

# **The Identification Project**

Improving access to specialist services  
for people who are visually impaired

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## Foreword

Why are some visually impaired people not accessing the aids and equipment, information and support that could improve their quality of life?

This report presents the findings of an identification project which took place in Clydebank between August 2003 and March 2004. The project had the following four aims:

1. To identify those with a significant visual impairment who are not known to specialist health or social care services
2. To allow people with a visual impairment to articulate the impact that sight loss has on their lives and define their needs
3. To explore how services meet these needs and identify gaps in service provision
4. To explore the reasons why, in some cases, there is little or no contact with specialist services

This research suggests that it is unlikely that there are large numbers of visually impaired people living in Clydebank who are unknown to services of any kind. However, it was evident that two-thirds of those interviewed would benefit from current specialist input e.g. from their local Social Work Sensory Impairment Team.

Thanks must go to all those who were involved with this project. A number of service providers working in Clydebank gave their time and shared their thoughts and this contribution was invaluable. A special word of thanks to the thirty-three visually impaired people who openly and honestly shared their stories with me.

Susan Campbell  
Health Researcher, Visibility  
June 2004

## Summary of findings

- In Clydebank, the blind and partially sighted registration data held by the local authority underestimates the number of people who are living with a significant sight loss
- 67% of participants would benefit from a new or re-referral to specialist services e.g. local Social Work Sensory Impairment Team
- 100% of participants described a reliance on others to help fulfil many aspects of daily living
- 36% of participants had fallen or tripped as a result of their sight loss
- 61% of participants were no longer able to get out on their own because of their eyesight problems
- 94% of participants were living with additional impairments or serious health problems
- 100% of participants experienced difficulties in the kitchen. 45% of participants were reliant on someone to prepare food for them

# **1. Background**

It is difficult to know exactly how many people are living with serious sight loss. It is well documented that blind and partially sighted registration data, held by local authorities, underestimates the number of people living with a significant visual impairment and is not a true reflection of the number of people who might benefit from contact with specialist services. RNIB's survey<sup>1</sup> of the needs of visually impaired people, carried out over ten years ago, concluded that there could be three times as many people having problems with their sight (severe enough to warrant registration) as appear on the official registers. As registration is the formal gateway to specialist services, there is concern that many visually impaired people are not able to access the advice, equipment and support that could improve their quality of life. It can also be argued that the formal process of assessment, triggered by registration, is led by service providers and may not accurately reflect the range and diversity of the needs of the visually impaired person.

Research conducted in 2001 by Visibility (formerly Glasgow and West of Scotland Society for the Blind) on behalf of Greater Glasgow NHS Board, explored the views of professionals and visually impaired people in relation to health and social care provision. This work highlighted an often difficult journey through 'the system' and the many points at which visually impaired people lose contact with services, often before accessing the support necessary to meet their needs. The research showed a clear need to improve access to emotional support and practical help in both the hospital and community setting.

Building on this previous research and to establish the extent of unmet need, Visibility was commissioned by Greater Glasgow NHS Board to conduct an in-depth identification project within a specific geographical area. In partnership with West Dunbartonshire Council, this project centred on Clydebank to explore how many people are living with a serious sight loss, but are unknown to specialist services, how these individuals would define their needs and how current services meet these needs.

## **2. Are there people out there?**

## **2.1 Action plan**

There have been very few studies conducted with the aim of identifying those with a significant sight loss who are not in touch with specialist services. Informed by previous research in West Dunbartonshire, a four-phase action plan for identification was developed for this project.

In Phase 1, a sample of people from West Dunbartonshire Council's register of blind and partially sighted people were contacted to ask for their assistance in the project. In particular, people who were registered several years ago, were selected.

Phase 2 involved working closely with social care providers within West Dunbartonshire Council e.g. Home Care, to identify visually impaired people who are not in touch with specialist services.

Phase 3 centered on the local community, in order to identify people with significant sight loss who may be attending, for example, lunch clubs or church groups.

Phase 4 involved working in primary care with GP's and nurses to identify visually impaired people.

## **2.2 Talking to service providers**

Prior to implementation of the action plan, it was essential to build good relationships with service providers working within the Clydebank area. Not only was this important for actioning various aspects of the project, but the valuable insights gained from the conversations with service providers, helped to shape the development of the project. The researcher was keen to stress the distinction between services, and specialist health or social care services, when talking to service providers. An individual with a significant sight loss may be in receipt of services e.g. they may have a Home Help who hoovers and dusts their home every day, but this service, although very beneficial to the client, is unlikely to address their needs fully as a visually impaired person.

The majority of the service providers to whom the researcher spoke, knew that visually impaired people might be registered blind or

partially sighted. However, most were unaware of the often long and difficult journey people with serious sight loss face on their way to accessing services. There are barriers and gaps in 'the system' that have to be overcome and some visually impaired people may become lost and fail to make contact with specialist health or social care services.

Many of the service providers were unaware that only Consultant Ophthalmologists can register patients using a BP1 form and that receipt of this form, by a Social Work department, triggers a response to assess the person's needs. This opens the door to specialist services. When the researcher explained the significance of registration, many service providers raised concerns that there may be more people with significant sight loss not in touch with specialist services than they originally thought. Many service providers were surprised to hear that there are likely to be significant numbers of individuals eligible for registration who are not currently registered e.g. individuals who have never been referred to the acute sector, individuals who have been discharged from the acute sector before they became eligible for registration, individuals who chose not to be registered and individuals for whom registration has never been discussed.

A recurring theme in many of the interviews with service providers was the strong sense of community in Clydebank. Many older people have lived not only in Clydebank, but also in the same property for all of their lives. Much of Clydebank was destroyed when the Luftwaffe blitzed Glasgow in 1941 and many elderly people, employed in the town e.g. Singer's sewing machine factory, felt a loyalty to the area, which remains today. Older people tend to 'look out for each other' and a concerned individual who perhaps hadn't seen their neighbour for a few days would be unlikely to ignore this.

A number of initiatives are currently in place within Clydebank Local Health Care Co-operative (LHCC) to reach the housebound, elderly and those living alone. For example, there is a high uptake of the winter flu-jab among Clydebank residents. Clinics are well attended and those who do not attend are contacted and offered a home visit.

### **2.3 The flu-jab clinic**

The majority of patients attending flu-jab clinics are elderly and the

researcher attended a clinic with the aim of identifying individuals for the project. As the clinic had been well advertised, 246, mostly elderly, patients attended the two-hour session. The clinic was exceptionally crowded and the majority of those at the session appeared to know one another. The researcher talked briefly to twenty-two patients after they had received their injections (flu & pneumococcal). Of the twenty-two patients, five were currently attending Gartnavel Hospital in Glasgow as Ophthalmology outpatients, sixteen patients said they have their eyes regularly tested by their Optician and one patient with Diabetes was on his way to the Eye Casualty department at Gartnavel Hospital. The researcher talked to the patients in a very crowded room and it was not appropriate to ask for detailed personal information from individuals. Although no one was identified for the project through this approach, it provided a useful overview. Everyone the researcher spoke to was aware of the importance of having their eyes regularly examined. Five out of twenty-two people (23%) in this random sample were currently attending Gartnavel Hospital as Ophthalmology outpatients. These figures reflect the high prevalence of serious eye problems among older people.

