

Cambridge Centre
for Housing &
Planning Research

Sight Loss is not Life Loss

Project Evaluation for
Southampton Sight

August 2014



UNIVERSITY OF
CAMBRIDGE

Contents

1) Introduction	3
2) Methodology	6
3) Achievements against targets	7
4) Successes and challenges	8
5) Client outcomes	18
6) Conclusions	25
7) Contacts	26

This research was conducted by Dr Gemma Burgess and Sam Morris at the Cambridge Centre for Housing and Planning Research. To reference the report:

Burgess, G. And Morris, S. (2014) Sight Loss is not Life Loss: Project Evaluation for Southampton Sight. Cambridge: Cambridge Centre for Housing and Planning Research.

1) Introduction

1.1 Southampton Sight

Southampton Sight is a small local charity based in Southampton established in 1899. They are the main provider of long term support and social activities for those with sight loss in Southampton. The aim of the service is to enable people with sight loss to achieve their individual aspirations.

There is range of services for those with sight loss and their families who live in Southampton and the surrounding areas which fall broadly into two categories. One is the provision of information, advice and support, which includes one to one assessments to identify individual needs and a resource centre with aids and adaptations. The other main type of service provision is social activities held at the centre, for which subsidised transport is provided, and includes lunch clubs, Tai Chi and musical entertainment.

Southampton Sight also offers a free talking library service which is used by over 100 service users, many of whom are house bound. There is a newsletter which promotes the service and gives information about advances in treatment, technology and equipment.

1.2 Sight Loss is not Life Loss

The aim of the project is to support people with sight loss living in Southampton to live full and active lives and to reach their full potential by providing a range of services that build and complement the existing work at the organisation. This project provides:

- An information, guidance and support service.
- Access to specialist equipment and resources via a specially designed resource centre.
- Peer support through a social group.
- Volunteering opportunities.

The project aims to deal with a wide range of issues, which have been identified through discussions with those who have sight loss in the Southampton area and with professionals based at the Southampton Eye Hospital and in the Sensory Services Team. The issues include:

- Emotional issues associated with sight loss, for both the individual and the individual's family, in particular when people are first diagnosed with sight loss as often major adjustments to everyday life need to be made.
- Practical issues associated with sight loss, for example, carrying out day to day tasks; these include things such as catching a bus or making a cup of tea which can be challenging.

- Isolation Issues. Sight loss can lead people to feel isolated, this is particularly true of the more elderly service users, but also children feel isolated, as many are in mainstream school and do not mix with similar conditions to themselves. As around two thirds of registered blind or partially sighted adults are not employed, this can increase feelings of isolation.

Many people contacting Southampton Sight find that they are given lots of information about their eye condition and how it will be treated in the short term but they have no information about long term implications, how it will affect their everyday life and additional services and support that may be available locally to them. This project aims to address that by offering more services locally and by acting as an information hub, to provide those who are visually impaired with details about all the support and information available. Emotional support is also available through the peer support programme.

1.3 Evaluation

The Cambridge Centre for Housing and Planning Research at the University of Cambridge has undertaken an independent evaluation of the Sight Loss is not Life Loss project.

1.4 Background to sight loss

This background section is drawn from information provided by the RNIB about sight loss in the UK¹. Almost two million people in the UK are living with sight loss. That is approximately one person in 30. Sight loss affects people of all ages, but older people are increasingly likely to experience sight loss.

- One in five people aged 75 and over are living with sight loss.
- One in two people aged 90 and over are living with sight loss.
- Nearly two-thirds of people living with sight loss are women.
- People from black and minority ethnic communities are at greater risk of some of the leading causes of sight loss.
- Adults with learning disabilities are 10 times more likely to be blind or partially sighted than the general population.

Age-related macular degeneration is by far the leading cause of blindness in adults. Other significant causes of sight loss are glaucoma, cataracts and diabetic retinopathy.

