***Low Vision***

A person with low vision is one 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 Aid***

A low vision aid is any piece of equipment used by people with low vision to enhance their vision.

### ***Low Vision Services***

A low vision service is a rehabilitative or habilitative package which provides a range of services for people with low vision to enable them to make the best use of their eyesight to achieve maximum potential.

These definitions have been adopted within this report, although the report considers the use of optical low vision aids.

## 2.2 Low vision aids

In general terms, low vision aids fall into two categories, optical and non-optical. Optical aids are devices which seek to improve either near vision or distance vision most often by magnification but sometimes through minimisation, depending on the eye condition. Most commonly, optical aids are dispensed at a low vision clinic within a hospital eye service. Optical aids can also be prescribed and purchased from some community-based optometrists. Often, when people choose to buy optical aids, it is without optometric assessment perhaps from a non specialist shop, a catalogue, or over the internet. There are many instances where the aid is unsuitable for the task for which it is used, or the person is unsure of how to use it and this experience can influence subsequent attitude to the use of aids.

Also important are non-optical aids to support independent living, such as task lighting, liquid level indicators, and "bump-ons" on cookers. Many items are available to be purchased by the individual, but sourcing the items is not easy, and again catalogues and the

Internet are a major source of information. If registered as blind or partially sighted, an assessment of need is carried out and a range of aids are supplied by social work. In areas where good practice prevails, the aids would be part of a rehabilitation package that includes training, information and support. However if not registered, many people are unaware that these local services exist.

In terms of both optical and no optical aids, the range which is available privately is much more extensive in terms of technological sophistication than those on offer within the hospital or social work provision. However sophistication and expense does not necessarily mean “better”, rather it points to the limited choice which is made available by service providers.

### **2.3. Low Vision Services**

The biggest provider of low vision services by far, is the hospital eye services<sup>5</sup>. The hospital eye service (HES) provides a range of different functions and the low vision function of the HES is concerned with assessment and provision of optical devices. There are other important aspects of low vision support such as the provision of non-optical aids, equipment and rehabilitation techniques and these are most often provided by social work departments. Social work departments may subcontract to other organisations such as RNIB, Guide Dogs, or local societies for the blind. Exact service delivery arrangements vary from area to area.

The report of the Low Vision Consensus Group<sup>20</sup> makes the point that the key to good quality low vision services is the local integration of ophthalmic and rehabilitative care and support services. However such integration is not always available and much of the debate about effectiveness of low vision services centres on the lack of integration of the component parts:

## **3. Effectiveness of Low Vision Support**

There is debate<sup>13, 14</sup> about the effectiveness of different models of low vision service provision and concern about the lack of high quality comparative evidence of the different approaches. To date, evidencing the effectiveness of low vision interventions has focussed on two main areas<sup>4,10,11,12</sup>, the service delivery characteristics and quantitative analysis of usage.

### 3.1 Indicators of Success

The indicators of usefulness<sup>4,10,11,12,16,17</sup> of a low vision aids are generally measures such as the change of reading print sizes, duration of reading, frequency of use, and the range of tasks. In many of the studies into low vision aid use, there is the sense that if reading ability has not increased, or that the aid is not used several times a day, then the aid is not beneficial to someone's life. It seems that the quantity and not the quality of low vision aid use is being evaluated. It raises the question of how is use defined and how is usefulness judged? For example, it may be that someone doesn't use the aid very often, but when they do, it is to undertake a task that is important to them and the aid makes that task possible. Many studies explore the functional effectiveness of the aid in isolation from the personal characteristics of a visually impaired person and the context of their life, so what a visually impaired person might consider success, may not be considered successful use by an external agency.

Currently there is a lot of work underway in terms of defining models of good practice in terms of service delivery. Much of the evidence is from countries outside of the UK but there is some evidence from Fife and Devon that interdisciplinary low vision services have a positive impact on the quality of life of service users<sup>17</sup>.

### 3.2 Barriers

Although work is currently being undertaken around services and usage<sup>13,14,16,17</sup>, little attention has been given to issues that may prevent an individual deriving maximum benefit from low vision services. Van Boemel<sup>18</sup> has explored barriers to using aids and accessing low vision services and identifies three main areas for consideration. Van Boemel suggests that the attitudes and expectations of the person may be a barrier, so if there is disbelief or low expectation, then that is the most likely outcome. It is also true that if there is little or no knowledge of either the service or the aid, then there is less likelihood of a positive experience. Secondly the family / carer unit can strongly influence the behaviour of the visually impaired person, both positively and negatively. Finally, the setting in which the service is being provided can make a difference. Van Boemel suggests that a hospital, with busy health professionals, where treatment and cure services are the predominating culture, may not be the right environment.

A study<sup>19</sup> in Australia investigating barriers to accessing low vision services concluded that eye care professionals did not provide people with information on the availability and role of low vision services. They found that lack of understanding of the term low vision and the poor knowledge of the role of low vision rehabilitation were major obstacles to accessing support.

#### **4. Aims, objectives and methodology**

The aim of the study was to provide an insight into factors which influence the use of low vision aids and in particular the factors which promote and barriers to magnifier use.

The objectives of the study were to identify;

- What the pattern of use at 2 months, 6 months after receiving optical device
- What factors help and hinder the use of a magnifier?
- What expectations do patients have of a magnifier and were those expectations met?
- Can indicators be identified which would predict success?
- What are their views about the way in which low vision services are provided?

To ensure patient confidentiality, a selection of patients were approached in the first instance by optometry staff at Gartnavel Hospital and asked if they would be willing to take part. The optometrists were asked to consider patients who were being prescribed magnifiers for the first time. If the patient agreed to take part, the researcher then spoke to them and gave them a large print letter describing the process. This gave the patients time to consider whether they wished to be involved. The researcher then telephoned the patient and arranged a home visit within 2 weeks of their low vision appointment. A second visit was organised three – four months after they had attended the clinic. Each visit lasted about 1-2 hours.

## 5. Profile of the participants

In total, fifty patients were invited to take part, of those, forty accepted the invitation. When telephoned to arrange the first visit, fifteen people declined, with most of them expressing they didn't want someone visiting them at home or a disinterest in getting involved.

