

**Services for People**  
**with a**  
**Visual Impairment**

**Preliminary Findings**

**Draft For Consultation**

**Glasgow and West of Scotland Society for the Blind**  
**February 2002**

## **Forward**

This report contains the findings from the first phase of a project, funded by Greater Glasgow Health Board to examine the current service provision for visually impaired people.

The first section of the report reviews some of the recent literature, both national and local, to set the context of the project. The second section draws together a series of interviews conducted with providers and users of services and identifies options for action. These are seen very much as initial findings and it is acknowledged more work is required, however, it is useful to capture this first phase to allow subsequent phases to be shaped.

Whilst some of the material presented here may seem very familiar to some, it was apparent in the interviews that this is not universally true. It is hoped that presenting the full spectrum of provision across health and social services that the extent of the gaps in the continuum of care will be highlighted.

Many thanks must go to all those who participated in this work and who gave of their time, freely discussed their views and shared their ideas. In particular, thanks go to colleagues at Glasgow and West of Scotland and to the Sensory Impairment team at West Dunbartonshire who provided enormous help, support and guidance. Finally, to the Health Board, who have funded this work, and created an avenue for the needs of the visually impaired to be brought to the fore. I look forward to the next phase and there are many, many, people who look forward to action and improvements to services for visually impaired people.

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February 2002

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## **References**

## **1. Introduction**

The impact of losing your sight is profound. Not only does it have medical and social implications, but it has far reaching consequences on almost every aspect of a person's life. There is little doubt that sight loss is a major public health issue with about two million people in the UK estimated to have a severe visual impairment. In recent years, there have been advances in the clinical procedures, but the need for services both medical and social will continue to rise as the number of elderly people increases. In fact, about 90% of blind and partially sighted people are aged 60 and over, and in the next thirty years about 40% of the UK population will be over 60.

So what services are in place to support those people who lose their sight and how well do those services meet the needs of individuals who are visually impaired?

Many national reports have addressed these questions and almost all identify that visual impairment requires to be given a higher profile in service provision and that needs of visually impaired people are not being met in any sort of consistent or coherent manner. A recent report<sup>1</sup> describes provision as a lottery, with many shortcomings within organisations, across organisations and across geographical areas.

*“The system as it stands is allowing blind and partially sighted people to slip into ill health and premature dependency by not addressing the risks arising from inadequate services and the absence of appropriate support “*

Against this background and in discussion with Greater Glasgow Health Board, Glasgow and West of Scotland Society for the blind has been commissioned to review current service provision for people with a visual impairment.

Working with a range of service providers and services users, this review aims to provide a picture of the current situation, identify gaps, highlight examples of good practice and make recommendations for action.

The review has been structured into three main phases. The first phase is an in depth examination of one area within Greater Glasgow Health Board. The second phase will concentrate on extending the analysis to other areas of the city, to allow contrasts and comparisons to be made. The final phase will be a consideration of the recommendations, dissemination of the review and the development of action plan to take forward the recommendations. It is anticipated that the review will be completed by autumn of 2002.

The area chosen for the first phase of the project is the part of West Dunbartonshire Council that falls within GGHB. In the same area, a similar piece of work was undertaken in terms of hearing impairment and it is hoped it will pave the way for the recommendations to address the needs of the visually impaired. Should any areas of overlaps be identified from the two projects there is the potential for these to be taken forward together.

This report reviews some of the key documentation and presents the findings from the first phase of the project.

## **2. Strategic Context**

There are several key documents that need to be considered as part of the strategic context within which this review has taken place.

### **2.1 Our National Health: A Plan for Action**

In December 2000, "Our National Health: A Plan for Action"<sup>2</sup> was launched. The plan outlines proposals to improve the health of the people of Scotland, to deliver high quality health and a social care services, and to address inequalities in health more effectively. Within this plan, there are several themes which although they are not specifically aimed at those with a visual impairment, if they are addressed, should improve their experiences of the system.

*"we must build an NHS which listens better to patients and responds more effectively to their needs"<sup>2</sup>*

### **2.2 Joint Futures**

Again, not directly related to visual impairment, the new Joint Future<sup>3</sup> agenda of the Scottish Executive should make considerable differences to the way in which community care is delivered. It defines a “ person centred approach “ and requires that agencies should have a single shared assessment. At a local level, there is much discussion over the impact of the new agenda.

### **2.3 The Disability Discrimination Act**

The Disability Discrimination Act<sup>4</sup> (1995) has made it unlawful for disabled people to be treated less favourably and by 2004, service providers will have to have taken steps to ensure that disabled people can access services. This act, and the fear of litigation under the act, has made many organisations consider the needs of disabled people and within that, the needs of the visually impaired.

### **2.4 Sensing Progress**

In 1998, the Scottish Office published “Sensing Progress<sup>5</sup> “ which examined social work services for people with a sensory impairment. This document put forward seven recommendations to improve social work provision. These included concerns over the effectiveness of current joint working, the speed of response by agencies and the limited way in which needs are being considered.

### **2.5 Report Of Certification and Registration Working Group**

One of the major conclusions of Sensing Progress was that a short life-working group be convened to review the efficiency of the arrangements for registration as a blind or partially sighted person.

*“Certification and registration are not good indicators of assessed need or of the prevalence of needs in the community. Nonetheless they perform an important function. The wide variation in practice both between authorities and within authorities tends to undermine the efficiency of schemes and sometimes to create a degree of personal confusion<sup>5</sup>”*

The group began by asking what the process was seeking to achieve and the following objectives were identified.

- Identifying those who need practical, emotional and social support
- Passport to benefits and services
- Point of transfer of information between health and social care
- Statistical information to inform planning

The group reached the damning conclusion that:

*“none of these objectives were being adequately and effectively met<sup>6</sup>”*

The report recommends that the Scottish Executive introduce a system of notification that identifies clients at a much earlier point and is based on a much fuller assessment. Within this, the support offered should be based not only on clinical criteria but also on quality of life issues. The clinical basis is also questioned and suggestions made.

## **2.6 RNIB Reports**

RNIB is at the forefront of setting the strategic context for visual impairment and has published several reports of relevance here.