## **2.4 Demographics**

Clydebank is often perceived as a place offering residents a low quality of life and few opportunities for employment. People living in Clydebank however tend to see the area in a much more positive light and this is especially true for older people. Clydebank sits within West Dunbartonshire Council and is served by NHS Greater Glasgow. Almost all of Clydebank's 47,000 residents are registered with Clydebank Health Centre and 17% of the population are over 65 years of age.

There are approximately 321 registered blind or partially sighted people living in Clydebank. The RNIB have estimated that there could be three times as many people having problems with their sight (severe enough to warrant registration) as appear on the official registers. Adopting these figures, it is possible that there could be as many as 1,000 significantly visually impaired people living in Clydebank.

## **3. Identification**

### **3.1 Process**

By working through the action plan for the project, forty adults were identified for interview and of those, seven were not interviewed by the researcher, for a variety of reasons:

<b>Reason for non-participation</b>	<b>Number of people</b>
Didn't want to be interviewed	3
Researcher advised not to interview	2
Deceased	1
Seriously ill & hospitalised	1

Two individuals were identified whom the researcher was advised not to visit. Both men had a history of alcohol abuse and inappropriate behaviour while intoxicated. During the Identification Project, the researcher met with a Community Safety Constable who was keen to stress the sense of community within Clydebank. The constable thought it unlikely there would be a large number of people completely unknown to health or social care services, but felt that there was a small group of individuals who were completely isolated. In her opinion, these are often men, aged 55-75 years, who are living alone, following separation from a partner. They are frequently abusing alcohol and are unlikely to have any contact with health or social care services. These individuals are likely to be estranged from their family. Neighbours are unlikely to show concern for these individuals and they often only become known to health or social care services when they are found intoxicated in a public place, or have died at home. The researcher was concerned to hear this, as there could be a number of individuals with serious sight loss, not accessing services, within this group.

The researcher gave informal presentations on the Identification Project to a number of groups (Clydebank Blind Club, Visual Voices Community Group and Gartnavel Diabetic Patients Group). She wrote to a number of voluntary organisations, participated in a local event, as part of Older People's Week and had an article featured in 'Bankie Talk' (Clydebank Talking Newspaper).

The visually impaired people who form the Visual Voices group had a good knowledge of the services available for people with sight loss. Many of those attending the group had been in touch with West Dunbartonshire Council's Sensory Impairment Team over the last

year and were keen to tell the researcher how beneficial they had found the service. Two members of the group had received information and support from Visibility's Patient Support Worker in the Eye Department at Gartnavel Hospital. Although no one was identified directly through any of these methods, one individual attending the Visual Voices group mentioned the project to two visually impaired friends and both participated in the Identification Project. As part of Older People's Week, the researcher took part in an open day in Clydebank. The majority of people to whom the researcher spoke felt their sight wasn't bad enough to need the help of specialist services. The researcher spoke to two registered blind women who had both received input from the Sensory Impairment Team in the last year and felt the service had helped them.

The thirty-three participants in this project were identified through a variety of sources, the details of which are shown in the table below:

<b>Source of identification</b>	<b>Number of participants</b>
Identified by Home Help	8
Responded to letter from Sensory Impairment Team Manager (West Dunbartonshire Council)	8
Identified by Patient Support Worker (Eye Department, Gartnavel Hospital)	6
Responded to letter from GP	5
Attended presentation at local church	3
Word of mouth	2
Wife read article in Clydebank LHCC newsletter	1

A considerable effort was made to recruit as many participants as possible for this project. A letter was sent to 350 Home Helps working in the Clydebank area asking them if they knew of anyone with serious eyesight problems who was not in touch with specialist services e.g. one of their clients, or someone living within their local area.

Sight problems in Home Care clients should be identified when a Home Help Organiser initially assesses a client. Should a sight loss problem develop which causes the client difficulty, the Home Help should inform their Home Help Organiser. Home Helps identified only fifteen individuals as having difficulty with their sight who were

not receiving specialist services. The researcher was only able to interview eight of the fifteen individuals identified by Home Helps, due to the non-participation reasons discussed earlier e.g. seriously ill and hospitalised.

Twenty individuals from West Dunbartonshire Council's register of blind and partially sighted people were approached by letter from the Sensory Impairment Team Manager asking for their assistance in the project. In particular, people who were registered several years ago, were selected. Eight individuals contacted the researcher in response to the letter and all were interviewed in their own homes. When the Identification Project began in August 2003, a number of patients living in Clydebank had been in contact with the Patient Support Worker in the Eye Department at Gartnavel Hospital. Six individuals agreed to be interviewed by the researcher. A GP working in Clydebank Health Centre wrote to eleven of his visually impaired patients asking if they would participate in the Identification Project. Five individuals contacted the researcher in response to the letter and were subsequently interviewed.

The researcher contacted a number of churches, community groups and voluntary organisations in the Clydebank area. The response from one church was particularly positive and the researcher visited the parish to talk about the Identification Project. Twenty-five individuals attended the church meeting and all appeared to have some degree of sight loss. Three individuals identified themselves as not receiving specialist services and asked the researcher to visit them at home to discuss their needs. Another participant in the Identification Project contacted the researcher after his wife read an article in the Clydebank Local Health Care Co-operative (LHCC) newsletter. Approximately 1,000 newsletters are distributed to sites in the Clydebank area including Clydebank Health Centre, libraries and leisure centres.

## **3.2 Participants profile**

### **3.2.1 Age and registration**

Of the thirty-three participants (25 females, 8 males), seventeen

were registered (blind = 14, partially sighted = 3) and sixteen participants were not registered. Twenty-six participants were over the age of 65:

<b>Age</b>	<b>Registered</b>	<b>Not registered</b>	<b>Total</b>
Aged 85 and over	4	3	7
Aged 75 to 84	5	9	14
Aged 65 to 74	3	2	5
Aged 55 to 64	2	1	3
Aged 54 and under	3	1	4

### **3.2.2 Reason for sight problem**

Fourteen participants described themselves as having more than one eye condition or sight problem e.g. sight loss following a stroke and cataracts. Some participants were able to give a name to the main reason for their sight loss e.g. glaucoma, but mentioned they had been told something else was wrong with their eyes. Whilst Age-related Macular Degeneration (ARMD) is the leading cause of visual impairment among older people, only four participants said ARMD was the reason for their eyesight problem. It is likely that more participants were actually affected by this condition as several participants said they didn't know what was wrong with their eyes and others said they had been told 'old age' or 'wear and tear'.