“I'd rather not have someone come to the house”  
“I'm too old to be bothered by stuff like this”

Of the twenty-five, who agreed to take part, eighteen were females and seven were males, with the majority of people aged between 75 and 84.

Age	Males	Females	Total
Under 55	1	0	1
Aged 55 - 64	0	2	2
Aged 65 -74	2	3	5
Aged 75 - 84	3	8	11
Aged over 85	1	5	6
	7	18	25

### 5.1 Living arrangements

Thirteen of the group lived on their own. Eight women and one man were widowed and another two men and two women had never married. The remaining twelve of the group lived with others. Ten of the group lived with their partners, five with husbands and five with wives, whilst one lived with her sister and one lived with her daughter.

If the living arrangements are broken down by age and gender, ten of those living on their own are over the age of 75 and nine of those are women.

### 5.2 Registration

When asked whether they were registered (blind or partially sighted) or not, twelve people were uncertain. As the interviews progressed, they described interventions indicating that there had been some social work involvement, which increases the likelihood that they were in fact registered.

“a woman came out and gave me a white stick and put dots on the cooker”

“a got a letter from social work about visiting me, how did they get my name?”

Ten people could give a definite answer about their registration status and knew whether they were blind or partially sighted.

In terms of referral data held by the optometry department, it can be seen that thirteen people were registered and the majority of those were aged between the ages of 65 and 85. For those who were not registered, the majority were aged 75 and over.

<b>Age</b>	<b>Registered</b>	<b>Not registered</b>
Under 55	1	
Aged 55 - 64	1	
Aged 65 -74	4	2
Aged 75 - 84	5	4
Aged over 85	2	6
	13	12

### **5.3 Eye Condition**

No attempt was made to recruit patients with the same eye condition or the same level of vision. The intention was to have a cross section of patients attending the clinic, with different levels of vision, receiving different types and strengths of aids. This was to give an insight into whether there were any common themes for people irrespective of the clinical factors.

Of the group of twenty-five, fifteen people were clear about their diagnosis, ten of them thought they had ARMD, one with diabetes, two with cataracts, one with glaucoma and one with iritis.

Four people said their condition was something to do with ageing, and of those, three people made comments which indicted that they had ARMD.

“said it was old age and wear and tear”

“all they ever say to me is regeneration or something like that”

“can see with the outside of my eye but not the inside, but don’t know what to call it”

<b>Eye Condition</b>	<b>Person's View</b>	<b>Records</b>
Age Related Macular Degeneration (ARMD)	10	19
Ageing	4	
Glaucoma	1	1
Cataracts	2	
Iritis	1	
Multiple Conditions	0	3
Diabetic Eye Disease	1	2
Don't know	6	0

Of the group of twenty-five, six people didn't know what their eye condition was.

“wondered if it was something to do with my stroke”

“think it is scratches on my retina”

“I have hardening of the arteries so that has something to do with it”

When optometrists examined patient records, a slightly different picture emerges, with the majority of people having ARMD and three people having a combination of conditions.

## **5.4 Health Problems**

In addition to problems with their sight, fifteen of the group admitted to other health problems and three have more than one additional condition. The most common conditions are heart problems (5) and diabetes (5). Other conditions include stroke, arthritis, asthma, hearing problems and back problems.

## **5.5 Aids Dispensed**

As mentioned, the study is not about the technicalities of how and what was prescribed for people but about how people manage with the aid they were given. Just over half the group were given a hand held magnifier often in conjunction with tele-binoculars, or pocket sized magnifiers. Of the group, ten people were given one item, nine being given two items, and six people were given three items.

Type of Aid	Number
Hand Held x 2.5 – 3.5	5
Hand Held x 5 - 7	6
Hand Held X 8 -12	2
Pocket X 2 - 4	3
Pocket x 5 -10	2
Dome	5
Telebinoculars	4
Stand magnifier	5
Easy View	2
Telescope	3
Near view Binoculars	2

In terms of strength of magnifier, there were two people who were given magnifiers of magnification of x 8 or above and another 6 who required above x 5. This is significant magnification and was needed by one third of the group, with just less than a third of the group needing only low magnification.

Interestingly, the optometry records for each patient were checked one year after the study, and four people had returned for another assessment. A further two people had returned to be assessed, so it would seem that for these seven people at least, there was sufficient interest in a low vision aid to be re-referred.

## **6. Living with Low Vision**

All those who took part were interviewed using a semi structured interview schedule (appendix 1). The questions were designed to help them to reflect on their lives now, and their lives “before” when they had no sight difficulties. The interviews were taped, transcribed and analysed for common themes.

### **6.1 What I miss**

Nearly 70% of the group said that they missed being independent and being able to do things on their own. It was clear that the participants didn't like depending on other people to do things like read their mail, take them shopping, drive them around.

## Factors which Influence the use of Low Vision Aids

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<b>What I miss or find difficult</b>	<b>Number</b>
Being independent	17
Reading books	16
Doing things / Going places on my own	12
Watching TV	10
Travelling / Going abroad	10
Knitting, Sewing, Tapestry, Crochet	9
Shopping	9
Reading the paper	8
Baking and cooking	8
Gardening / weeding/ cutting grass	7
Seeing bus numbers	7
Reading my own mail	7
Driving	6
Playing bowls, golf, clubs	6
Not recognising people, can't see faces	5
Crossing road	5
Seeing my food / pouring drinks	5
DIY	4
Writing	4
Handling money	4
Putting on make up, nail varnish	3
Doing the crossword	3
Going into town	3
Singing in the choir / can't read music	3
Hobby was model trains, now too fiddly	1

They really missed the spontaneity of being able to do what they wanted to do when they wanted to do it. They also really missed their hobbies knitting, gardening, sport or the choir.

“I love baking and cooking and I've been told we can get some talking scales so I hope they will help”

“used to love knitting and sewing and sometimes I feel I am just sitting”

“biggest change is I can't get out on my own, I can't just get into my motor and drive”

“I was a tailoress all my life I made all the clothes for my family, now I can't even thread a needle”

## 6.2 Boredom and Loneliness

Throughout the interviews, there were strong feelings of boredom being expressed, as people now found it difficult to fill their days. In addition to the boredom, for some, but not all, isolation and loneliness were real problems.