### **2.6.1 Insights**

“Insights<sup>8</sup>” is a comprehensive and detailed account of the range of support available to visually impaired people in Scotland. The report highlights the range and diversity of provision across the geography of Scotland. Within this, it identifies some of the difficulties, such as fragmented provision, inadequate low vision services and poor support for patients. It defines collaboration across services and current coordination of services as: -

*“being more often noticeable by its absence despite clients being dependent at any one time on several agencies“*

### **2.6.2 Prevalence**

Data from Insights and other RNIB surveys<sup>7</sup> demonstrates that the formal registration of visual impairment through the BP1 under estimates the scale of sight problems by a very considerable margin. A further piece of work, which examined OPCS data and prevalence data, concluded that the number of people on register is some 23 % of those eligible to be registered.

Despite the fact that registrations are under reported, when registration data is examined over time, there are some dominant trends. These would need to be extrapolated to give estimates of the real figures. For example, in 1997, Scotland's registered blind population stood at just over 33,800, by contrast in 1976 the number was just over 9,100. This is a trebling of registrations in 20 years.

The latest figures from the Scottish executive<sup>9</sup> show that: -

- over 80 % of those registered blind, are over the age of 65
- 48 % of all registrations, are women over the age of 75 (reflects the greater number of women in this age group)

When additional disabilities are considered, it is estimated that 21% of all those registered blind fall into this category and of these, over a third are deaf.

Some as yet unpublished data provided by a local ophthalmologist shows that if registration data for all ages and all conditions is examined, then: -

- 50 –60 % are due to age related macular degeneration
- 10 % are glaucoma
- 8 % diabetes
- 4 % short-sightedness
- 4 % strokes
- 3 % damage to the optic nerve
- all the other conditions put together are 15 %

### **2.6.3 Patients Talking**

In 2000, “Patients Talking <sup>10</sup> “ was published which describes patients’ experiences of attending eye clinics. This report was followed by a larger more in depth study into the same subject, “Patient’s Talking 2 <sup>11</sup>“ which found very common themes.

These are: -

- Appointment card print size too small
- Problems finding eye clinic
- Unexplained delays in the system
- Rushed consultations with no information to take home

Both studies identify the need for improvements in terms of information, counselling, support and follow up.

*“ the one outstanding finding of this study is the lack of initial counselling and support for people facing serious and permanent sight loss . Seventy percent wanted someone to talk to about their concerns but only 19% had been offered the opportunity<sup>10</sup> “*

## **2.7 “Improving Lives”**

RNIB, NALSVI (National Association of Local Societies for the Visually Impaired) and 85 other organisations have recently joined forces as the Improving Lives Coalition. This group is committed to promoting changes that will end the lottery of community care for blind and partially sighted people. In their report “Improving Lives<sup>1</sup>“, they document evidence collected across Britain into the problems experienced by blind and partially sighted people. This report is an uncompromising account and states that: -

*“ the time has come to take a strategic grasp of the whole cycle of care for the blind and partially sighted people and to make available the resources and structures that will start to meet the needs of all those whose failing sight is adversely affecting their quality of life”*

## **2.8 Closing the Gap**

Many of previous reports identify issues for either the health service or social services; however, one report looks at the gap in provision between these two statutory providers. "Closing the Gap"<sup>12</sup> was produced by the Visual Handicap Group, which comprises of 10 major voluntary organisations involved in visual impairment. This report identifies examples of valuable joint initiatives where health, social and voluntary agencies are working well together. It documents evidence of good practice from around the country and a common theme throughout the document is that: -

*"early intervention and recognition of need, rather than registration status is the best trigger for action ..... The sequence and phasing of support is increasingly being recognised as of real importance in people's successful adjustment to losing their sight"*

## **2.9 Low Vision**

In 1999, "Low Vision Services – Recommendations for future service delivery"<sup>13</sup> was published. This document identifies that to maximise remaining vision, there needs to be a system which offers early assessment, prompt advice, and the provision of low vision aids and training in their use. The report recommends a national framework for low vision services and highlights that :

*the key is local integration of ophthalmic and rehabilitative care and support services "*

The suggested mechanism to take forward these actions at a local level is the establishment of local low vision service committees that can develop minimum standards for local services. A recent account of progress towards these goals identified that 18 low vision committees have been set up, with interest expressed in another 30 areas. Most of these committees have begun to investigate local service provision and three have reached the stage that they have secured funding and commissioned new services. However, it is also interesting to note that all of these committees have been set up in England.

## **3.0 Local Context**

There are several mechanisms at a local level that shape the context within which services for the visually impaired operate. Again there are many references that don't directly refer to visual impairment but are highly relevant.

### **3.1 Health Improvement Plan**

The Health Improvement Programme 2001 – 2006 <sup>14</sup> describes how the NHS in Greater Glasgow intends to improve the health of the population. The main reference to visual impairment is contained within the section on Sensory Impairment. The document identifies that there are about 20,000 adults with a visual impairment who live in the health board area, of whom around 7,000 are registered blind or partially sighted. The document states that: -

*“The needs of these quite substantial numbers of individuals have never been addressed by the health service in Glasgow in a systematic manner“*

### **3.2 Planning and Implementation Groups**

Within the HIP, a programme of development is proposed which appears to have arisen from the Planning and Implementation Group (PIG) for sensory impairment. This interagency group, led by Glasgow City Council, and supported by Greater Glasgow Health Board, and several voluntary organisations meet to plan and develop services. It should be noted that this group does not involve the other five local authority areas in which Greater Glasgow Health Board residents live, and that although other local authorities have PIG's they may not be for sensory impairment.

### **3.3 Community Care Plans and Registrations**

In terms of strategic context at a local level, the other main documents are the Community Care Plans developed by each local authority in conjunction with the health board. As the population of Greater Glasgow Health Board is distributed over 6 local authority areas, there are six community care plans of relevance. The latest data from the Scottish Executive gives the numbers of registrations by local authority and also describes these as a percentage per 1,000

of the population. The six local authorities and the associated percentages are given below: -



Given that the focus of this phase of the project is West Dunbartonshire, a brief overview has been included.

### **3.2.1 West Dunbartonshire Community Care Plan 1998 - 2001**

West Dunbartonshire was created as a unitary authority in April 1996, with a population of 95,760. In the Community care plan<sup>15</sup>, visual impairment is considered as part of the section on sensory impairment. Data from OPCS indicates that around 2,400 people in West Dunbartonshire have some degree of visual impairment. There are a total of 605 people registered blind and 291 registered partially sighted.