<b>Sight problem</b>	<b>Number of participants affected</b>
Cataracts	16
Glaucoma	8
Diabetic retinopathy	4
Macular degeneration	4
Stroke related sight loss	3
Multiple sclerosis related sight loss	1
Retinitis pigmentosa	1

### **3.2.3 Additional health problems**

Almost all of the participants (31) stated that they were living with other serious health problems or impairments and fifteen of those stated that they had more than one condition. The most common of these were heart condition (12), significant hearing loss (10),

Diabetes (5), Osteoarthritis/Osteoporosis (3). Recent figures from the Scottish Executive<sup>2</sup> show that 20% of those registered as visually impaired in Scotland have additional disabilities.

### **3.2.4 Living arrangements**

Just over half of the participants (17) were living with a partner or relative and two participants had carer responsibilities for either a partner or child. Of the sixteen living alone, three lived in sheltered housing and eleven were widows; two participants had lost their partner in the last six months.

Interestingly, women who had never married, or had been widowed for a significant number of years, described how they 'had to cope' with their sight loss:

'When you are on your own you have to get on with things and find a way to cope. You learn to ask for help when you need it.'

'Being a widow, I have always just had to manage. What else could I do?'

Three participants mentioned that they had thought about moving into sheltered accommodation 'for the company' and 'to know someone is there if they have a fall'. However, the three participants mentioned that, should a sheltered house become available, they now feel unable to move, as their sight has deteriorated to such a level that, 'they wouldn't be able to get around in a new house.'

## 4. Case studies

Although sight loss in later life is relatively common and often accepted as part of the ageing process, the impact of impaired vision cannot be underestimated. The case studies that follow illustrate the effect that visual impairment has on the social and functional aspects of a person's life. The researcher encouraged participants to articulate the impact that visual impairment has on their lives and explored with them how current services meet their needs. These case studies show that although the three individuals are currently, or have been at some point, 'in the system' their needs relating to their sight loss are not being met.

The case studies relate solely to interview transcripts, however in order to maintain confidentiality, interviewees' names have been changed.

### Mrs B

Mrs B is 85 years old and lives alone. Mrs B has had no sight in one eye since the 1940's. Her eyes were tested two weeks ago at home by the Optician who told her he now wants to check her eyes every year as 'her good eye is deteriorating'. The Optician told her, 'she won't go blind but she'll only see a little out of the eye eventually'. The Optician also told her that she wouldn't be referred to the hospital, as there is nothing that can be done.

Mrs B has a Home Help for an hour every day and, as her sight is so poor, Mrs B asks her Home Help to sign her own timesheet. Mrs B has been out of her house three times in the last five years. If Mrs B wants a hot drink, she tends to wait for her Home Help, or a family member, to call in and do it for her. Mrs B said, 'if I want to make a cup of tea I have to watch, as I put water all over the place. I am pouring and I don't think the water is coming up, so it's all over the table and running all over the place'. Mrs B is concerned that 'the doctor thinks she should be in a home'.

Mrs B has given up reading books and says 'I can't read now because the print in the books is too small. If I could get a wee magnifying glass I might be able to finish the book I was

reading'. Mrs B has great difficulty reading her post and waits

until someone comes in to read it to her. Mrs B mentioned that no one has ever talked to her about helping her with the problems resulting from her failing sight. She was told about eight years ago that someone would come out to see her, but that never happened. Mrs B, said 'I know there are things to make things easier. I knew a blind woman who had a wee thing to put on her cup. There are a lot of things I have heard about but no one has come out to see me about them. I would welcome any help.'

### Mrs Mac

Mrs Mac is 78 and very recently 'lost her sight' following a stroke. Her husband died two months ago and she is now the sole carer of her daughter who has had Parkinson's Disease for ten years. Trying to describe what her sight is like, Mrs Mac said, 'my sight is very hazy and I can only see the bottom of things. It's like someone has drawn a line across my eyes and I can only see below that line. I can't see you sitting there or things at the side at all.'

The Western Infirmary told Mrs Mac that a clot in her brain is causing the problems and her eyesight won't get any better. Mrs Mac said 'the doctor (in Neurology) told me to register partially sighted, but I don't know where to go to register. The doctor told me the Optician would do it'. Mrs Mac visited a local Optician in Clydebank to discover she may also have cataracts. Mrs Mac recently received a letter from Gartnavel Hospital to say that it may take up to a year before she is seen. Mrs Mac explained that her sight problems are making things very difficult at home. She said, 'I can't find things in the kitchen and then I knock something down'. Mrs Mac has a Home Help for an hour every weekday who attends to the hoovering, dusting and dishes that need washing.

Mrs Mac said that 'she doesn't expect anyone to help her'. She no longer goes out on her own. She can't see where she should be signing her name on things now and she can't see bills or fill in forms. She worries greatly about her daughter's failing health. Mrs Mac would like an alarm to wear around her neck in case she has a fall. She thinks her Home Help is trying to organise this for her.

She would also like a telephone with bigger numbers as she finds

it very hard to dial a number.

### Mrs W

Mrs W is 92 years old and lives alone. Glaucoma and cataracts have affected both of Mrs W's eyes and until a few months ago she had been attending Gartnavel Hospital. Mrs W believes she has now been discharged as they 'didn't tell her to come back' following her last visit. She asked the doctor at the hospital if she could be registered but the doctor told her 'no, as long as you can see out of one eye'.

Mrs W doesn't go out on her own anymore, as she 'can't see the pavement'. She finds it difficult to see the television, she can't recognise faces and can no longer write as she 'can't see to write'. She can't do any knitting or sewing anymore because of her eyesight.

Mrs W was told at Gartnavel Hospital that, 'there was nothing more that they could do, so she should get herself a bright light.' Her son bought her a small lamp for her living room but it doesn't help. Mrs W was unsure what to do about improving the lighting in her home but spoke to the Housing Department who told her, 'she would need to pay for new lights in her home'. Mrs W said, 'if I could get help with my lights it would make a difference. I can pay for them, I just need someone to do them'.

## **5. The impact of visual impairment**

Participants in the Identification Project were interviewed using a semi-structured interview schedule (appendix 1) and were encouraged to 'tell their story'. It was important that the researcher established what sort of contact, if any, participants had with specialist health or social care services. The interviews took place between September 2003 and March 2004. Each interview lasted approximately one hour and participants were interviewed in their home. Every interview was taped and transcribed and themes identified from the transcriptions.

## **5.1 What visually impaired people said**

### **5.1.1 Timescale**

One of the aims of this project was to allow visually impaired people to articulate the impact that visual impairment has on their lives. Two participants had been visually impaired since childhood. Fifteen participants described their sight loss as sudden with the remaining sixteen participants describing losing their sight gradually over a period of time. Only one participant commented that, 'losing your sight gradually is better than losing it overnight as you have to learn to adapt as your sight gets worse.' The majority of those interviewed said they had noticed they were losing their sight within the last five years:

<b>Noticed sight loss</b>	<b>Number of participants</b>
In the last year	5
In the last 5 years	16
In the last 10 years	3
In the last 25 years	6
In the last 50 years	1
Since birth or childhood	2

### **5.1.2 Impact**

Participants were keen to describe the impact their sight loss has had on their life, and the lives of those around them:

‘It’s the simple things that have become so hard, you just take things for granted when your eyes are ok.’