“It is such a long day with nothing to do. I wake really early and I’ve got all my housework done by 9.00am so I go into town. I can get a bus from just outside the door. When I get home I have my tea and go to bed. I can’t see the telly so what is the point of staying up. The radio is my best friend. I put it on the pillow at night and I go to sleep listening to it”

“Since I moved here I don’t know anyone except my brother and I get terribly lonely at times. He comes once a week to take me to supermarket, on Mondays, we have our dinner but then I have to get through the whole rest of the week on my own. I used to read avidly and it is dreadful not to be able to read books or watch TV”

## 6.3 Level of Support

When examining the range of tasks that people find difficult or miss being able to do, it is worth noting that several of the participants were well supported and many of the household tasks were done for them. This is particularly true for those living with a partner, or other family member and particularly relating to shopping and cooking.

“My daughter does all my shopping and I walk up the road to my son’s house for my dinner every night, or he brings it down for me and I microwave it. He is a chef so it is always very nice”

“My husband has problems with his legs and I have the problems with my eyes, so we get by with my legs and his eyes”

“My wife is just great, she cooks, she drives and if it wasn’t for her encouragement and support, I don’t know what I would do. It is a real turn around, all our married life I brought her tea in bed. I still try to do it, but most of it is in the saucer, but she doesn’t complain”

“My daughter does everything, I think I could still cook a meal if I had to, I make a cup of tea with that wee thing that hangs over the cup”.

## 6.4 What the aid is used for

Participants were asked about what they used their low vision aid for and again a range of tasks was identified. Whilst the list has similarities to the range of tasks that participants were finding difficult, there are some exceptions such as cooking, or gardening. Generally this was because either people didn't find the low vision aid useful for these tasks, or someone else carried out the task and therefore they didn't need to use the aid.

"I tried to use it to help me knit but it is just too awkward"

"It doesn't help me do the wee things like pour a cup of tea or sew on a button"

Activity	Number
Reading the paper	14
Reading instructions	13
Reading letters	12
Reading TV programme	10
Bills, receipts, hymns	10
Bank statements	9
Watching TV	8
Controls on cooker	7
Packets / tins	6
Medicines	4
Doing the crossword	3
Bus numbers	3
Sorting money	3
Recipes / knitting	4
Playing bowls	2

Two people found that with their low vision aid they were able to carry on playing bowls and three people use them to see bus numbers. In the main, the low vision aids were used for reading small amounts of text or for watching the TV.

"I've astounded my husband, I read my prescription and this morning a letter arrived and I could see which one of us it was addressed to "

Sometimes this use of the magnifier to read sell by dates, or bills etc is referred to as "survival" reading. This is when people use aids for tasks which are important to them, tasks which they do not want

someone else to do for them or they may have no choice but to do themselves through lack of support.

“I get a lot of information, bank stuff, housing stuff; I don’t want my neighbours reading that to me”

## 7. Usage of a low vision aid

At both the first and the second interviews, people were asked how often they used the aid. Generally the question elicited a fairly vague reply except for those who felt that the aid was of little use to them. In fact there were only two participants who did not use the aid from the outset. For one of the participants, it was because she found it awkward due to arthritis. However the other participant was finding it difficult to adjust to his sight loss and could not see the value of a magnifier.

### 7.1 Frequency

All of the remaining participants were asked to define more precisely how often they use their aid.

	First Interview	Second Interview
Several times a day	17	8
Once a day		3
Every 3 / 4 days	5	3
Once every week	1	7
Once a month		
Rarely	2	2
Never		2

Of the twenty-five participants, twenty-three reported that they had used the magnifier, with 70% of participants stating that they used the magnifier several times a day. This had fallen to 32% by the second interview. The number of people who used their aids 3 / 4 days a week or more had fallen from 88% to 56%.

No attempt was made to judge whether the person was using the aid correctly, but four of the people interviewed asked for advice. One person was of the opinion that there was something wrong with the design of the low vision aid because he couldn’t get the aid flat on the page and kept losing the place. It may indeed be the case that the design of the magnifier could be improved but it also seemed to indicate an uncertainty over technique. No attempt was made to

evaluate whether the lighting conditions were optimal, but observation suggested that for many people it wasn't, with little awareness of its importance.

## 7.2 First Interviews

The first interviews were carried out between two to four weeks after they had been given the aid. Four of the group actively expressed views that the aid had made a significant difference to them.

“got two magnifiers and see that wee one, it is just magic, there were lots of things I couldn't do, and now I can”

“those aids they gave me at Gartnavel are brilliant, this one is good for reading the paper and these are great for the telly”

All but two people in the study had tried to use the aid, but with varying degrees of success. Almost everyone expressed some degree of frustration and surprise that aids were tiring and difficult to use.

“it is so frustrating especially when you are in a hurry”

“thought it would make things clearer and easier to read, but it isn't that simple”

“have you ever tried one, it is really hard, you need to just persevere”

“it is tiring so only try it for a short time then go back to it”

## 7.3 Second Interviews

By the second interview, there was a noticeable drop in usage. The second interview was carried out between 10 and 14 weeks after the first interview. The maximum length of time anyone had use the aid for was eighteen weeks and the shortest was twelve weeks. Over this period of time, it seemed that participants had decided what it was worth using the device for, and which tasks were just too difficult, tiring or time consuming.

“can't get the hang of the hand held magnifier, still trying to use it most days but it is a struggle, to read across even a line is difficult”

“ I don't use it a lot, not even everyday because I find it such a strain”

“tried the hand held but just can’t read a book so use it for bills and receipts”

“ don’t use it for the paper it is too difficult with the columns but packets, prices and bills that sort of stuff is fine”

Participants were a lot less excited about the aid by the second interview. In the first interview, there were expressions of hope and that they were going to make it work even if it was difficult. Some of the early enthusiasm had worn off by the second interview although for some it was now an important tool for them, part of day-to-day life.