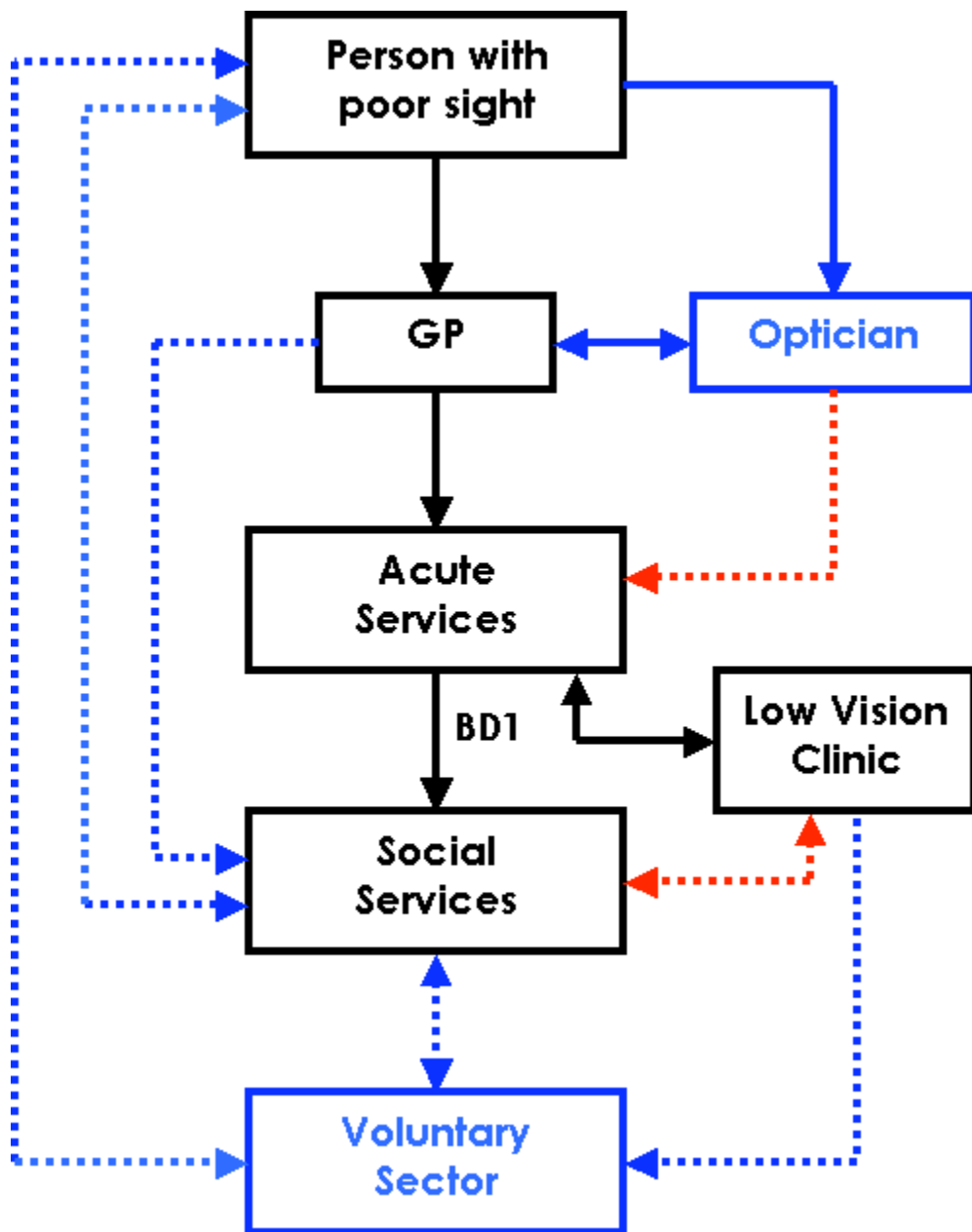
## **4. A Patient's Journey**

To fully appreciate the scope of services being reviewed, it is worth describing the possible pathways through the current system of service provision. This identifies the range and diversity of encounters that may be critical for any individual. This is best described in conjunction with the diagram below.

### **4.1 Primary Care / Community**

When a person is having difficulty seeing they go first to either an optician or their GP. Very often if a patient visits the GP, he will refer to an optician. If the optician feels that specialist treatment is required, they refer back to the GP, who then refers to a hospital. The visual problem may already be

affecting the person's quality of life in terms of daily living, independence or employment.



#### 4.2 The Acute Sector

There are a variety of scenarios that may occur at the point of contact with the hospital and these are largely depended on the

condition and the prognosis for the individual. The waiting time for an appointment to a hospital specialist varies but for Gartnavel Hospital is anything from 20 - 45 weeks. Also within the hospital setting, there is a range of professionals involved in caring for the patient.

#### **4.2.1 Ophthalmologists and Ophthalmic Nurses**

An ophthalmologist will take the diagnostic and treatment decisions although it should be noted that ophthalmic nurses play a key role within the system.

*“The nursing role within the eye clinic is crucial to the efficient and effective functioning of the system”*

It may be that some course of treatment is embarked upon or it may be that surgery is required which means another waiting list. It may mean attending the hospital as an outpatient for a period of time. However when the treatment is finished the patient will be “discharged”.

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

Usually, It is only after the ophthalmologist has seen the patient that there is a referral to the low vision clinic. These clinics run by optometrists and here patients are offered advice and equipment that allow them to make the best use of their remaining sight. The equipment is dispensed free of charge at the low vision clinic. The referral time to the low vision service can be anything from 3 months – 9 months.

#### **4.2.3 Registration**

It may be that at some stage in the process, the patient may be alerted to the fact that the condition will ultimately result in loss of sight and registration is discussed. If the person agrees, the consultant will complete a BP1 form that is sent to the patient’s local social work department. However there are situations in which someone with poor sight does not qualify for registration because of the current clinical criteria or the person chooses not to be registered as it is a process which is voluntary.

Where in the Greater Glasgow Health Board area a person lives, defines what and how quickly things happen after registration. For those who live in the city, the sensory impairment team of Glasgow City Council Social Work department will act on the BP1, but the BP1 could go to any of the other five local authorities some of whom do not have dedicated specialist visual impairment services.

### **4.3 Social Services**

The arrival of a BP1 form at a social work department triggers a statutory response to assess the person's needs. For those living in West Dunbartonshire, the certificate and a letter is sent within about two weeks and it is around six weeks before the case is allocated and a dedicated social worker for the visually impaired visits.

The social work assessment identifies the need for support and assistance. Depending on the assessment, other referrals may be made, most commonly to the rehabilitation worker within the sensory impairment team, who focuses on living skills with the person, to promote independence and safety. If the assessment highlights the need for equipment, this will be provided at a standard charge of £10.50 and a visit maybe organised to the local resource centre where equipment can be viewed and tried.