‘It hasn’t been easy for my husband, he was shattered when I was told my eyes wouldn’t get better. He has to do everything now.’

‘In the period between seeing the Optician and being referred to the hospital, my husband and I were both very distressed as we realised the problems with my eyes were serious. My husband ended up being given Diazepam to calm him down.’

<b>Impact of sight loss</b>	<b>Number of participants</b>
Difficulty in the kitchen	33
Difficulty with/given up reading	32
Difficulty with/can’t see television	31
Faces a haze/can’t see faces	28
Can’t see to write	27
Can’t go out on their own	20
Difficulty/stopped signing name	14
Given up/difficulty knitting/sewing	8

Other comments included:

‘Watching the television is terrible, I need to have my nose against it to see it. I hardly put it on now.’

‘Last year I was able to change all the clocks myself when they went back. I couldn’t see this year to do them.’

‘Sometimes I miss when I’m standing using the toilet which is terrible, but I just can’t see. My wife must hate it.’

‘Instead of pouring a drink of lemonade into a glass my wife makes me drink out of the two litre bottle as she knows I won’t

spill it.'

'I can't see faces at all. People pass me when I'm out with my daughter and although they say hello I don't know who it is. It really worries me as they must think I am rude.'

### **5.1.3 Kitchen skills**

The RNIB's 'Lost Vision' report<sup>3</sup> found that almost half of visually impaired people cannot cook for themselves. All thirty-three participants in this project mentioned experiencing difficulties in the kitchen and either don't cook for themselves or make something simple to eat e.g. toast. Fifteen participants mentioned that they are totally reliant on someone to prepare food for them:

'My sons come in and make food for me. I just can't see in the kitchen now. They worry that I won't eat otherwise.'

'My Home Help makes my meals. I couldn't manage without her.'

Eight participants described themselves as being 'banned' from the kitchen by a partner or relative because of their sight loss:

'My husband doesn't let me in the kitchen. He is too worried I will burn myself, he says it's too dangerous. If I want a cup of tea I wait until my husband does it for me. He cuts my dinner up for me too.'

Three participants mentioned that their kitchen skills had improved following help from their local Sensory Impairment Team:

'I've got it all organised in the kitchen now. I can make a cup of tea or a pot of soup. I use the board I got to help me and I take my time. I don't use a kettle, I just boil a small amount of water in the teapot and then pour that into my cup.'

'Someone came and put wee red bumps on my cooker and that has helped me. I try to make my porridge in the morning now.'

### **5.1.4 Acceptance**

Surprisingly, only fourteen out of thirty-three participants said they felt 'frustrated' at their sight loss. The majority of the older participants said they had accepted what had happened as, 'they couldn't do anything about it' and had expected their eyesight to deteriorate as they got older:

'At least I still have a wee bit of sight, I am better off than some old people. I have a lot to be thankful for and I don't wish for anything.'

'You have to accept things, you do as you get older. You have to look on the bright side of things as it could be a lot worse. At least I've still got my marbles.'

### **5.1.5 Loss of independence**

All participants described a reliance on others to help fulfil many aspects of daily living. It was important to understand whether this loss of independence and reliance on others was due to the participants' deterioration in sight, or due to other factors e.g. frail, elderly people are often less independent. Although many of those interviewed were elderly and had additional health problems, it was clear that they became reliant on others when their visual impairment became significant.

<b>Reliance on</b>	<b>Number of participants</b>
Home help	11
Relative	10
Partner	9
Neighbour	2
Visual support worker	1

Many participants described themselves as 'totally reliant' upon another person and were able to articulate their loss of independence:

'My son has to do everything for me now. He reads all my mail, pays my bills, gets my pension and does my shopping. I don't do anything for myself now, I just sit here most of the time.'

'My husband does everything now. I miss being able to go out myself and doing things for myself. I don't know how I'd survive

if he wasn't here.'

'I don't know what I'd do if I didn't have my Visual Support Worker. She helps me with everything.'

### **5.1.6 Mobility**

Many people cope with impaired vision by adapting their lifestyle and reducing mobility. Twenty out of thirty-three participants commented that they were no longer able to get out on their own because of their eyesight problems:

'I don't go out on my own at all now. Pavements can be different heights and I fell once out on my own path.'

One participant described herself as totally housebound as 'no one would take her out'. Twelve participants described themselves as able to get out on their own but the majority were using taxis, not crossing roads or travelling very short distances e.g. newsagent at the end of the road. Participants also described themselves as feeling very nervous or frightened when out alone:

'When I am outside now I am frightened when I am walking along. I wouldn't cross the road myself as I only see half of the cars as they drive along. I am always worried there might be a child that I don't see and I bump into them. It takes away your confidence.'

Eighteen out of thirty-three participants commented that someone does their shopping for them because of the problems with their sight. Thirteen participants are taken shopping by someone and only two participants said they are able to shop alone. One participant who shops alone will only use the shop at the end of his street as he doesn't have to cross any roads and the staff in the shop assist him.

### **5.1.7 Accessing the health centre**

The researcher asked each interviewee if they were unwell, how they

would access services at their local health centre e.g. their GP. Only six interviewees said they would be able to get to the health centre on their own, with four saying they would have to take a taxi door-to-door and would be very nervous out on their own. Ten participants said they wouldn't be able to go, even if someone were taking them i.e. they would insist on a house call. The other seventeen interviewees said they could get to the health centre as long as someone went with them. This finding has obvious implications for visually impaired people accessing services in the community. West Dunbartonshire Council's Sensory Impairment Team operates an Outreach Service at Clydebank Health Centre for two hours every fortnight. Individuals who were previously unknown to the Sensory Impairment Team do attend the Outreach Service although the majority of those have a hearing impairment rather than a significant sight loss.

### **5.1.8 Vulnerability**

Two participants mentioned that they had recently been a victim of crime. Five men attacked one participant as he walked along his road, while the other participant was the victim of a bogus caller in her home (she had stopped using the safety chain on her front door as she was no longer able to see well enough to use it). The researcher was concerned that many of the participants she visited at home left their front door unlocked or ajar, when they were expecting a visitor.

Older people with sight problems have an increased risk of accidents and falls<sup>4</sup>. Although the researcher did not specifically ask, twelve participants mentioned they had fallen or tripped as a result of their sight loss, with four participants requiring hospital treatment. It is well documented that older people fall but the research evidence suggests that older people with sight problems are not only more likely to have a fall, but are at a greater risk of multiple falls, compared to their fully sighted peers.

### **5.1.9 Mental health**

Research conducted by the Thomas Pocklington Trust<sup>5</sup> found that

although onset of visual impairment has significant emotional consequences, which include anxiety, depression and feelings of loss, there is little professional recognition of this, or offers of help and advice at this critical time. Nine out of thirty-three participants described feeling, 'very depressed' because of their sight problems. Five participants were currently taking anti-depressants and two participants described themselves as 'having suffered a mental breakdown' since they lost their sight.