The number of people in the UK with sight loss is set to increase in the future as the UK population is ageing. In addition, there is a growing incidence in key underlying causes of sight loss, such as obesity and diabetes. This means that, without action, the numbers of people with sight problems in the UK are likely to increase dramatically over the next 25 years. It is predicted that by 2020 the number of people with sight loss will rise to over 2,250,000. By 2050, the number of people with sight loss in the UK will double to nearly four million.

In 2008 sight loss cost at least £6.5 billion, and this is likely to increase as the number of people with sight loss increases. This figure does not include the cost of sight loss in

¹ <http://www.rnib.org.uk/knowledge-and-research-hub/key-information-and-statistics>

children. This cost is made up of £2.14 billion in direct health care costs, such as eye clinics, prescriptions and operations and £4.34 billion in indirect costs, such as unpaid carer costs and reduced employment rates.

There are around 360,000 people registered as blind or partially sighted in the UK. The RNIB found that only eight per cent of registered blind and partially sighted people were offered formal counselling by the eye clinic, either at the time of diagnosis or later. In the year after registration, less than a quarter (23 per cent) of people who lost their sight say they were offered mobility training to help them get around independently. Almost half of blind and partially sighted people feel 'moderately' or 'completely' cut off from people and things around them. Older people with sight loss are almost three times more likely to experience depression than people with good vision. Only one-third of registered blind and partially sighted people of working age are in employment.

Evidence suggests that there is a strong link between sight loss and reduced psychological wellbeing, particularly amongst older people who develop sight loss later in life (RNIB, 2013²). People living with sight loss report lower feelings of wellbeing, reduced self-confidence and lower satisfaction with their overall health. People with sight loss were four times more likely than those with no impairment to be dissatisfied with their health.

Many blind and partially sighted people require support in order to remain independent. Sometimes this is provided by social services, but typically it is provided on an informal basis by family, friends and neighbours. The type of support provided by social services includes equipment, adaptations and home care. 36,085 blind and partially sighted people were in receipt of support from social services in England in 2011/12. This represents a 26 per cent decrease in the number of blind and partially sighted people receiving adult social services since 2008/09.

The provision of emotional and practical support at the right time can help people who are experiencing sight loss to retain their independence and access the support they need.

² <http://www.rnib.org.uk/knowledge-and-research-hub-research-reports/general-research>

2) Methodology

2.1 Interviews with management/delivery team

Interviews were conducted by telephone with the Southampton Sight staff responsible for delivering and managing the Sight Loss is not Life Loss project. The interviews discussed the successes and challenges of the project and service user outcomes.

2.2 Interviews with agencies referring to the service

Interviews were conducted by telephone with the local agencies referring people to the Southampton Sight service to explore the reasons for referral, the support expected from the service and service user outcomes.

2.3 Interviews with volunteers

Interviews were conducted by telephone with volunteers working with Southampton Sight. These explored their reasons for volunteering, their experience, and outcomes for both themselves and service users.

2.4 Analysis of existing data and monitoring information

Relevant data and monitoring information, provided by Southampton Sight, were analysed to assess the achievement of deliverables and targets.

2.5 Service user interviews

In depth interviews were conducted by telephone with service users of the Southampton Sight service.

The interviews explored how the service user was referred to the service, the issues they were facing at the time, the support they have received, the outcomes for the client and their satisfaction with the service. The interviews were semi-structured.

Informed consent was ensured for all interviews. Southampton Sight contacted service users to see who was willing to be contacted. A sample was taken from this list of service users. All responses were anonymised in reporting.

2.6 Analysis

The data from the interviews and from existing monitoring information was analysed to assess the achievement of outcomes and deliverables. Outcomes for service users was analysed from the client interviews.

3) Achievements against targets

Sight Loss is not Life Loss is a three year project. Monitoring data to the end of year three were available for the evaluation. Of the 1115 contacts by service users with Southampton Sight by the end of year three, 70% were by telephone or other and the remaining 30% were drop in sessions or appointments.