Other council departments may also become involved; most commonly these are home helps, benefits workers, housing, education and employment. Information should be provided on community based activities and voluntary organisations.

One of the critical issues to be noted is that each local authority differs in the way in which support is offered. Sometimes these differences are small, and sometimes there are radically different levels and quality of support.

## **5.0 Assumptions about the Patient's Journey**

There are many assumptions about this journey. In an ideal world, it is a confident, mobile, healthy person who goes to their GP with an eye problem. They are then moved through a system in which they have an active participatory role, and they are provided at an early and appropriate time with the treatment, information, advice, support and aids. However, seldom does the system work like this and there are many points at which the patient's journey deviates from this pathway.

The first assumption is that the person with deteriorating eyesight actually comes into the system. For many older people the reality is that they don't go to see an optician or the doctor and may be isolated, depressed, housebound and at risk.

Assuming the person is referred into the hospital system other issues become evident: -

- transport, to and from
- location and accessibility of the eye departments
- can the appointment card be read?
- need for someone to accompany the person
- access to information, aids, emotional and practical support
- registration, eligibility and consent issues
- waiting times and the length of time in the system with declining sight

At the point of discharge from the hospital, patients may be told that there is nothing more that can be done, some patients may be registered and some may not. Registration will put the person in touch with social services. But if and when registration happens, it may take many months for social work to make contact with the patient.

So far the theory and rhetoric of service provision has been examined and it is clear that the patient's journey through the system is anything but smooth and easy. This needs to be considered alongside the reality of service provision and the next part of the report considers the views of key staff from a range of agencies.

## **SECTION 2**

This section of the report outlines the methodology and explores the perspectives given by a range of professionals in relation to service provision.

### **6.0 Methodology**

The professional perspectives were collected in one to one interviews. Some interviews were conducted with groupings of two or three individuals where it was felt the interaction would benefit the quality of the dialogue. A semi structured interview schedule was followed and this can be found in appendix 1. Almost all of interviews were taped and then transcribed. They were then examined for themes. The themes that emerged have been presented under the main headings of NHS and Social Services.

### **7.0 Perspectives on NHS Provision**

The themes from the interviews for the NHS have been further divided into two sections, primary care and acute sector.

#### **7.1 Primary Care Sector**

The Clydebank LHCC is made up of 10 practices, 34 GP's and has a practice population of about 50,000.

Several of those interviewed felt that it was uncommon to have someone who was visually impaired at the health centre, and health centre staff had difficulty in recalling more than a couple of people on the practice list who were blind. This is interesting to note because considering statistics alone, at least 500 blind or partially sighted people could be expected to be part of the health centre population. The other interesting comment was that there had been no complaints in terms of accessibility. A lift is available to reach the first floor, but the buttons could prove difficult for visually impaired patients. There may well be other very practical problems that

patients have and it is suggested that it is important to have visually impaired representatives on the health centre access panel. This is possibly also the case for hearing impaired and dual sensory impaired patients.

### **7.1.1 Initial Contact**

As stated earlier, for many people the journey starts at the GP, though several primary care staff felt that people with failing eyesight have self adapted to their situation, and only come into the primary care services when there has been some sort of crisis. The other major route is through the optician but it was suggested that many people, especially the elderly are reluctant to go to the optician because they feel that they will be sold a new pair of glasses.

A major gap in the system was seen to be that many patients don't go to either the GP or the optician because they believe that deteriorating eyesight is a feature of growing old and that nothing can be done. Whilst this might be true in terms of treatment, low vision aids, social services support, and independent living skills could be very beneficial.

One GP expressed the view that opticians should be able to refer to hospital specialist directly.

*“we can only assess for cataracts and retinal problems and our assessment for visual acuity is very crude, opticians make a much better job”*

Several professionals raised concerns about the hidden visually impaired population, that is people not currently known to the primary care system, although it was felt that the over 75's project is going some way towards identifying needs of this group.

### **7.1.2 Waiting times**

The long waiting times for hospital appointments indicate to the GPs that the system is under great pressure. It was commented that some patients can wait nearly a year to be seen at the hospital and then there are long waiting lists for the procedures. There was a certain reluctance to subject elderly patients to these lengthy waits and the potentially difficult journey to and from Gartnavel.

*“Access to the services is restricted because of huge demand, we would like to see the system opened up not rationed. In terms of registration, only the tip of the iceberg are registered as the threshold is defined by the flow of patients thro the hospital consultant “*

### **7.1.3 Gate keeping**

Whilst many see consultants as gatekeepers, some staff see the GP's in this role. Patients can be encouraged to see the GP about their sight but it then depends on the GP's decision. If the GP does not refer to a specialist, registration is not an option and the door to social services support and low vision aids may not be opened. GP's themselves expressed frustration that they are seen as gatekeepers and that other routes into the acute sector could be considered. The examples given included the situation in which a patient who has previously attended an ophthalmologist may have to go to the GP before they can be seen again in the hospital setting and also if the patient needs to return to low vision clinic, generally a referral has to come through a GP.

*“Home helps are key people with the elderly; if a home help could refer to an optician and an optician into the hospital system it would be a much easier route.”*

When registration was discussed, several issues came up. The first was a lack of understanding of the process, but when it was described, concern was expressed about needs of the patients during the period between discharge from the hospital and the visit from social services. It was felt that the primary care team could offer counselling and advice at this time.

*“Why does the BP1 go only to social services, there is still an element of care and particularly primary care, part of the problem is that the model is based on a disease model and not a functional model”*

It was commented that sometimes the GP doesn't know when a patient has been registered. A letter may have been written but often, administrative procedures within the GP practice means that

the letter from the consultant is filed and the primary care system is not switched on.

*“ make the administration system better and the care will be better because the system is switched on. In primary care, the administration staff could read the letter and trigger support from GP or health visitor“*

Another dimension that was discussed was that it might be useful to have the notes tagged so that it was clear to all that the patient was visually impaired.

#### **7.1.4 Gateways**

The Over 75's Project is seen as a real step forward in working with other agencies. This is a joint venture between social work and health in which patients, reaching their 75<sup>th</sup> birthday and annually thereafter, are offered health screening. An assessment is completed and the nurses refer as appropriate to support services. The assessment has been specifically designed as a single assessment tool reducing the need for clients to be reassessed by each organisation.