Six out of thirty-three participants had stopped working prematurely (mean = 15 years before retirement age) due to their sight loss:

'I had to stop work when I was registered. I felt so terrible and cried inwardly for months. I loved working and the fact that I couldn't work anymore was so hard.'

'I was 54 when the doctor told me I would have to stop work because of my eyes. I burst out crying. It was like the end of my life.'

Although it was a difficult question, the researcher asked many of the participants if they had thought about what they would do if their sight were to deteriorate further. Many participants responded very quickly, saying it wasn't something they wanted to think about. However, after this initial response, participants were keen to share their fears and many became visibly upset:

'I know my eyes will get worse, but I hope I'll be gone before they get really bad.'

'Losing my sight totally would be the worse thing that could happen.'

'If I was to go totally blind I know I couldn't cope here, I would have to go into a home.'

## **5.2 Nothing can be done to help**

Twenty participants commented an Optician or Ophthalmologist had told them that 'nothing could be done to help them':

'The last time I was at the hospital the doctor couldn't have cared less. I asked him if there was anything he could do to help me, but he said no.'

'When I went to my appointment and they said there was nothing they could do I felt terrible. I was thinking I would get laser treatment or something, but they said it would be no use. I was told not to come back, there was nothing that could be done to help me.'

'I was told at the hospital that they couldn't do anything for me. I felt shattered. I was told not to make any more appointments. The doctor told me not to worry as my eyesight will not go totally suddenly. He said I'll still be able to see a wee bit when I die.'

'The hospital told me not to come back as there was nothing they could do for me. I was in tears, it was so final.'

Although medically, nothing more can be done for these individuals this is not to say that they are unable to be helped in anyway. Unfortunately people frequently hear 'nothing can be done' and understandably don't investigate if there is anything else available to help them.

## **6. Awareness of what help is available**

One of the biggest issues preventing people from accessing specialist services is a lack of awareness about what might be available to help them:

'I am sure there are things out there that could help me but I don't know what they are. Glasses aren't any use and magnifiers aren't any use, but there must be other things.'

'The Optician told me that I would have to be referred to my doctor as there was something wrong with my eyes. Why didn't he tell me where I could get help? I had no idea there was any help available. The doctor referred me to the hospital, but I was really struggling with my eyes and it was only when they said I would go on the blind list, that I got any help. I would think the Optician is the first contact most people have when there is a problem with their eyes. There should be at least a notice there to tell you where to get help. There could also be a notice in the Health Centre, as some people see their doctor about their eyes.'

'I think there should be something that, when a person is diagnosed as blind, partially sighted or having some sort of problem, that the person who is telling them that, should say to them, that they can get help and they should contact someone and give them a card with a telephone number on it.'

## **6.1 Aids and equipment**

The RNIB's recently published 'Unseen' report<sup>6</sup> found that only 37% of people surveyed had been offered a liquid-level indicator and 31% had been offered simple bump-on stickers for their cooker to help them identify the settings. These figures are worrying as seven out of eight people surveyed by the RNIB were registered with their local authority as blind or partially sighted.

### **6.1.1 What people would like**

In this study just under half of the participants (14) commented that they would like 'anything' to help with their sight loss. When asked what they thought might help, respondents were able to name or describe a couple of things but stated they were unsure where they

could get them.

<b>What they would like to help</b>	<b>Number of participants</b>
Magnifier	4
Liquid-level indicator	3
Better lights	3
Signature guide	3
Big button phone	2
Large print crossword book	1
Glare glasses	1

Given that seventeen participants were registered blind or partially sighted and should therefore have had contact at some point with their local Sensory Impairment Team, it is surprising that more participants were not in receipt of some of the most common aids nor were they aware that the Sensory Impairment Team could provide them.

### **6.1.2 What people had to help**

When participants were asked if they had anything to help them with their sight loss, very few were able to name anything. Noticing various aids and pieces of equipment in participants homes, for example a big button phone or talking clock, the researcher was able to use these as prompts. Eighteen participants were then able to describe something they currently use or have used in the past: (See Table)

Many participants commented that, for example, their liquid level indicator or talking watch had broken and as they had no idea who to contact for help, they had stopped using it. Most participants were unsure where their aids and pieces of equipment had come from. Some participants mentioned that a relative had bought something for them e.g. big button phone from Argos or that 'someone had come out from the Council with stuff.'

<b>Aids and equipment</b>	<b>Number of participants</b>
Big button phone	6
Talking books	6
Bump-ons	4
Signature guide	4

White cane	4
Talking newspaper e.g. Bankie Talk	4
Talking watch	3
Liquid level indicator	3
Talking clock	3
TV magnifier	3
Task light	2
Non-slip mats	2
Plate with sides	2
Symbol cane	1
Small kettle	1
Anti-glare glasses	1

### **6.1.3 Signature guide**

Out of thirty-three participants, fourteen told the researcher they were experiencing difficulty signing their name or had stopped doing it all together. Only four out of thirty-three participants were in possession of a signature guide. When the Identification Project started, the researcher carried a few signature guides to show participants. As only four participants were in possession of a signature guide, the researcher demonstrated and left a guide with the remaining participants. Participants were delighted to receive the simple aid and many commented that they would start signing their name again.

### **6.1.4 Low vision aids**

Twenty participants mentioned that they were in possession of a magnifier (hand-held, stand- or spectacle-mounted lenses). Only one participant described their magnifier as 'useful', with seven participants commenting their magnifier 'helps a bit' e.g. to read a sell by date or cooking instructions on a packet.

Twelve participants commented that their magnifier was 'useless'. These participants described the high expectations they had for their magnifier, hoping it would have restored their ability to read large amounts of text e.g. a book and giving up using the magnifier when they found this not to be the case. Although ten participants described attending a Low Vision Aid Clinic, only four participants mentioned being given a magnifier following their visit. Other

participants mentioned purchasing, or being given a magnifier from a variety of sources (relative = 3, Optician = 2, blind club = 1, newspaper advertisement = 1, 'Betterware' catalogue = 1).

## **7. Lack of access to specialist services**

One important aim of this project was to explore the reasons why in some cases individuals with significant sight loss have little or no contact with specialist health or social care services. Workers in health and social care services may perceive visual impairment as inevitable in older people and non-urgent. As visual impairment is not life threatening and often not immediately obvious it is frequently ignored. One participant commented:

‘I tripped on the carpet last year and needed eleven stitches to my head. After that the Social Work department gave me an alarm for around my neck and came out to fit handrails at the front and back of my house. I didn’t mention to the Social Work people that I have problems with my eyes when they came out, but then, they didn’t ask.’