Outcome 1

Target - 250 people with sight loss will have greater independence by the end of year three.

This target was exceeded by 32% by the end of the project.

	Number of people with greater independence
Year 1	117
Year 2	217
Year 3	330

Outcome 2

Target - 250 people will have reduced social isolation by the end of year three.

This target had not quite been reached by the end of the project.

	Number of people with reduced social isolation
Year 1	99
Year 2	151
Year 3	192

Outcome 3

Target - 600 people with sight loss will have greater access to information, advice, support and specialist equipment in relation to their sight loss throughout the duration of the project.

This target was exceeded by 13% by the end of the final year of the project.

	Number of people with greater access to information, advice, support and specialist equipment in relation to their sight loss
Year 1	385
Year 2	499
Year 3	677

4) The Sight Loss is not Life Loss project: successes and challenges

This section draws on in depth semi structured interviews with Southampton Sight staff and volunteers and agencies referring to the service to understand the nature of the project and the key successes and challenges.

Nature of the project

4.1 Range of services

The project is quite holistic and provides a range of services. People with sight loss can access information, advice and guidance on a variety of issues. They can be signposted to a number of different sources of information and agencies. Support can be provided that is very practical, such as access to try equipment in the resource centre, but service users can also gain emotional support. There are a range of social activities that people can join and access using the subsidised transport. People may first contact the project about a practical matter relating to equipment, but then become involved in the social activities.

“They might get a leaflet about us from the hospital and come to ask about equipment but then they join for a coffee morning and then speak to someone else and that leads into joining the social activities”. (Southampton Sight Staff 2)

4.2 Referrals

Referrals into the service come from a range of sources. Some people are referred by service providers such as eye clinic liaison or reablement officers, others hear about it from family who found it on the internet.

“There are a variety of ways into the service. People may hear by word of mouth or are referred by the eye clinic etc. There is an informal assessment and discussion to find out what their needs are. It is not one size fits all. Sight loss varies hugely. The profile of users is people with various eye conditions and stages of sight loss”. (Southampton Sight Staff 1)

4.3 Service users

Although the services are available to all people with sight loss and there are service users who are of working age or families with children, the majority of people who use the project are older people who have age related sight loss.

“It is very open, a nice atmosphere and very welcome and open to everyone. And they provide transport and people can go on a taster visit to try within a week as sometimes people can be wary at first”. (Referral service 4)

Sight loss can mean that service users face a range of different challenges such as coping with everyday living within the home and mobility problems inside and outside the home.

“Most commonly it is being unable to prepare meals, having accidents at home and in the kitchen, falls at home, mobility problems and sensitivity to light which makes going out difficult on sunny days”. (Referral Service 2)

People find it too difficult or frightening to leave the house alone and lose their independence as everyday tasks become very challenging.

“Getting out is difficult for them. Things like going to the bathroom can be so difficult; they don’t know where the door is or the toilet roll. They are frightened to go on the bus, or to walk along a busy road. Getting on a bus is a challenge”. (Southampton Sight Staff 3)

“Being by themselves with sight loss their independence goes. There is one lady who is fiercely independent and who still puts her own washing out, but it is so difficult. She won’t give in. But some people give in and get frightened, frightened of falling over, of the unknown. They stay in the house. Even people who live with their children can be isolated as their children are out at work all day. They can’t even make a cup of tea”. (Southampton Sight Staff 3)

Many of the service users who participate in the social activities are older ladies who live alone and are otherwise very isolated and rarely have company or are able to leave the house.

“The social side is very important. It tends to be ladies....A lot are on their own. They don’t see people from one week to the next. Here they can get out and about and meet others in the same situation”. (Southampton Sight Staff 2)

Successes

4.4 Demand for the service

The project is on course to meet most of its targets and achieve the proposed outcomes. There is clearly demand for the service.