Initially the project has been established in two practices, and is now developing into other practices as GP teams become aware of the benefits. It is hoped to extend the project to over 65's using a self-assessment tool.

This project is seen by both social work and primary care as a very powerful model in meeting the needs of elderly patients in the area. There was great concern expressed that many people are being identified for the first time by the over 75's screening. However it is acknowledged that unmet needs are being uncovered.

*“It is now much easier to identify and meet clients needs which were hidden to the system”*

The project nurses routinely refer to chiropody, physiotherapy, occupational therapy, home helps, and welfare rights. However, there are problems because many of these services have long

waiting lists. If they uncover any severe visual impairment problems, they refer directly to the Sensory Impairment Team.

The project nurses felt that the main issues for visually impaired people are things like taking medication, cooking for themselves and all the problems to do with eating properly. Other issues such as: -

- boredom because they can't see the television or read
- isolation as they don't go out any more
- loss in confidence.

Although the project workers were not sure of any sources of community or voluntary support, they found the sensory impairment team very helpful. In particular, the booklet produced by the West Dunbartonshire sensory impairment team was seen as an excellent resource. This was thought to be available in the health centre.

#### **7.1.5 Gaps**

The main gap identified was the fact that for many people, visual impairment goes on undetected and therefore the patient is unsupported and possibly at risk.

In general terms, across the primary care providers, there was a lack of knowledge of the role of the voluntary sector and community-based groups. Some staff didn't know where information and help could be accessed. Links with social services were viewed as good although the GP's admitted that they had very little contact with social workers.

The over 75's nurse felt that it would be useful to be able to refer patients directly to low vision services. It was questioned as to why low vision aids couldn't be supplied locally. In fact, from all professionals there seemed to be a need to clarify roles and referral pathways as many questions were raised about who could refer to where in the system.

It was felt that visual impairment awareness training was a big gap for many. The over 75 nurses had attended and had found it very useful. Many of these local issues of training, information and role clarification could be addressed by a workshop / forum with all relevant professionals. Several interviewees raised this idea.

## **8. Acute Sector Perspectives**

The eye department at Gartnavel Hospital is one of two referral points for those with eye problems living within West Dunbartonshire. The other treatment centre is the Royal Alexandria Hospital in Paisley, which is in the Argyll and Clyde Health Board area. The eye department is also a centre of regional and national importance and therefore eye patients can travel from outside the Greater Glasgow Health Board area to the hospital for treatment.

It is estimated that about 60,000 patients a year are seen at the eye department. Health Board data from the Clydebank area, indicates that over the nine month period from January to September there were 583 new referrals in the 16-85+ age group. The data also indicates an average do not attend (DNA) rate of 15 %, with a high of 29% in the 15 – 44 age group.

There are 12 consultants covering a range of specialities supported by ophthalmic trained nursing staff, optometrist and orthoptists. A selection of all of these professions were interviewed.

### **8.1 Time**

Several very common themes emerged across the range of professionals interviewed. The most pressing issue was that of time, and a view that heavier and heavier demands are being put on the service. This translates into long waiting lists and rushed appointments with a feeling from staff that they were not able to fully support the patient's emotional and practical needs. It was generally acknowledged that: -

*“ one of the big problems is the time it takes to be processed through the system”*

### **8.2 Support**

Despite the time constraints of the system, generally, the staff felt that they provided support, information and contacts for patients. However, this was also an area of much frustration as many staff felt that they would like to do more, especially at the point of registration. There was awareness that this could be a very difficult time for

patients, who had been told that there is nothing more that can be done and many are said to leave the eye department, bewildered and uncertain.

There has been some discussion by the nursing staff about re-establishing a clinic for newly visually impaired people to provide extra support, counselling and follow up, but it was uncertain whether it would go ahead given current staffing levels. A consultant and an ophthalmic nurse had originally launched this idea. This clinic would help fill the gap for patients who are leaving the hospital system and the long delay before the local social services team makes contact.

There was an issue for the hospital staff in trying to keep up to date with the different packages offered by the different councils, community groups, voluntary organisations and self help groups. Over time there have been many changes in location, staffing and procedures across several local authorities. It was suggested that much closer links were needed with colleagues in social work and up to date information about services in their local areas, but for many staff, there was

*“still a huge gap between health and social work”.*

Many of those interviewed felt that a post, based at the eye clinic, and that acted, as a link between the hospital and the social work departments would be invaluable. There was some experience of this as a volunteer had provided counselling, support and information to patients. Although this was not currently available, it was a welcome support system. Another system is the GWSSB Helpdesk, which some staff found useful but many more felt that it's greatest weakness was that it was seldom open and that it wasn't open during the busiest clinics. There were those who felt that the desk was a very amateur substitute, irrelevant to a lot of patients, unappealing and unapproachable.

The concept of an “advisor” based at the clinic was put forward strongly as a way of bridging the gap that currently exists. The benefit of such a post would be a standardised approach to information, advice and equipment and a consistent way of signposting patients to sources of help.

*“there is gross disparity across the city, for instance West Dunbartonshire is excellent but for some of the patients, they are lucky to get a visit and even if they do it is no help to them”*

However a key characteristic of the approach would be to the use of a protocol to guide the interaction and a patient centred assessment tool that would ask patients about their needs.

*“Seldom is the inquisitorial approach used to ask patients what they are having difficulties with, there is an ethos of imposing the professional view of what the patient is going to get “*

### **8.3 Registration**

Some nursing staff commented that if they know that a patient is being registered, then information is provided, but it was recognised that this far from universal practice. This is just one facet of the overall inconsistencies around registration. Many staff, including the consultants, felt that there is wide variation in the practice of registration, with an admission that the consultant often forgets. In general, there seemed to be lack of awareness of the role that registration might play. It was worrying to note that only a few staff acknowledged the direct link between registration and support. In fact, some staff seemed unaware that people with very poor vision may miss out on social services support because they are not registered.

There was also general agreement that the BP1 form is a historical tool with little significance today. It does not provide useful information across the services on which cases can be prioritised. Another problem was seen as the fact that there is no central register and that it is difficult to get national statistics. This problem also manifests itself at local level where it is very difficult to produce epidemiological data on registrations for the Greater Glasgow Health board area.