“there are still frustrations but they are now minor”

“I just couldn’t do without them, I have one in the kitchen beside the microwave, this one by my chair and then the one I use all the time is in my handbag”

## **7.4 Spectrum of Potential**

Within the group, it would seem there is a spectrum of potential use of the magnifier. At one end of the spectrum are those who do not believe that a magnifier is of use. In the first interview, two people used the aid rarely and felt so negative that it could be argued that little could be done to change their views. By the second interview, they had stopped even trying to use the aid and had been joined by another two who admitted that they rarely used the aid. This group could possibly be described as the “doubters”.

“what I wanted was help with my eyes, I went to Gartnavel and all they gave me was a wee magnifying glass, it is no use, it doesn’t help at all”

At the other end of the spectrum are those who could be described as the “determined” and want to use all the resources at their disposal. Initially there were seventeen who seemed prepared to try the aid but this had dropped to eight by the second interview.

I’ve had a good and interesting life. Sometimes you have to push yourself if you want to move forward and I don’t want to go back”

“I can read the paper with it, but it takes me hours, but then I’ve got hours”

In the middle, there is a group who could be considered as “undecided”. By the second interview, this was a group of 13 people, just over half the group, whose use of the aid could possibly be enhanced by extra support and training.

“makes it a bit better, but not as good as I thought”

“it is stressful because you know you are struggling and you say to yourself is it worth it”

It is this middle group who could be influenced positively or negatively and may well be more susceptible to their environment both personal and in terms of the quality of service delivery. A supportive, encouraging environment either within the home or as part of a service could promote the use of the aid. Equally those who feel unsupported may move more towards the negative end of the spectrum and reach a point where no amount of encouragement and support would help.

### **7.5 Attitudes and Acceptance**

It would also be easy to assume that those requiring higher magnification and therefore with greater degree of sight loss, may have a more negative attitude than those who only need small amounts of magnification. Equally, assumptions could be made that those who lived on their own might find it more difficult to manage, as they had no help. In fact attitudes and acceptance of sight problems differed from participant to participant almost irrespective of support or severity of sight problems. The following cases illustrate the polarity found.

The first is a married man, whose children live close by, who isn't registered and who was given a low magnification aid.

“I used to be a chauffer and now I can't even go out my front door. I feel like a prisoner, and may as well be dead. TV is just a blur; glare is a problem, can't see anyone's face and can't even make myself a cup of tea anymore. Don't go out it is too dangerous, I'd get myself killed. I just can't accept that my eyes don't work, it is a living death”

This is in contrast to a widow living on her own, no children, and nearest family living several hours away, registered blind and has a high magnification aid.

“There is a wee lassie who lives up stairs who pops in to see if I am ok but otherwise I don’t see anyone. I retired when I was sixty and about three weeks later my husband took a stroke. I nursed him ‘til he died a few months back, blind or no blind I cared for him. I have a home support on a Monday and she takes me to the supermarket but the rest of the week I manage. I do my own house work, my washing, cooking, what else have I got to do with myself. I’ve got a gadget for pouring and button things on the cooker and washing machine. I manage fine but then I have to don’t I, there isn’t much of a choice”

These two cases provide an insight into the spectrum of attitudes to coping with a low vision. Across the group there was little that could predict how an individual might react to the situation in which they found themselves. It seemed to be linked to an intrinsic quality, shaped by life experience. This is reflected in the answers people gave when asked to describe their attitude to coping with low vision.

“wish it were different, but it isn’t so get on with it”

“a lot is about being happy with what you have got. I was widowed young, brought up two children and kept a job, now I feel very fortunate and have no worries”.

“time weighs heavy, sometimes I think I’m depressed here I am three score years and ten, can’t see, can’t hear and a dickie heart”

“my friend is very good to me, she says no more of this crying nonsense, there are people a lot worse off, which I admit but that’s not helping me”

“I think it is your religion and the way you have been brought up, I’ve got through life happy with what I’ve got”

### **7.6 Expectations**

When asked about their expectations of the low vision aid clinic, fourteen of the group were not very sure what would happen. In fact, there seemed to be a level of confusion because they had been told that nothing could be done for their sight. The remaining eleven of the group were clear that they were going to be given things to help them see. Two of the participants had asked to be referred because they had heard of low vision aids and thought they might be useful and one was advised by her GP to attend.

“I was told that I would get an appointment for the low vision clinic at Gartnavel but I thought they would give me glasses”

“wasn’t sure why they were sending me to another hospital because they said nothing could be done, but it was great”

However, many were disappointed by the aids because they didn’t match their expectations, but it is important to note that didn’t mean that the participant didn’t use the aid.

“wouldn’t say that it doesn’t help but it isn’t easy”

“thought it would make more of a difference, but it is still worth it”

“its disappointing they have done less than I thought they would”

### **7.7 Appearance of aid**

Five participants admitted that they didn’t use their aid in public because it was cumbersome. They felt embarrassed and were worried that they might be ridiculed.

“I get embarrassed when I can’t see the prices but would be even more embarrassed to get that thing out in a shop”

“I’m a bit self conscious, I know people are looking at me but try not to let that stop me”

“it is partly embarrassment that stops me using it when I’m out”

## **8. Views on low vision service provision**

Many of the participants commented on how helpful they found the staff at the clinic. About half the group (10) said they had been able to try many items, whilst for the others, the choice seemed to be more limited. However, three people said that despite the pleasantness of the staff, they found the whole thing a difficult experience, as they had to face the fact that their sight would never return and that all that could be done was to be given a gadget.

“tried lots, that girl was first class, she really worked hard to try to find something to help me with my bowling”

“when I got the magnifier, tried lots of different ones, they just kept asking is that better or worse, you end up not knowing”

When asked about whether they had been given instructions, again there was mixed opinions, with eight feeling very clear about what the device did and how to use it. Another ten people said that it was only after they left the clinic and tried to use it, did they realise that it wasn't quite so easy. Six of the participants felt quite strongly that they should be some training available and fifteen people mentioned more support would help. Various suggestions were put forward as to what and where that support might be given. Several of these included suggestions about the return of equipment which wasn't being used.

“there should be proper training and support, too many people end up teaching themselves, like me. What about a group, there must be loads of us struggling on our own?”

“what I would suggest is that you are given a return date and then we could give back the ones we don't use and try other ones”.

“I think the low vision clinic is good. You have to make an appointment and I understand why, but I think it could be more open especially to people that they have already allocated them to.”