“There is frailty and anxiety. About half blind and partially sighted people don’t leave the house very often. The massive thing we have achieved is that this is a place people can come and chat and listen to music and socialise and pass the time of day. Day centres barely exist anymore and there is a strong case for it. There is a need for an active social centre”. (Southampton Sight Staff 1)

There is no other similar service available locally for people with sight loss to access appropriate information, advice, support, equipment and social activities.

“There is nowhere else for people to go. It is the only one they can access.” (Referral Service 1)

4.5 Referrals and local networks

The interviews showed that Southampton Sight has developed good local networks with statutory service providers and the local authority sensory teams, such as Southampton City and Hampshire County Councils, and other voluntary agencies such as the national charities Action for Blind People and Guide Dogs.

“Most people come to see us when they are coming to the end of their paid employment. I direct them to Action for Blind People as they have an employment project but I can help with form filling etc..... I maintain the facebook page and the website to reach people. When I started I made contact with the job centre and employment services and got referrals and go to events”. (Southampton Sight Staff 4)

This enables a good system for referring people to the project and also prevents duplication in service provision. It also helps to ensure that all support needs can be met in the short and longer term.

“I refer to Southampton Sight because we don't have social activities. We refer to them for what we don't do. We do assistive technology but Southampton Sight now provide support with this and they are local to people. It is where people can get to easily. And they can get to support groups, activities and reading groups etc that are more accessible. And it is long term. We are in and out. We assess needs and refer out. But Southampton Sight are in it for the long term”. (Referral Service 4)

4.6 Newsletter

The project has a newsletter that is sent quarterly to people on the database in preferred formats, with the most popular being large print and audio memory stick. The newsletter includes updates on activities and dates of future meetings, news on current medical research, a blog written by a teenage service users and creative writing from the 'writer's salon'.

“We have a newsletter that goes to over 700 people every quarter in various formats such as spoken or large print. It keeps people in touch”. (Southampton Sight Staff 1)

4.7 Information, advice and guidance

An important part of the service provided by the project is information, advice and guidance to people on a range of issues. This can be particularly welcome for people who have recently been diagnosed with sight loss and who are coping with the implications of their diagnosis, as well as trying to find answers to numerous practical questions. This information and advice is not provided by the health services involved in diagnosing, treating and managing sight loss.

“On a standard patient journey people get 10 minutes with a consultant who doesn't tell them how to get advice and help”. (Referral Service 2)

The project steps in and provides information and advice to people at this difficult time, information which can be difficult to source without help.

“When you talk to people who have lost their sight it is very common to hear people say they found useful things out but two or three years too late and they say ‘if only I had known earlier’. It is frustrating. People find it hard to access information. And it doesn’t stay in. People can be told things when they are in a state of shock. About a quarter of people leave the consulting room not knowing the name of their eye condition. We have a wealth of information here on condition management and it is important to understand your condition. We get lots of speakers from consultants to talk to groups. We get different speakers usually from Southampton hospital. There are medical advances it is important for people to know about as soon as possible”. (Southampton Sight Staff 1)

4.8 Support – practical

The project provides practical support to people with sight loss to support independent living. The interviews showed that the resource centre is considered an invaluable resource by service providers in the sector. The resource centre has a wide range of equipment for people to try before they make any decisions about what to purchase to best suit their needs. The alternative would be to order equipment from a catalogue but this can lead to unsuitable, expensive purchases.

“They have got a very good resource centre where people can try equipment before they buy it. They don’t know about anything and can buy rubbish.... People who use the resource centre say it is great. They can try things at the centre which are expensive.” (Referral Service 1)

“There is not much else in the area and they are very helpful on IT and the equipment centre. It is not common to be able to locally try equipment before you buy it and they have the whole range which saves people ordering things which are not right. If they haven’t got their sight they need someone to help them send things back”. (Referral Service 4)

Without access to resources and equipment many people would have been unaware of things that could help with their sight loss.