### **8.4 Networking and Communication**

Some acute sector staff felt that their links with social work were good, whilst others felt very *“distanced from the social care “*. When it came to links and knowledge of voluntary sector, again some staff

seemed to have good contacts but others who felt that it would help to have a greater awareness of the support and assistance that could be provided. One consultant acknowledged that:-

*“GP’s are informed of registration but it is not exactly an official link, we never verbally communicate except in rare circumstance, similarly we don’t often speak to social services”*

Apparently, multidisciplinary meetings used to be held at Gartnavel with representatives from ophthalmology, social work, and the voluntary sector. These were seen as being very useful and some staff would like to see all the interested parties being brought together on a regular basis. Though it is worth noting that staff were unaware that it was only social work staff from Glasgow City Social Work Department who were involved in the group. This concept, that Gartnavel requires to engage with several different local authorities seemed news to some staff, who assumed that communication with Glasgow City Council is sufficient. This seems to be based on a false assumption that there is good communication, sharing of information and networking across all social work departments.

### **8.5 Low Vision Services**

The low vision service at Gartnavel is not only a local service but also a regional centre. It is viewed as an excellent service, with excellent staff, but also a service that is over stretched.

The hospital optometrists felt that many of the patients who had been referred to them didn’t know why they were there and many had unrealistic expectations of what low vision aids could do. Patients were generally referred when no treatment options were left and they were still trying coming to terms with losing their sight. It was felt that a major problem for the system was the long waiting times and that waiting times would be shorter with more staff and fewer referrals from outside of Glasgow.

When asked about the weaknesses of the services, the optometrists endorsed many of the views expressed by their acute sector colleagues. Time pressures, poor communication between providers and with patients, lack of support for patients, and the inconsistencies of registration. When the low vision service in particular was

discussed, the hospital optometrists were very concerned that the contact is very much a one off assessment and the provision of equipment. This gave no opportunities for follow up, and raised the question of whether the patients ever use the equipment that is provided. A local survey several years ago identified that less than a third of low vision aids were used. It was highlighted that equipment was being prescribed in ideal lighting conditions, but there was no way of knowing whether the lighting was optimal in the home setting.

Generally consultants refer patients, but some are referred from social work or from a GP, especially if they have been through the system before. If the optometrists believe that the patient has reached the stage at which registration is appropriate then they need to refer back to the consultant. This seemed to them an unnecessary loop. They would also like to be able to refer to social services as they come across many cases of patients with very poor vision who are not in contact with social services. It was identified that these patients can get lost in the system and find themselves outside the care and social support cycle.

Another major concern was the type of equipment that was being offered, in that, only inexpensive, unsophisticated equipment is generally given. But it was also commented that the department budget was inadequate and pressure was often exerted to try to reign in expenditure. There is a further undercurrent that suggests that information about wider ranges of aids is not made available to people either in the hospital setting or through social services departments.

It was said that if our system is compared with any other Northern European country it is "*like the ark*". Sweden is seen as model of good practice and they have low vision specialists who are trained in the both equipment provision and rehabilitation skills.

The Low Vision Service at Caledonian University was included in the project. When asked to identify the weaknesses of the current system rather than the specific service offered at Gartnavel, the following points were cited: -

*“lack of coordination, lack of resources, people have to wait ages, there isn’t the opportunity for follow up, people feel pushed from pillar to post, better communication is needed”*

Optometrists at Gartnavel and those at Caledonian University identified a lack of coordination between the range of different professionals involved. It was suggested that there should be better liaison between those carrying out the low vision assessment and those supporting the patient in the community. It was put forward that patients should be able to get a low vision assessment without seeing a consultant but that seldom happens and that the referral to low vision is often late in the patients’ journey.

*“ Patients should be referred to low vision while they are going through treatment and not when there are no treatments left, an assessment for low vision aids should be done as soon as the patient starts to struggle”*

There was a view, that for some hospital staff, treatment is the main area of interest and the whole issue of rehabilitation is peripheral. Though within this, it was acknowledged that the attitude to low vision and rehabilitation varies widely. It was also suggested that better liaison between the hospital and the community would help, as the hospital assessment is too quick for many of the questions to be answered. It was proposed that a key part of the service should be support and counselling by a dedicated worker.

### **8.5.1 Good Practice**

In terms of good practice, a low vision aid would be provided and then a follow up at home to ensure that the patient is using the device properly and that lighting conditions are sufficient. However this does not happen because of the huge number of people needing the low vision service and the non-existence of domiciliary link with the hospital optometry service. There could be services introduced to enable patients to access low vision aids more easily and there are schemes in which optometrists have a contract with a hospital to provide low vision aids. The provision of low vision aids outside of a hospital setting is not common, partly because it is very time consuming and therefore not profitable, although there are a few High street optometrists who are developing this side of their business.

Several examples of good practice were discussed in which multidisciplinary teams offered a coordinated and cohesive approach to patients with low vision. In particular, there are projects in which everyone from consultants to optometrists, to rehabilitation workers, counsellors, social workers and equipment were co-located, almost a one-stop shop approach.

## **9.0 Social Services Perspectives**

As has already been mentioned, the way in which social services support people with visual impairment varies widely from local authority to local authority. In West Dunbartonshire, there is a small, dedicated sensory impairment team.

### **9.1 Sensory Impairment Team**

The sensory impairment team has seven staff, but most of the staff have responsibility for both visual impairment and hearing impairment. There is a team leader post which is currently vacant, two social workers, one for visual Impairment and one for hearing impairment, a development worker, a support worker, a rehabilitation worker and a technician. There are resources rooms in Clydebank and Dumbarton that are open to the public but by appointment.

#### **9.1.1 Accessing the SI team**

Clients can access support from the sensory impairment team in several ways. The first and most common route is through the certification and registration process. When the BP1 is sent to the team, a letter is sent to the patient with their certificate and the patient is informed that a social worker will visit. In West Dunbartonshire, the letter is sent within about two weeks and a visit is set up within about 8 weeks. At this visit, an assessment is completed, and based on the needs identified, equipment and further support is provided. It is estimated that about six BP1's arrive each month.

There are however other routes to the SI team, but these tend to be local and without the BP1, there are almost no referrals from Gartnavel. Again this raises the question of what support is made available to those who are not registered. There are a few direct referrals from GP's but again not many. This generated questions around the timing of social support provision.

*“Why is it only after registration that the practical and emotional needs of the clients are raised and why don’t GP’s refer to social work at the same time as they refer the patient to the hospital?”*

Other members of the primary care staff do refer to the social work department or directly to the sensory impairment team. This is certainly the case now the over 75’s project is running. Also, other social work staff, such as generic social workers, home helps, and occupational therapists refer to the SI team and this is the main route for clients who are not registered to access support and equipment. It was commented that the community care team have a lot of clients who have a significant level of visually impairment and that it might be helpful to have a protocol that outlined when to refer to the sensory impairment team.