When a person first notices a problem with their eyesight they are likely either to visit an Optician or their GP. If a patient visits their GP, they may be referred to the local eye department for further investigation or advised to visit an Optician to have their eyes tested. If the Optician feels that specialist treatment is required, they will write to the individual’s GP suggesting a referral to an eye department. It is possible that the visual problem may already be affecting the person’s quality of life in terms of independence and daily living. The waiting time for an appointment to see an Ophthalmologist varies but some patients may wait up to one year for their first appointment.

## **7.1 The critical role of opticians and GP’s**

The researcher was surprised to hear, from some Community Opticians working in the Clydebank area, that they were unaware of the Sensory Impairment Team. The Opticians commented that Social Work services were usually only required when a patient is in crisis and hadn’t thought of suggesting to anyone that they contact their local Social Work department for help with their sight loss. The Opticians mentioned that they refer approximately 5% of their patients to Ophthalmology Outpatients, or Eye Casualty, every year, but that they do not have the time to follow-up these referrals.

It is possible that some individuals may fall out of the system at this early stage.

West Dunbartonshire Council’s Sensory Impairment Team receives very few referrals from GP’s or Community Opticians and only a few GP’s working in Clydebank Health Centre refer patients to the Outreach Service. One GP, working in Clydebank Health Centre, who does refer patients to the Sensory Impairment Team, assumed that all patients are followed-up at regular intervals by the team. GP’s

or any other members of the primary health care team can immediately refer individuals to social work services, or a relevant specialist organisation, for input e.g. Visibility, Deafblind Scotland. However, GP's and others working in primary care may be unaware of the scope of support available to someone with a visual impairment.

When first noticing a problem with their eyes, twenty-five of the thirty-three participants visited an Optician and eight saw their GP. All eight participants who visited their GP were referred directly to their local eye department.

Of the twenty-five participants who attended an Optician initially, four were not referred by the Optician (via their GP) to a local eye department. It is important to establish why these participants were not referred to the acute sector, as it is possible, at this early stage, that they were prevented from gaining access to specialist health services. All four participants were told, by their Optician, that, as there was nothing that could be done to improve their sight, they would not be referred to an eye department:

'The Optician wants to see me every year but she said there is no point in referring me to the hospital, as there is nothing that can be done.'

'The Optician said she couldn't do anything for my eyes, but she would give me another pair of reading glasses. The glasses were no use at all when I got them. The Optician said there was no point sending me to the hospital as they wouldn't be able to do anything for me, as it was just wear and tear.'

'The Optician says there is no point referring me to the hospital, but I am finding it so hard to see and wish he would do something to help me.'

'I have my eyes tested twice a year at the Opticians as I wear glasses. He told me that I am blind in one eye now. My other eye is bad but the Optician says it's because of my MS. I am not being referred to see an eye doctor, as there is nothing they can do.'

Understandably, some Opticians don't see the point in an ophthalmic referral if the sight problem is thought to be untreatable. However, it is possible that Opticians are not aware of the role of registration as the formal gateway to specialist services. If a visually impaired person is not referred to a Consultant Ophthalmologist, it is likely they will remain unregistered and their needs may go unrecognised. The Optician may also decide that it is not worth putting a patient, who may have become eligible for registration (or re-registration from partially sighted to blind), through the process of waiting for an appointment to see an Ophthalmologist, when nothing can be done to improve their sight.

Opticians interviewed for the Identification Project commented that due to the number of cases of ARMD presenting at their practices, patients with the early stages of the condition are not immediately referred to a Consultant Ophthalmologist. Early-stage ARMD patients are often managed by the Optician in their practice for up to two years by supplying glasses and encouraging the patient to have their eyes tested every six to twelve months. An ophthalmic referral often occurs when glasses are no longer able to help. A number of participants commented that they felt their Optician was reluctant to refer them to an Ophthalmologist, despite the fact they were experiencing significant difficulties:

'My eyesight had been getting worse and the Optician said I needed new glasses. I took them home and they made no difference, I could hardly see. I went back the next day and they tested my eyes again and said I would have to go to the eye hospital. When I went to the hospital they said they would have to register me blind.'

'The Optician wasn't very good. Practically everything had become difficult like reading, recognising faces and seeing anything clearly. When she tested my eyes she said I needed new glasses. I went the next day to a different Optician to see what they would say and he sent me up to Gartnavel there and then. He gave me a letter and I went straight up to the hospital in a taxi as he said there was something not quite right with my eyes.'

Many of the participants who were referred by their Optician to an

Ophthalmologist commented that they no longer see the point in attending an Optician following their discharge from an eye department:

‘I worry about developing something else like a cataract. I don’t go to the Optician anymore though as I was told at the hospital they can’t do anything for my eyes now.’

However one participant commented:

‘I wasn’t going to go to the Optician anymore, as the doctor at the hospital told me that nothing could be done for my eyes, my Diabetes had damaged them. I am glad I did, as the Optician found a cataract and is referring me back to the hospital for treatment.’

## **7.2 Sight loss with other medical problems**

Sight loss may be perceived as a small part of a larger problem e.g. stroke, head injury, Multiple Sclerosis and for this reason some individuals may not access ophthalmic services. Individuals who are referred to their local eye department may find they are actually not eligible for registration as nothing is actually wrong with their eyes.

In this study, three participants were experiencing significant sight loss following a stroke and one participant had sight loss assumed to be related to his Multiple Sclerosis (MS). The participant with MS commented that he attends an Optician twice a year but he is not being referred to a Consultant Ophthalmologist. He explained that his sight loss is assumed to be part of his MS and nothing can be done to improve his vision.

Two of the three participants experiencing deterioration in their vision following a stroke were already under the care of a Consultant Ophthalmologist for cataracts. The remaining participant experiencing sight loss following a stroke was told by her Neurologist to ask an Optician to register her partially sighted. On examination, the Optician was concerned that this lady may also have cataracts and made an ophthalmic referral. This participant received a letter to say she was currently in a twelve-month waiting list to be seen at Gartnavel Hospital.

### 7.3 Awareness of sensory impairment teams

Overall, participants had little awareness of their local sensory impairment team:

‘Nobody says to you at the doctors or the Opticians or even at the hospital that there is a department within Social Work that can help you when your sight goes. I didn’t know they existed until my daughter phoned her friend who works in Social Work.’

Participants talked of ‘a man coming out and sticking red bumps on my washing machine’ or ‘a woman came out, she must have been from the hospital as she knew my eyes had got bad and asked me if I would like a wee thing to go on my tea cup.’ On further questioning it transpired that eighteen participants had received input from a Social Work Sensory Impairment Team member. Twelve of the eighteen individuals recalled being visited by someone, ‘after being at the hospital about their eyes’ and six individuals who were not registered had received input. Five participants commented that they thought they would have received a follow-up visit:

‘Someone came out to see me when I was registered blind but that was twenty-two years ago. No one ever phones to check if I need anything or if I’m ok. At least I have a brother than comes and helps me with things but what do people do that are on their own with no one?’

‘No one has been out to see me about my eyes for years. My sight is much worse now and it would be good if someone visited to see if I need anything’.