“It would be quite difficult to come back because of the travel, would be better if the service was more local”

“you leave the hospital and by the time you get home you can't remember, if there was a class or something”

“I think you should be contacted from time to time to see how you are getting on someone could phone, or you could come back to the hospital after maybe six months”

## 9. Summary of factors influencing usage

From the interviews, it would seem that there are several factors that influenced whether people used their low vision aid. These can be summarised as follows:

<b>Factors which Promote (Positive Factors)</b>	<b>Factors which Prevent (Negative Factors)</b>
Quick success in using the aid	Difficulties / Embarrassment
Ease of using the aid	Doesn't meet expectations
Encouragement to be independent	Overprotective social circle
Support and training	Left to "struggle on" themselves
No other choice	People doing everything for them
Positive attitude / acceptance	Negative attitude / defeat sense of hopelessness

For many people in the study, both positive and negative factors seemed to be in operation and no real pattern emerged across the group. What is clear is each person makes an individual choice as to how frequently and for what task the aid is used. This is different for different people and reinforces the need for services to cater for a wide range of individuals with a wide range of needs. The study also demonstrates that the technique of survival reading should not be underestimated and that frequency of use alone is not a good indicator of usefulness.

The study highlights that the more positive factors experienced by an individual, the more likely it is that the person uses the aid. If the concept of a spectrum of potential is used then, it would seem that the majority of people in this study were in the middle group of "undecided". This study suggests the factors influencing usage may have a bigger impact on the "undecided", tipping them either way. However, there is little doubt that for the majority of people further support, in particular, encouragement to use aids, practical advice,

and emotional support would be welcomed. This may translate into higher patient satisfaction with the aid, and may also be reflected in the frequency of use.

## **10. Low vision services locally**

It is important to position the experiences recorded in this study within both the local, and the emerging national context of low vision service provision.

In the Greater Glasgow Health Board area, there is one low vision clinic based in the eye department of Gartnavel Hospital, one of the busiest ophthalmology units in the city. As an initial stage of the study, optometrists from the clinic were brought together to share their perceptions of and describe the way in which the service currently functions.

### **10.1 Low vision clinic**

There are two dedicated clinics each week. The current waiting time for a low vision appointment is 3-6 months. The service sees around 900 people every year and the patients can be referred from ophthalmologists within the eye department, and from other hospitals and GP's. The criterion for referral is not based on registration status and a patient can be seen at the low vision clinic whether they are registered or not.

### **10.2 Source of referral to clinic**

Appointment data suggests that the majority of the referrals to the LVA clinic are tertiary, and internal to Gartnavel, although there are also a significant number of tertiary referrals from other hospitals. Cross border referrals from other Glasgow hospitals and other health board areas in south, west and central Scotland are necessary because of the lack of low vision services in these areas and because the eye department at Gartnavel Hospital is a centre of excellence for certain specialities. The specialist nature of Gartnavel may also mean that there is an additional level of complexity of cases seen.

Views were expressed that the tertiary referral happens not necessarily because the value of low vision aids is well understood within the medical world, but because no further treatment options are available. Often the only avenue left for the medical staff, before discharging the patient from the hospital, is to refer to the low vision

service. It is a last port of a call within the hospital-based services and the referrer at least feels they are doing something positive at an essentially negative time. The reality of this approach is that many people's lives are already significantly compromised by the time they reach the low vision aid clinic and that it is "too little, too late" in terms of referral procedures to the low vision service.

### **10.3 Lack of awareness of service**

Optometry staff expressed views that many of the patients referred to the low vision clinic didn't know why they were there and/ or had unrealistic expectations of what a low vision aid could do. It seems as though there is a very strong case for better explanation of the function of the low vision clinic to be given to patients and better public and professional awareness of the role of low vision services is necessary.

### **10.4 Clinic appointment**

Patients are give an appointment which lasts about 45 minutes and if the assessment demonstrates that an aid would be a useful, then the aid is usually available to take away on the same day. Records reveal that most patients are prescribed at least two optical aids, most commonly a handheld magnifier and a dome. During the interview some time is devoted to teaching how the aid should be used. No information, either written or taped, is given to the person, which means they need to rely on the verbal instructions and "trial and error".

Patients are told that if they are having problems or wish a return visit, to contact the clinic directly, if it is within a two-year period. However if a return visit is needed outwith this timescale, a second referral needs to be made by the request of GP, support agency or ophthalmologist.

### **10.5 Patient support service**

Previous research<sup>23</sup> by Visibility highlighted that people facing serious sight loss need to know what help is available and from where. This work led to the establishment of a new patient support service based within the eye department at Gartnavel Hospital and managed by Visibility. In its first year, the patient support service saw 720 people and of those, the optometry department referred 161 people, who required advice and support. This demonstrates that optometry staff

recognised the need for such support. The patient support service acts as much needed bridge from the hospital services to community based services giving people information and advice about where to find equipment and support locally.

## **10.6 Potential demand**

Statistics<sup>22</sup> from the Scottish Executive show that in Scotland in 2003, there were 38,000 people registered as blind or partial sighted and in the same time period there were 3,491 new registrations. This means that approximately 9% of all registrations are new registrations. In Glasgow City Council area there are 8238 people on the register and approximately 750 new registrations per year, suggesting registration alone could absorb almost all the available service at Gartnavel. In fact the service sees registered and unregistered people in about equal proportions. However, as discussed, registration status is not a good indicator of need, with many unregistered people having difficulties with day-to-day tasks that could be alleviated by the provision of low vision support. It is difficult to estimate the potential demand for the low vision services, but it seems clear that it could be far more than the 900 cases per year currently seen.

## **10.7 Integration with rehabilitation**

In the Greater Glasgow Health Board area, all other low vision support including mobility training, daily living skills, task lighting, and non optical aids such as talking watches, liquid level indicators, etc should be provided by local social work departments. However, patients attending the hospital clinic can live in any one of twelve local authorities in the West of Scotland. Each of the twelve local authorities operates a different model of service provision. Some social work departments have specialist visual impairment teams with trained rehabilitation staff, but many do not. In those areas where there are no rehabilitation staff, services may be purchased on behalf of residents requiring specialist support. In reality, the demand for specialist support for people with a visual impairment far outweighs the supply and results in long waiting times.