Staff commented on the way in which the BP1 is completed, or more correctly that the forms were often incomplete and that the missing information would have been very useful. This is exacerbated by the poor links with the hospital.

### **9.1.2 Appropriateness**

It was acknowledged, that for many people, contact with the social services department carries a stigma and this may be why they opt not to be registered.

*“ social services are like some sort of police who put you into a home, if you are not coping“*

It was stated that many clients are initially quite resistant to social services input and bewildered about how and why the social work department are involved.

*“It seems bizarre that they went into the medical system with an eye problem and it results in a social worker landing on their doorstep, how does that happen?”*

### **9.1.3 Rehabilitation**

For the majority of clients, the provision of practical aids is required and this is often where the rehabilitation worker and resource worker become involved. A standard charge is applied irrespective of the amount of equipment provided. However there is debate within the authority about what should be provided for this sum, although equipment allocation is to be based on need. In particular, it was suggested that there is a need for good direct lighting especially if the client is using a low vision aid; however there seems to be an issue over the provision of desk lamps with low energy bulbs. There was a suggestion that a scheme of bulk buying of equipment would reduce the costs.

There was a view that many clients had been supplied low vision aids at the hospital that they did not use. Often members of the SI team have to teach patients how to use the equipment. The team were aware of other areas of the country where the local rehabilitation workers are specifically trained by the low vision clinic to provide domiciliary support.

### **9.1.4 Links with other providers**

The development worker post was set up as a response to Sensing Progress<sup>5</sup> to take forward joint working. This has enabled the SI team to establish better links with the statutory providers and voluntary sector. It was felt that it has enhanced the strategic input into the council, the health board, and the primary care trust and enabled stronger community links to be developed.

At an operational level, some links other with providers were seen as good, but it was felt that there was room for improvement. For example, there are good links with some individuals on the hospital staff, though overall, the contact and communication between the SI team and the eye clinic services was considered poor. Much the same picture emerges when the links between GP's and the SI team are considered. In terms of strengthening the links and sharing information, the sensory impairment team would be happy to provide direct support to the eye clinic on a sessional basis. This could provide some counselling for patients and a point of collection for the BP1. This could also be the case in primary care, a copy of the BP1 could be sent by the Sensory impairment team to the GP when letter

of certification is sent to the patient. This would allow primary care support to be offered whilst the patient is waiting for a visit from the social worker.

On a more strategic level, there is no visual impairment forum where health and social work meet either on a local basis or on a citywide basis.

### **9.1.5 Training**

The sensory impairment team offer awareness training within the council. It is well received and apparently in demand by other departments but it was also noted that uptake of the courses by fieldwork staff is variable. Comments were also made about the route by which training is negotiated within the council and the LHCC, in that visual Impairment training has to fit within overall training programmes. This has implications for the frequency, and seems to operate against tailor-made packages for small groups of staff. However, there is an acknowledgement that there is a huge training need and in particular, there is a wish to provide more training for key staff such as residential care workers and home helps. There was some discussion that it would be very beneficial to offer training on a multidisciplinary basis across health and social work, which would offer not only information and awareness but also a better understanding of roles.

### **9.1.6 Gaps**

When team members were asked to consider gaps in provision, the main issues which were put forward were those to do with the social isolation of the clients and their practical needs such as shopping, dealing with paperwork and going out. It was acknowledged that many clients are effectively housebound because of their blindness. Two main factors were identified. The first is the lack of befrienders who would either visit the clients or take them out as sighted guides. The second is the lack of activities to which the clients could be taken. The only option for a lot of clients is day centre provision, which was seen as not being appropriate from some clients. Ensuring the needs of clients in residential accommodation was also seen as a problem.

In terms of an avenue that allows visually impaired people to shape services, there was a view put forward that there is no local forum in which blind people can be consulted or where they can voice their needs. In contrast there is a Deaf Forum locally.

Other gaps such as training, networking, coordination, referral pathways, more timely support and a mechanism to identify those the system might have missed have already been highlighted.

## **9.2 Social Work Department Perspectives**

A range of professionals from other social work departments such as home care, housing, elderly services, residential care, day care, over 75's and generic social work teams were interviewed and their views grouped together.

### **9.2.1 Awareness**

It was stated, almost irrespective of the team that for many clients, visual impairment was a difficulty, but not necessarily the problem that brought them into contact with the service. Equally, concern was expressed that the social work assessment was not particularly sensitive to visual impairment and even if it was identified, the priority given to visual impairment may not be that high. Underlying the issue of prioritisation, were the questions of when was visual impairment a problem, and at which point was referral made to the sensory impairment team? These seemed to be an area of doubt and open to individual interpretation. There was also a view that poor eyesight may not be something that the client wishes to disclose for fear of consequences.

Some staff had been on the training run by the SI team and felt that regular updates should be offered. Those who hadn't received any training would welcome the chance and staff from residential and day care particularly voiced this. Some staff would like to see a more comprehensive training package, as they felt that training could be a "*hit or miss affair*". It was also put forward that it was important that the training was carried out at all levels and not just front line staff. This is because middle managers that have to take decisions on client issues brought back by front line staff.

### **9.2.2 Isolation**

Isolation was seen as the main issue for almost all visually impaired clients. All social work staff interviewed raised isolation as a problem not only for those in who received community care but also those in residential care. Linked to isolation is the issue of mobility. Moving around, getting out and about, are problems for visually impaired people and difficult for the services to resolve without the resources to provide sighted guiding and transport. A major constraint is the availability of transport. This was raised as an issue for day care and residential care. At a simple level, it was felt that if there was more transport available, clients could be taken out more. On an individual basis, the lack of befrienders and guides means that many clients whether in their own homes or residential care, remain stranded indoors, lonely and bored.

### **9.2.3 Other Gaps**

Many of the gaps identified by the social services team echo those brought up by their colleagues. Unmet need, coordination, referrals, protocols, counselling and support, information and advice, and knowledge of voluntary agencies were identified. All of these have been discussed earlier in this report.

## **10. Summary Of Emerging Issues**

Throughout this second section, many issues have been raised in relation to statutory service provision. It seems appropriate to capture these and briefly summarised before moving on. The summary has been constructed using the organisational headings.