“One session was on assistive technology and there was a man who until he lost his sight five years ago had been driving and in employment. An electronic magnifier was passed around and it was very emotional because he said it was like he could see again....When he tried the magnifier it was amazing, he said you get used to what you can’t see. From that we have referred him on to a company where you can rent equipment as it is very expensive. Without this initial thing he wouldn’t have known there was something that could help him to see”. (Referral Service 4)

4.9 Support – emotional

The interviews showed that an important part of the project is the provision of emotional support to people with sight loss. Research participants described the shock of being diagnosed with sight loss and how this can lead to depression.

“The consultant tells them they are registered blind but not what that means. They feel disabled, useless and it can be a spiral into depression and isolation which is

worse if people live alone and can't drive. People lose their independence". (Referral Service 2)

People often contact the project to discuss equipment but can benefit from having someone to talk to and emotional support once they access the centre.

"At the appointment people get real time and space to talk. It is more than just about equipment but this can be what people like to hang things on". (Southampton Sight Staff 1)

"The appointment is in depth. We allow an hour, this allows time for people who are anxious to talk, people are often upset. They have just had bad news, that they have lost their sight. We don't rush people as people tend to be rushed at the hospital.... When they have finished at the hospital, the consultant has said 'sorry your sight loss is permanent and there is nothing we can do'; we pick it up from there... When people are at the beginning of their path they tend to be very emotional. Losing your sight is like a bereavement and they can be angry and upset. A lot of my time is spent listening. People want to talk and tell you how they are feeling." (Southampton Sight Staff 2)

The social contact with other people who have also experienced sight loss can be a source of support and an opportunity to share information on how to manage.

"Depression is a big thing. Their world has changed. They lose their independence as they cannot drive. Social isolation is a big problem..... They get support and can learn from each other and get tips on how to manage". (Referral Service 1)

"They get emotional and stressed. There they get peer support. Sometimes talking to someone with the same difficulties people open up more. It can be the small things. Someone once told me that he got a torch that can be strapped to his head and puts it on when he eats his meals....It sounds silly but things like that can really help. But it sounds better coming from someone who is in that situation". (Referral Service 4)

The impact on peoples' lives can be profound.

"The difference it makes is the difference between existing and living". (Referral Service 4)

4.10 Tackling isolation

The interviews show that a very important impact of the project is its role in tackling social isolation for people with sight loss. This can be particularly pronounced for older people who live alone and do not have family close by. The social activities provide an opportunity for people with sight loss to meet others and for some is the only form of regular social contact.

"For me the best is seeing people happy. I see the people who come in for the social events like musical entertainment and teas. These are successful. For some people it is the only place they come to. They can mix with others with sight loss who know what they are going through. They get the camaraderie. For me this is most

important for the older ladies who were sighted but lost their sight as they got older and find it very frustrating. It is good for them to be around people in the same boat and gives them support". (Southampton Sight Staff 3)

The project provides subsidised transport to and from the centre by minibus and volunteer drivers trained in guiding. Without this, interviewees said that most older people would not attend the centre and would be very lonely and isolated.

"Without the service they would have been very isolated. We provide something that is not otherwise there. They wouldn't get out without it. The nearest RNIB shop is London so they would have to order from a catalogue and it might be useless. There is reduced rate transport which is important as taxis are expensive and people probably wouldn't come with it". (Southampton Sight Staff 2)

"We provide transport only for older people. Without this they would not come. Even those with families wouldn't be able to come as they work in the day. We have a lady who comes who recently lost her husband and we are the only people she sees in an entire week. But she broke her hip and hasn't been able to come. It is not in my job but I phone her to check she is ok. Otherwise she wouldn't speak to anybody. We are hoping she will be back this week. She is very lonely. She is not the only one. There is another lady who fell over that I phone". (Southampton Sight Staff 3)

The service enables people to make friends who they can contact outside of the centre.