As discussed earlier, the researcher gave a presentation to a local church group as part of the Identification Project. Twenty-five individuals attended the meeting, all of whom appeared to have some degree of sight loss. Talking to the group, many were unaware that there was a service within their local Social Work department for people with sight loss. A few people mentioned that this was enough to put them off contacting the service due to their negative perceptions of Social Workers:

‘Social Workers try to put you into a home when you’re old.’

‘Those people ask you lots of questions about your money and I don’t want that’.

Interestingly, it was clear that a few members of the group had attended the Sensory Impairment Team’s Outreach Service at Clydebank Health Centre, or had a member of the Sensory Impairment Team visit them at home. Many people were unsure whom they had actually seen at the health centre, or who had visited them at home, but they knew it had something to do with their eyes. The majority of the group were keen to stress that they had been told either by their Optician or by an Ophthalmologist that nothing more could be done for them. On hearing this, they had accepted that there was no help available.

## **7.4 Assessment and follow up**

Research conducted by the Thomas Pocklington Trust<sup>5</sup> revealed that sensory impairment teams are under-resourced and typically assess needs after considerable delay, or on only one occasion, when the individual may not be receptive to offers of help. Such teams are often unable to offer a regular monitoring and follow-up service.

West Dunbartonshire Council’s Sensory Impairment Team receives between ten and fifteen referrals a week for services for people who are blind, partially sighted, deaf, hard of hearing or deafblind. The team estimates that approximately one-third of these referrals are for people who require a service due to a visual impairment.

Although approximately two-thirds of referrals are for people who are hearing impaired, visually impaired individuals often require greater input from the team e.g. mobility training and daily living skills. The team receives approximately five BP1 registration forms a month. The majority of forms relate to individuals being newly registered blind, or partially sighted, however, some relate to individuals whose registration status has changed i.e. they were previously registered partially sighted and are being re-registered as blind. Non-registered individuals receive the same service from the team as those who are registered. The manager of the Sensory Impairment Team continues to work towards reducing the waiting list for services, which, at April

2004, is two to three months, for those who are visually impaired.

As is the case in almost all health and social care services, clients are not routinely followed-up, unless a new referral is received for that individual. When a member of the Sensory Impairment Team visits an individual, their needs are assessed at that point in time, but clients are encouraged to make contact with the team should their needs change. Most participants interviewed for this project had little awareness of their local Sensory Impairment Team and mentioned that they didn't know where they were based, or how they would get in touch with them.

Although seventeen out of thirty-three participants were registered, (blind = 14, partially sighted = 3), the majority were unsure what registration meant:

'The doctor told me that I was going on the blind register as partially blind. He told me not to worry as I won't go blind totally. He didn't tell me what it meant.'

'I signed to be registered blind but I don't know what it is.'

'I asked about being registered partially sighted and I was given a form to sign although what registration means wasn't explained to me.'

As the registration process was not explained to many participants, they were not aware that the form they had signed was sent to their local Sensory Impairment Team who then got in touch to offer help and advice.

Registration is entirely voluntary and as previously discussed the RNIB estimates that only one in three people who are eligible to register as blind or partially sighted have actually done so. There are several reasons for this, many of which were applicable to the sixteen non-registered participants in this project. A few participants were not in contact with specialist eye services because the health or social care professionals they had been in contact with did not appear to realise how bad their sight was. Some participants were unaware of the benefits registration offers and a couple of participants mentioned that they didn't want to be 'labelled' as blind.

## **7.5 Other social care services**

Referrals to West Dunbartonshire Council's Sensory Impairment Team come from a number of sources. Although data on the source of referral is not routinely recorded, the team believe that the majority are telephone self-referrals from individuals, or concerned family members, or neighbours. Occupational Therapists, Community Nurses, Health Visitors and the Community Older People's Team also refer individuals to the Sensory Impairment Team. Very few direct referrals are received from GP's or Home Help Organisers.

### **7.5.1 Home care**

Many elderly people, especially those who are housebound, have a Home Help. Based on this fact, it was thought that an effective way of potentially uncovering people with a significant visual impairment, would be to work with the Home Care Service. Newly recruited Home Helps, working for West Dunbartonshire Council, receive sensory impairment awareness training as part of their induction programme. They, therefore, should, be able to notice if their client is experiencing difficulties. Home Helps in the Clydebank area were asked to identify, with consent, any client that they felt was experiencing a significant deterioration in their sight who was not in touch with specialist services. Fifteen individuals were identified by Home Helps and the researcher interviewed eight of the fifteen. Another five participants, who were identified in other ways, had a Home Help from West Dunbartonshire Council's Home Care Service.

Due to the needs articulated by three participants, the researcher made a consented referral to the Sensory Impairment Team for specialist input on their behalf. All three participants currently had a Home Help from West Dunbartonshire Council and had been identified by their Home Help as someone with significant sight loss who is not currently in receipt of specialist services. None of the three participants had been referred by the Home Care Service to the Sensory Impairment Team for specialist input, despite the obvious difficulties they were experiencing due to their sight loss. These three elderly participants gave the researcher significant cause for concern and on making one referral, the researcher was told the individual would be prioritised by the team, due to the complexity of her needs and family situation i.e. recently bereaved and sole carer of her daughter. Although the three participants were

keen to tell the researcher how beneficial they found their Home Help, it was obvious they were experiencing significant difficulties due to their sight loss and would benefit hugely from Sensory Impairment Team input:

‘My Home Help is wonderful as she keeps my place lovely and clean. I can’t see well enough to do it. So many things are hard now. I can’t cross roads, I can’t tell the time on any of my clocks and I’ve slipped on water that I’ve spilled from my kettle. It’s been very sudden although I am 81 now so I suppose these things happen as you get older. I can’t read or do crosswords and I can’t see the television. If I go into a shop I have to ask the assistant to take the money out my purse as I can’t see the difference between my money. No one at the hospital seems to care about these things.’

## **7.6 Giving participants information**

The majority of older participants in this project expressed few needs for services or help and appeared to have adjusted and accepted the restrictions imposed by their sight loss. As previously discussed, it transpired, during the interviews, that eighteen participants had received input from a Social Work Sensory Impairment Team member at some point in time. Many participants commented that, ‘they hadn’t seen anyone for years’ and ‘wouldn’t know how to make contact with anyone’. West Dunbartonshire Council’s Sensory Impairment Team produced a leaflet containing their contact details and other useful information for people with

sight loss. The researcher gave this leaflet to thirty-two of the participants she interviewed. Although one participant was registered to Clydebank Health Centre, he lived within the Glasgow City Council boundary and was currently in touch with the Sensory Impairment Team at Gullane Street, Partick. On receiving the leaflet from the researcher, seven participants commented that they didn’t currently need any help from the Sensory Impairment Team or other services, as they felt they were ‘coping’. Although the researcher agreed that input from specialist services was not currently required, many aspects of daily living for these participants was currently fulfilled by a partner, relative, friend or neighbour.