### **10.1 Primary Care**

- People don't come into system, so needs are undetected and unmet
- Lack of opticians referral to hospital
- Potential of early referral by GP to social services,
- GP's notification of registration could trigger a primary care appointment
- Notes could be tagged, alerting all to the visual impairment

- More VI awareness training of health centre staff and community based professionals
- Joint training for health and social services on roles, referral pathways, protocols
- Visual Impaired user representation on health centre access group, practical issues on agenda
- Information on community and voluntary organisations should be available to staff, patients and carers in suitable formats
- Specialist visual impairment team worker at health centre providing information and support

### **10.2 Acute Sector**

- Emotional and practical support is essential
- Advisor post, piloted and evaluated
- Information about and at registration should be available
- More thorough completion of BP1
- Re establish forum between Gartnavel, social work and voluntary agencies
- Joint VI training across agencies
- Training in low vision aids to social work teams
- Opportunity for follow up by low vision clinic / out posted service
- Domiciliary low vision service linked to localities
- Examine the range and diversity of low vision aids provided

### **10.3 Social Services**

- Notify GP's of registration
- Sessional social work support at eye clinic
- Establish referral pathway with low vision clinic
- Low Vision training for SI team
- Domiciliary low vision service link to Gartnavel
- Protocol for referral between social services teams
- In house training for home helps, residential and day care
- Joint training initiatives, who does what, when and how
- Establish local multi disciplinary group and user involvement
- Develop joint local initiatives e.g. sighted guiding

## **11. Options for Action**

Several common themes can be identified from the summary and brought together. They have been set out in table form and are discussed as options that need further debate.

<b>Theme</b>	<b>Gap / issue</b>	<b>Options /Targets</b>
Coordination	Interagency forums Voice of Visually Impaired	Function at <ul style="list-style-type: none"> <li>• Strategic level</li> <li>• City wide</li> <li>• Operational</li> <li>• Local</li> <li>• User involvement</li> </ul>
Communication	Referral Pathways Recording systems Protocols	<ul style="list-style-type: none"> <li>• GP's</li> <li>• Low vision</li> <li>• Hospital</li> <li>• SI team</li> </ul>
Training	Understanding roles Awareness of VI	Target Groups <ul style="list-style-type: none"> <li>• Multidisciplinary</li> <li>• Within council</li> </ul>
Counselling and Support	Link workers Helpdesks	Based with <ul style="list-style-type: none"> <li>• Hospital</li> <li>• LHCC</li> <li>• Council</li> <li>• GWSSB</li> </ul>
Information	Conferences Information packs Awareness	Target audience <ul style="list-style-type: none"> <li>• Multi-agency</li> <li>• public</li> </ul>
Pilot Projects	Low Vision and rehabilitation	<ul style="list-style-type: none"> <li>• Local domiciliary low vision worker</li> </ul>

### **11.1 Coordination**

It would appear that coordination is a key issues at several levels. Firstly at health board wide level, there is no multi - agency forum providing the strategic direction. Such a forum could develop proposals for an integrated approach to service provision and not the rather fragmented system that currently exists. There is also the need to establish local forums to develop a coherent and integrated

operational programme. There is the potential to involve service users in this local forum to provide a vehicle to take account of their views. Equally a users forum could be set up alongside an operational group.

### **11.2 Communication**

Communication between service providers should improve through the establishment of the above forums, as would networking between the range of professionals involved. However there are several specific issues around communication and coordination which need addressing.

Participants expressed uncertainty or dissatisfaction with the current referral pathways and alternative referrals systems were suggested. There was some discussion about developing protocols for referral to clarify pathways through the system. For example, if the GP's made a referral to social services at the same time as a referral was made to the hospital, then patients requiring practical support would access help much early. Other links that were highlighted in the review were between hospital and GP, GP and low vision, low vision and social services, sensory impairment team and community care teams.

### **11.3 Training**

This was a major issue for all the service providers, both in terms of in house training and joint training. In particular, many of the social work staff such as home helps, day care staff, and residential workers would like visual impairment awareness training. There was a clear need for joint training initiatives in which not only awareness could be discussed but also roles, responsibilities and referral pathways. The joint training should involve health service staff, council staff and relevant voluntary agencies.

### **11.4 Counselling and Support**

For many staff, counselling and support are integral parts of their job. However it was recognised that there is still a huge unmet need. There is also an issue of timing and it was acknowledged that often support and someone to talk to, comes too late in the patient's journey.

There were several suggestions made in terms of providing extra support to patients. For many staff, locating the support at the eye clinic would be invaluable and was seen as the way forward. Community based providers expressed a view that support should be located at a more local level and there is an example in Forth Valley of a specialist nurse employed by the primary care trust who links across agencies.

The model that seemed to get the most universal support is to have a full time paid eye clinic liaison worker. One of the important features of this approach would be to locate more control with the patient. At present the patient role is seen as passive and information, advice and equipment is given as deemed appropriate by the professionals. What is needed, are interactions in which people are encouraged to participate in defining their own needs and then are directed to the relevant source of help. For the support to be effective the service needs to be easily accessed, confidential, part of the care system, and the worker needs a wide knowledge of service provision across the statutory and voluntary sector. Internet access would also be useful.

### **11.5 Information and Sharing Information**

It was felt that there was a need for information to be given to clients, especially at the point of registration. It was put forward that one central source of information would be less confusing and that it could be as simple as a help line number.

There were also a large number of issues raised about information sharing across organisations and it was suggested that a seminar or conference in which all service providers could be brought together would be a useful way forward. Certainly it was suggested that it would be good to hear of the findings of this review and be able to debate possible future developments.

Public Awareness raising was also discussed as there are many misperceptions of visual impairment and that a wider understanding of the issues would create a more supportive climate.

### **11.6 Pilot Projects**

Several of the above suggestions could be translated into pilot projects but there were a couple of ideas in particular which could be taken forward. Both ideas relate to low vision.

There was a difficulty recognised that there is no domiciliary optometry and that the sensory impairment team often find themselves in the position of providing help and advice on low vision aids. It would be possible to train a worker, possibly another rehabilitation worker, to provide domiciliary support and act as the link between the hospital and the client at home.

## **12.0 Conclusion**

It is useful to have documented the evidence to date and this draft report will provide the template for further reporting. It should be noted that there are two areas that require inclusion, views of service users and views of voluntary sector agencies. However this document can be seen as a discussion tool that informs the future development of the project and the forerunner of recommendations for action.

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