"People really do make friends. We ran a two day course at Southampton Sight recently but the outcomes were quite emotional. People only knew each other for two days but at the ends kisses were exchanged and phone numbers were swapped and there had been tears". (Referral Service 4)

4.11 Wellbeing and quality of life

The project can help to improve the wellbeing and quality of life of people with sight loss, particularly older people who become isolated.

"For the elderly the common problem is social isolation. People are afraid to go out. They are also afraid to be a burden on other people, even family. It affects their quality of life and independence". (Referral Service 2)

The project helps people with sight loss to build their confidence and ability to manage independent living.

"It is a springboard for people to go on to other things. It gives people confidence. And the activities like going to the museum and Stonehenge we don't lay on transport so they have to make their way independently. This is good for getting them out and about. They can bring a companion. We try to get them thinking about how they would get somewhere for a certain time and this promotes their mobility. People found it a challenge but enjoyed it". (Southampton Sight Staff 4)

It can be very enabling for people with sight loss.

“There was a lady on the course who is 70. All she wants to do is to be able to go out for a walk. She applied to a walking group but they refused to take her because of the risks. But at Southampton Sight she made friends and she can now go out walking. And some are sighted as Southampton Sight has lots of volunteers. She made contacts and friends but it is also enabling. She is now thinking about setting up her own walking group with Southampton Sight contacts”. (Referral Service 4)

4.12 Meeting the gap left by reduction in statutory services

The project appears to be filling some of the gap left by the cutbacks in statutory services. One of the impacts of service cuts has been the loss of the eye clinic liaison officer post at the eye clinic, the person who tends to provide support and signposting to people who have just been diagnosed with sight loss.

“There have been changes to the office recently. The service has in the past been run by different charities and organisations but recently by Hampshire County Council in partnership with Southampton City Council. But the cutbacks have hit Southampton hard and they had to pull out so now it is only open here part time Thursday and Friday morning. We are trying to get other charities to keep it going instead”. (Referral Service 2)

“We are campaigning around this and the loss of the eye clinic liaison officer post at the eye clinic. They might be ex nurses or social workers and form the link between leaving the consultant and the world of social care. They are a shoulder to cry on. When people are told they are losing their sight it is a shock and the officer bridges the gap when people ask ‘what do I do now?’ We have stepped in for the short term”. (Southampton Sight Staff 1)

4.13 Awareness raising

The project works to raise awareness about good health and eye care and to inform people about the latest medical advances in sight loss treatment and management.

“We also do awareness raising and some campaigning to promote the key health messages about taking regular eye tests and diabetes and sight loss”. (Southampton Sight Staff 1)

4.14 Volunteers

The project has between 50 and 60 volunteers who undertake a variety of roles, including driving, facilitating social groups and giving advice at the local eye clinic. Some of the volunteers themselves have sight loss. Volunteering can particularly be of benefit to people of working age with sight loss who are often not in employment.

“There is support for partially sighted people but also volunteer opportunities. One of the issues of isolation is for people of working age. Two thirds of registered blind or partially sighted people of working age do not work. People who lose their sight in their 40s don't tend to get back into work. They need support to participate fully and get back into work. Volunteers tell us that they treat it like a job. It gives them

confidence and hopefully they will go on to work. We intend to develop a buddying scheme". (Southampton Sight Staff 1)

"The feedback has been incredible. People feel they can be heard. They go on to volunteer. ... {Service user} is our champion and describes the difference it has made to him. He now comes back and supports us when he can. He sees it as a life changer". (Southampton Sight Staff 4)

The project has been successful in engaging with men of working age who are often difficult to engage with and they form the majority of the volunteers.