Clearly there is high demand on optometric and rehabilitative provision. The current structure of a centrally based hospital service and community-based social work support makes it difficult to provide an integrated, easily accessible service. The need for integration across health and social care is not new but is at the heart of the problems with supporting people with low vision.

## **10.8 Gaps and Opportunities**

When the optometry staff were asked to identify the gaps and opportunities in the current system, the need for follow up support for patients attending the low vision clinic was identified. There is a clear, unmet need to bring patients back for a review to see how they are progressing, provide further instruction, or change the aids.

However the service currently runs at capacity but suggestions were put forward that this type of support and follow up could be offered as a community based service or even a domiciliary service. Views were expressed that staff who had undertaken specialist low vision training rather than an optometrist should / could run such a service. If home visits were also part of the remit, the adequacy of lighting could also be assessed. These tasks are usually the domain of the rehabilitation officer, but not all local authorities have such a post, and where they do exist, they seldom work in tandem with the low vision clinic at Gartnavel.

It was clear that optometry staff wished to be able to provide a more holistic, integrated service with the facility to review progress of patients. However there was also an acknowledgment that it is difficult to achieve within the current model of service delivery. There was much discussion of the role of community optometrists and the way forward was seen as community-based services which could provide and support people with optical low vision aids. Such a service could also have a domiciliary function similar to that already provided by community optometrists but widened to include the prescribing of optical low vision aids. There are a few community-based optometrists who already provide a low vision service but the cost of the aids is borne by the patient and there is no link to rehabilitation services.

## 11. National picture

A study by the RNIB<sup>5,21</sup> and Moorfields Eye Hospital, London that examined the nature and extent of low vision services in the UK, found that the standards of service provision varied widely across the country.

“the provision of low vision services in the UK is unacceptably poor in three fundamental areas: accessibility, distribution and delivery”

Some areas of the country had no low vision services at all and therefore people had to travel long distances. This may mean that they do not attend and self select out of the process. Some areas have very restrictive referral criteria therefore the service was not an offered to many people. For example, some services use registration as the sole criterion for referral to a low vision service. If registration alone is used, it acts as a gatekeeper with many unregistered people who would benefit from ophthalmic and rehabilitative care and support services being denied access.

In the recent report from the AMD Alliance International campaign published in 2003 achieved these standards and the report concluded that:

“The receipt of low vision services in the UK remains a postcode lottery. Some areas have excellent easily accessible services whilst others have none at all..... With adequate funding and commitment from relevant professionals community based low vision services need to be established that respond to local need and which are easily accessed by those people needing them and not just those who meet the criteria for registration.”

### 11.1 Pilot projects

The NHS Eyecare Services review in England has developed a new patient centred pathway for low vision and rehabilitation. As part of this process, eight pilot sites have been established, with four of these examining integrated practice for low vision services. It is hoped that the evaluation of these pilot sites will provide baseline guidance and standards for the future delivery of low vision and rehabilitation services.

In Scotland, the review of eye care services is currently underway and again several different models of service delivery are being piloted and the evaluation of these projects which will be used to inform future developments.

### **11.2 Key elements of a low vision service**

Within the framework and recommendations for low vision services<sup>20</sup> as set out by the Low Vision Consensus Group, the key elements of a low vision service are defined as:-

- Planning the rehabilitative process, setting goals and support in understanding the limitations involved
- Addressing psychological and emotional needs
- Providing information and advice
- Assessing the person's visual function and providing aids and training
- Facilitating modification to the home, school and work environments
- Support to include the family / carers

The report recommends that these key elements can be taken forward through the creation of local Low Vision Services Committees (LVSC). By December 2004, 66 of these LVSCs had been set up across England, with representation from health, social care, education and relevant voluntary sector agencies. Warwick University was commissioned to evaluate how much progress has been made since the launch of the concept in the 1999 report. They conclude<sup>30</sup> that LVSCs have made significant progress but also that they have faced significant difficulties. Their key strength is seen as the potential to provide a mechanism through which consultations with service users can be facilitated and links between service providers can be developed. Currently there are no Low Vision Services Committees in operation in Scotland.

### **11.3 One model of good practice**

Many of these key elements are evident in the low vision service in operation in South Devon, the service has been able to demonstrate high patient satisfaction<sup>16</sup>. The service sees about 1,000 patients a year, with about nine new patients and eleven follow-ups each week.

The initial part of the consultation is with a low vision therapist and focuses on a discussion of the condition. This is followed by an

optometric assessment that concentrates on the person's visual needs, aspirations, visual acuity, field loss, and the lighting needs. From this, the level and type of magnification is determined and a selection of aids is offered for trial. Guidance and training is given and in 99% of the cases, the patient leaves with their new aids.

Following this low vision assessment, the patient is taken to see the rehabilitation officer from the local social services team who is based within the same unit. The rehabilitation officer reviews the social and rehabilitation needs and discusses outstanding issues. Any equipment such as task lighting, liquid level indicators, talking watches that is deemed helpful is dispensed and an appointment for a follow up home visit is made. The service operates to a defined standards and performance is measured against these, with 100% of patients giving a rating of at least satisfactory and 65% of patient using their low vision aids more than twice a day.

### **11.4 Other models of good practice**

In the UK other models are in operation, such as Fife and Birmingham, and common to these services is the interdisciplinary team approach. In Northern Ireland, the low vision services were only provided in large hospitals, very much like the Gartnavel model studied here. However, recently there has been a move towards integrated hospital and rehabilitation services<sup>25</sup>, and now satellite clinics are operating, opening up access to low vision services outside of the major cities.

In Wales, a new project funded by the Welsh Assembly<sup>24</sup>, to provide low vision aids in the community is currently underway. This is in response to problem of accessing centrally based, hospital services given the rural nature of Wales. Community based optometrists are being trained and accredited to provide low vision services free of charge.

Many of these developments are changing the way in which low vision services are delivered. It is hoped that any further developments in low vision services look at a person centred integrated approach across health, social work and voluntary sector.