Following the interviews with thirty-three participants, the researcher

made three consented referrals to West Dunbartonshire Council's Sensory Impairment Team. The researcher also encouraged a further nineteen participants to make contact with the team. Thirteen of these nineteen participants said they would do this and were glad they had been given the contact details of the team. Unfortunately, six of the nineteen participants the researcher felt would benefit from contact with the Sensory Impairment Team, commented that they didn't want any contact with them, or any other services, although they knew it could help them:

'I know it would help but I don't want someone to come out and see me to talk about this. I would rather keep my mind off it. I want to be left alone.'

One participant asked the researcher to refer them to Visibility's Supporting People project as someone had told them about it. The project ensures that people with sight loss have the opportunity to live more independently and provides staff (Visual Support Workers) to assist with for example, food shopping, reading mail and completing forms. The researcher made the referral and this participant now has a Visual Support Worker for five hours per week.

## **8. Conclusion**

Thirty-three participants were identified and interviewed for this project. The researcher felt that twenty-two of the thirty-three participants (67%) interviewed would currently benefit from contact with their local Sensory Impairment Team. For some of these individuals, they simply needed to know where they could buy a big button phone or how to change the battery on their talking watch. However, three of the twenty-two participants articulated significant difficulties due to their sight loss and were newly referred, with consent, to West Dunbartonshire Council's Sensory Impairment Team. Rather worryingly, the three participants referred to the

Sensory Impairment Team for assessment by the researcher were currently receiving another Social Work service (Home Care) from West Dunbartonshire Council. Although having a Home Help was beneficial to these clients, the service alone was failing to meet their needs as visually impaired people. West Dunbartonshire Council's Sensory Impairment Team does not receive many referrals from Home Care. A significant sight loss should be noticed when a client is assessed initially for Home Care, or if the sight loss has been more recent, the Home Help should inform their line manager (Home Help Organiser). The client would then be referred to the Sensory Impairment Team for input. None of the three individuals referred to the Sensory Impairment Team by the researcher had previously been referred by Home Care. It is worrying to think that, had this Identification Project not occurred, these individuals may not have gained access to the aids and equipment, information and support that could improve their quality of life. There is a role for a Community Health Worker for visual impairment in Clydebank. Such an individual would work actively in the community to identify those unknown to services and develop close working relationships with Opticians, social work departments and primary care staff in order to improve access to health and social care services for visually impaired people.

Many of the participants in this project have been living with sight loss for a number of years. Although the majority of older participants expressed few needs for services and appeared to have adjusted and accepted the restrictions imposed by their sight loss, it was clear many of them would benefit from a new or re-

referral to specialist services e.g. their local Sensory Impairment Team. Although specialist services know about their clients, clients don't necessarily know or remember that specialist services are available to them. For many visually impaired people their one and only contact with specialist social care services occurs following registration. Visually impaired people need to be encouraged to contact social care services, as and when their needs change. This is especially true for visually impaired people who are not registered, as they are likely to have little or no contact with specialist social care services.

The extent to which registration figures reflect the prevalence of visual impairment in the population will remain a controversial issue.

Registration is voluntary and while it provides access to a number of benefits and concessions there are a significant number of visually impaired people who are not registered. The Scottish Executive is carrying out a review of the registration and certification process and this may in time lead to more accurate statistics. From this small Identification Project, it is unlikely that there are large numbers of visually impaired people living in the Clydebank area who are completely unknown to services of any kind. It would be a valuable exercise not only extending the Identification Project across West Dunbartonshire, but also replicating the project in another local authority area to be able to compare and contrast the results. However, it is clear that a significant number of visually impaired people living in the Clydebank area are not currently in touch with specialist health or social care services. While some people are receiving help, this may not be specifically related to their sight loss. Specialist services need to reach out and find these people. If this is to be achieved, closer working relationships are essential between social work, primary care staff and Opticians.

Although visual impairment can occur at any time in life, it is primarily an impairment of old age. Many visually impaired people, therefore, need access to services for older people, as well as specific services for their visual impairment. Many of the participants interviewed for this project would have benefited from information, support, aids and equipment when their visual impairment first started to make an impact on their quality of life. This research provides evidence that visually impaired people are less able, than their sighted peers, to carry out many of the basic

activities of daily living independently, or with as much confidence. However, like the rest of the population, there is a great diversity in the needs and wants of individuals with sight loss. People should be able to access services when they first notice their sight loss impacting on their quality of life and these services must continue to be available, as the needs and circumstances of visually impaired people change over time.

## 9. Recommendations

It is recommended that:

1. the role of a Community Health Worker for visual impairment be piloted
2. the Outreach Service at Clydebank Health Centre is extended
3. a research project is developed to examine the increased risk of trips and falls for those with a visual impairment
4. a research project is developed to identify the needs of people with serious sight loss unrelated to an eye condition or eye injury e.g. sight loss related to stroke, head injury, Multiple Sclerosis
5. Community Opticians and GP surgeries should be supported and encouraged to work more closely with Social Work Sensory Impairment Teams
6. a pilot referral scheme is developed between Opticians and Social Work Sensory Impairment Teams
7. a self-assessment tool is developed and piloted with individuals who have not been visited by a Social Work Sensory Impairment Team member in over five years
8. a research project is developed to follow individuals who have been discharged from the acute sector before they are eligible for registration
9. Sensory Impairment Awareness training should be a regular and mandatory part of training for all council services. Part of the training is knowledge and understanding of the role of the Sensory Impairment Team
10. the Identification Project is extended across West Dunbartonshire
11. the Identification Project is replicated in another local authority

area

12. an annual follow-up letter is piloted with those who are newly referred to Social Work Sensory Impairment Teams

## 10. References

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## **Appendix 1 – Interview Schedule**

- 1 Story of losing sight.
- 2 Details on condition, describe how much sight.
- 3 Are they registered?
- 4 Additional or associated health problems.
- 5 General mood (anxiety, insomnia, appetite).
- 6 Hospital (for eyes).
- 7 Remembering being told about condition/sight loss/registration.
- 8 How do they feel now?
- 9 Home (lives alone/with, managing).
- 10 Contact with family and friends, visitors to home.
- 11 Other contacts e.g. Home Help, GP, social work, voluntary organisations.
- 12 Who would you like to be in contact with?
- 13 When did loss of eyesight start to make an impact?
- 14 What did you do about it?
- 15 How do they spend their time, before and after sight loss?
- 16 Impact of sight loss on daily life (personal care, domestic tasks, paperwork).
- 17 Coping with this.
- 18 What did they do last week/yesterday?
- 19 Do you use any equipment to help you (see)?

- 20 Thinking just about sight loss, changes to life.
- 21 What do you miss?
- 22 What would you like to be able to do?
- 23 Has anything helped you to deal with these things?
- 24 Who can you ask for help?
- 25 Local service at health centre, would you go, would it help?
- 26 Needs (info, advice, support, equipment).
- 27 What would make a difference to you?
- 28 Impact of sight loss in future.
- 29 Anything else you would like to tell me?
- 30 How would they rate their sight loss.