## 12. Wider context of assistive technology

Many people with a disability are given equipment to aid them live their lives. In this wider context, some research has been done into non-use of assistive technologies. Wessells<sup>26</sup> et al reviewed the current literature in this field and comments that:-

“Most studies so far have been of a quantitative nature but non use is a complex subject with many variables among which several have to do with the personal characteristics of the user”

This was very much the premise that drove this study, to provide qualitative data on the views of visually impaired people about the aids that they have been given. Wessells identified four main categories that influence the use of technology and there are some very interesting parallels with this study.

<b>Non Use of Assistive Technology</b>
<b>1. Personal / Client Factors</b> Age, gender, diagnosis Own expectations Expectations of social circle Acceptance of disability Emotional maturity Inner motivation Severity of the disability Use of multiple devices
<b>2. Related to Device</b> Quality of the device Appearance of device
<b>3. Related to Users Environment</b> Social circle support Physical barriers Presence of alternative opportunities Marketplace
<b>4. Related to the Intervention</b> Taking users opinions into account Instructions and training Correct provision Follow up service

## **12.1 Personal factors**

Whilst factors such as age, gender, diagnosis have been found to affect whether someone is likely to use an aid, research<sup>26</sup> has shown that those who use assistive devices can be characterised as emotionally mature, having inner motivation, patience and striving for independence. This is true for many people in this study. It would seem that those who have reached a point of acceptance of their sight problems, yet are striving to be independent, are those who are using the aids to their greatest advantage. Also those who have fought what they consider to be “ bigger battles” consider their sight loss as just another thing to overcome, and if aids will help, then they are used.

Research<sup>27</sup> into the field of non-use has also shown that the more severely disabled someone is, the more dependent they are on the device and the more likely they are to use them. It would be difficult to say that that is true in this study, but there are certainly two people with major eye problems who rely heavily on their aids.

An important motivator<sup>27</sup> in the use of assistive devices is the meaningfulness of the occupation being facilitated. If the task is important to the person, then they will use all means available to complete the task, equally the reverse may be the case. This may explain the finding that those who feel they have no choice and they want to complete the task, tend to use the aids more. This also supports the idea of survival reading, where aids are used for specific tasks which the visually impaired person feels are important to them.

## **12.2 Factors related to the device**

Wessels puts forward evidence that both the quality of device and the appearance of the device influence use. Again this is echoed by this study. Those who were concerned with appearance of the low vision aid were less inclined to use them. The small pocket magnifier or dome evoked the least amount of embarrassment and were used more often. Personal choice, based on the appearance of the aid, goes some way to explaining the absence in this sample of the more complicated devices such as spectacle mounted Keeler type aids.

## **12.3 The Environment and the Client's Environment**

The impact of social support on the use of aids has some interesting parallels. The literature review<sup>26,27</sup> identified that the presence or

absence of a social support circle affects the degree of device use. Those who use devices, indicate that their circle of support provides encouragement to use the device. There is evidence of this within this low vision aid study, where partners / family members support and encourage the use of aids as a route to independence. However, it is also the case that those who lack social support, rely on the aid far more, as evidenced by the survival reading.

Sonn<sup>28</sup> found that the primary reason for non use was that the device was too complicated and certainly there were those in this study who found the device difficult to use, and “gave up”. If people were made aware of the intricacies of using a low vision aid and the fact that it might take a significant period of “training”, then expectations would be more realistic.

For people with a visual impairment, the environment can have a major impact. This is true of both the hospital environment and the home environment. In this study, the eye department at Gartnavel hospital is a busy place and the majority of people from the study group weren't very sure of why they were there. Against this background, they are assessed, given an aid and instructed how to use it in a short space of time, perhaps not an ideal environment. This supports the view of an integrated service which would allow for training and follow up both at hospital and within the home.

### **12.4 Intervention related factors**

Wessels's paper states that devices are used more when opinions of the prospective users are taken into account, and proper instructions / training is given.

A common theme expressed by participants in this study is that the aid appeared to work in a clinic setting with optimal lighting. Several said that they emerged from their low vision clinic appointment slightly bewildered. This situation worsened when they got home and tried to use the equipment, as they couldn't remember what they had been told. In addition to which, they were trying to use the aid in less than optimal lighting conditions rather than a well lit clinic

This system of “one off” appointment at the low vision clinic coupled with physical barriers such as poor lighting means that the chance of a successful use of the aid is significantly reduced.

## **13. Discussion**

Previous studies into low vision aid use have been essentially quantitative and focussed on the issues such as task performance and frequency of use. Some studies have examined service delivery characteristics and issues such as lack of awareness of services, waiting times, etc.

This study set out to explore the way in which people use aids, but in a more holistic way. Frequency of use was recorded but so was the narrative from people about living with low vision and how low vision aids fit into their life. It is a small-scale qualitative study and with such methodology goes the possibility of bias. It could be argued that the study group may have been self-selecting with only those who had an interest in using the aid accepting the invitation to participate. Equally their participation may have made them give a more positive view of low vision aid use than they actually experienced. However, since the study is qualitative and was not set up to measure usage, the numerical data is of less consequence than the wider picture of factors which need to be considered.

### **13.1 Changing the Factors which influence use**

Trends found in this study have been examined in parallel with the wealth of literature into the non-use of assistive devices. Setting the study into this context, allows comparisons to be made. Indeed the findings from this study support the view that there are four main categories of factors influencing the use of assistive technologies. Whether the influence of each of these categories has an equal impact is less easy to define.

It is clear the personal characteristics have a profound effect on usage. At first glance it would seem that these are difficult to accommodate within a model of service delivery. However a high quality service, offered as part of a holistic and integrated service could minimise the influence of some of the negative personal characteristics and maximise aspects such as positive expectations, acceptance and motivation.

### **13.2 Choice and Use**

This study shows that the frequency of magnifier use does drop, but that the majority of people in this group use the magnifier perhaps once a week for tasks which are important to them. Gitlan<sup>29</sup> found

that use in the first month after discharge could predict later use and that the client's anticipation to use the device was the strongest predictor of use. In this study, use dropped dramatically between the first and second interviews, from seventeen (68%) people to only eight people (32%) using the aid several times a day after 4 – 6 months. This is evidence for the need for a review of usage after 1-2 months.

The study showed that aids are used when and how the participants wish to use them. If the task was reading the newspaper, then the aid was used everyday and if it was for checking the bank statement it was monthly. The terminology of survival reading is very appropriate, but for many this is disappointing and frustrating, as they had hoped to read again with ease. The magnifier did not fulfil the expectations of the most of the group, but was still seen as a useful tool. Some of those interviewed felt very positive about the magnifier, because it allowed them to continue tasks and in few cases continue with hobbies such as playing bowls and bingo.

### **13.3. Difficulties**

Most people gave the impression that the magnifier, even in a small way, helped them retain some independence, with 88% using the aid every 3 or 4 days. However those who seldom used the appliance felt that it didn't really help and found it difficult to use. It appears that there was no acknowledgement that optical devices can be difficult to use and that practice and training are important components of success. This validation of effort can make an important difference to people's motivation.

Some of the participants may have found the aid difficult to use because they were not using it correctly or may have been trying to use it in poor lighting conditions. This was not something that was assessed, as the technicalities of the low vision aid use were outwith this study. However it was observed that there was no evidence of good lighting within participants home and few people had task lamps. Good lighting is vital to those with low vision and future work could highlight the awareness of the importance of lighting and the reality in people's homes.

### **13.4 Need for Support**

In this study, fifteen (60%) of the participants said that more support would help and views were expressed that people would like further

training and the opportunity to revisit the clinic. This was needed not only on the practical / functional aspects of using a low vision aid, but also the wider issues of living with low vision. For example, having the confidence to go out alone was an issue and the impact of issues such as boredom, loneliness and isolation cannot be underestimated. It would be possible to provide opportunities for information giving and training which could also support new interests, confidence building and forums to meet others.

In terms of the functional aspects, optometry staff felt that a single clinic based appointment with no follow up was insufficient. It did not provide people with the adequate support to master the techniques required to gain full benefit from the equipment. Both staff and participants put forward a range of suggestions as alternative ways that the service could be provided. These included ideas for follow up either community based or hospital based, either in groups or as individuals. It was also suggested that the opportunity for a follow up appointment would tackle the issue of returning equipment that was no longer being used. There is a system being introduced in Wales where local opticians are being funded to conduct the follow up appointments for low vision aids. This means that people don't have to travel long distances to access support.

Several people suggested the idea of groups of low vision aid users to allow not only training in the use of the aid, but also for information and practical skills to be given. The group could provide peer support and may help to combat feelings of isolation and build confidence. The timing of this group could also be important because the visit to the low vision aid clinic for many signals the end of the involvement of the hospital services. If people are not registered, then they may be lost to any system of support and information. Identifying sources of help and support before people leave the hospital setting is critical in terms of those who have low vision but are not registered.

## **14. Conclusion**

This study demonstrates that living with low vision is difficult and has a major impact on quality of life. Loss of independence, loss of skills, and loss of confidence are major issues for people with low vision. They find themselves in a vicious cycle of everyday tasks / hobbies becoming difficult and then they are done less often, to the point that they may give up. Low vision aids help to break this cycle and can go some way to restoring independence and confidence. To have

maximum impact, low vision aids need to be provided as part of holistic package of care.

Low vision services operating to high standards can have a positive impact on the quality of life of visually impaired people. The service needs to operate within a climate of high public and professional awareness of the benefits that low vision aids can bring. Optical and non-optical elements of the service need to be integrated and the service needs to be easily accessible. Encouragement, information, training and support should be part of any model of service delivery so that an individual can make an informed decision about how and when they use low vision aids.

The study also highlights the complicated relationship between people and assistive devices and many of the findings here are consistent with the broader themes from research into this area. Kraskowsky<sup>27</sup> concludes in her literature review of this subject:-

“(we)..have an obligation to understand and apply the information available to enhance the appropriate prescription of adaptive equipment and encourage its use among clients”

This study provides many insights into how this might be achieved.

## 15. Recommendations

This study gives an insight into the needs of people using low vision aids. From the study the following recommendations can be made:-

- A new model of a low vision service delivery is piloted within GGNHSB. This service should be person centred, holistic and integrated across health, social work, and the voluntary sector. It should have the capacity to regularly review needs, provide equipment, advice and support on living with low vision.
- An easily accessible facility is established as part of the integrated low vision service where a wide range of optical and non-optical aids can be demonstrated and purchased.
- For people whose needs have changed / or are unsuccessful in using the aid, an easy system to return aids is set up.
- Support, training and advice on the use of aids, importance of lighting should be provided to visually impaired people, families and carers commencing within 6 weeks of receiving the aid.
- “Newly prescribed” groups are developed which would provide encouragement to use aids, seek to develop confidence and a build supportive networks.
- Visually impaired people, carers and families should be given information in accessible formats, about the low vision service, what it offers, how to access it, what to expect and where else to obtain help, advice and support.
- Within the review of registration and certification, a system is introduced which ensures that as soon as a person’s quality of life begins to be impaired by low vision, they have access to aids equipment, advice and support at a local level.
- A link worker project is piloted to provide support from hospital into community services, to ensure knowledge of how and where to get support, especially to those not registered. Located within the CHP’s, the role would involve training, awareness raising, home support and advice, links across services e.g. primary care, opticians, social work, and voluntary sector.

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## **Appendix 1**

### **Low Vision Interview Schedule**

1. Story of losing sight, how long ago, registration status, knowledge of condition.
2. What sort of things did they like to do and what about now ?
3. What is their general health like, how well do they keep?
4. How do they spend their time now, do you go out much, are you able to make a cup of tea etc
5. What causes them difficulties ?
6. How would they describe their attitude to their vision loss?
7. What help or support do they have, family friends etc ?
8. Describe attending the low vision clinic, what did they expect and did it meet their expectations?
9. What aids were given, what instructions?
10. How often do they use them, and what for tasks?
11. What do they like about magnifiers, what don't they like?
12. What did they expect from the magnifier?
13. How long has it taken to get used to it?
14. Is there anyone they can ask for help with it ?what would they feel about returning to LV clinic?
15. Is there anything else they want to say?



listening and responding to people affected by sight loss in the west of scotland

2 Queens Crescent  
Glasgow G4 9BW  
T: 0141 332 4632  
F: 0141 353 2981  
[www.visibility.org.uk](http://www.visibility.org.uk)

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