"One success has been reaching men of working age. They are notoriously difficult to contact and we have had real success. It is mainly men who have gone on the volunteer at the eye clinic. There is one lady but the rest are all men. This came out of the employment support programme". (Southampton Sight Staff 1)

4.15 Co-production – feedback and involvement of service users

The project tries to involve service users in the running of the centre and to empower people with sight loss to have a voice in the focus and operation of the project. Fifty per cent of trustees have a sensory impairment and two more trustees with sight loss are currently being recruited. There are regular focus groups with service users to get feedback on the project. There is encouragement for people with sight loss to volunteer and to be able themselves to support other people with sight loss.

"Those involved in focus groups are where we get ideas from service users. It is a blurred line between service user and volunteer which is a good thing and we try to encourage people to use their experiences to give guidance to other people.... We use volunteers who are blind and partially sighted to contribute. This is the direction the organisation is moving in. From paternalism in the sector to where blind and partially sighted volunteers and service users call the shots and to increase the number of blind and partially sighted trustees. We want to hear their voice correctly". (Southampton Sight Staff 1)

The service has engaged with users to find out what they want and has changed the services they provide to meet the needs articulated by people with sight loss and to engage a wide group of people.

"We listen to what people want and services change to meet individual needs. We are adaptable. This why we are looking to have more people of working age". (Southampton Sight Staff 4)

"Things are changing. It used to be the older people who were more engaged in activities. But they listened to what people want and have set up a facebook page to try and get younger people. And they run computer classes. They have tried to find what younger people want. They do all different types of day trips such as Stonehenge which attract different ages and interests. It used to be coffee mornings etc but now they are more active about asking people what they want before they plan activities". (Referral Service 4)

4.16 Longevity

One success is that the service has been operating for a long time and has a good local reputation and this creates a reliability that people can depend and rely on.

“The thing that works best is the personal contact. We are local and we know people and they know us. We have been here a long time. The older ladies especially rely on us and we know them, it is the personal touch and they can trust us and ask us things and they know we will look after them. Our strength is in being reliable”.
(Southampton Sight Staff 4)

Challenges

4.16 Engaging ‘hard to reach’ BME groups

One of the challenges for the project has been engaging with BME groups to attend the centre. There is a local BME population but they are not yet proportionally represented amongst service users.

“The monitoring shows we are on course to meet all objectives and milestones. People tell us of the need to meet people earlier in their sight loss journey. We want to reach into the wider community, for example the BME community are not reached in sufficient numbers, and we think this will come from a stronger base at the hospital.” (Southampton Sight Staff 1)

4.17 Service cuts

The reduction in provision of statutory services is challenging for service users and for voluntary agencies. The loss of services places pressure on organisations such as Southampton Sight who may have to step in to provide services and who have to divert time into campaigning against the loss of statutory services.

“We have a desperate situation with the local authority. They have cut sensory services beyond recognition and gone from eleven staff to five in a year and we are filling a gap in services.... With external service cuts we are needed more than ever. People cannot phone sensory services anymore, it is a one phone access call and you have to wait ages. Specialisms are under attack. We have been forced into campaigning though this is not traditionally what we do”. (Southampton Sight Staff 1)

“The sad thing in Southampton is that the sensory services team has been disbanded so there is no specialist provision. But they are anxious that people get the support they need so they will refer to us”. (Southampton Sight Staff 4)

4.18 Cost and funding limitations

The cost of equipment and activities for blind and partially sighted people can be very prohibitive. For example, training can be provided on using specialist computer software, but it is too expensive for most people to purchase. The low income of people with sight loss, particularly those of working age, can make participation in activities difficult.

“The challenge is how can we offer things that are not readily available when we have no money and they don’t either?” (Southampton Sight Staff 4)

The funding constraints of the project limit what the centre is able to provide.

“There is more we would love to do especially with sensory services being cut and opportunities for rehabilitation are now very low....But we need security of tenure as a charity to develop this.... We don’t have the resources to develop the computer training we would like to offer.” (Southampton Sight Staff 4)

4.19 Lack of local support services

There is a lack of local services to refer or signpost people to, such as courses to learn Braille.

“This area is quite barren of opportunities for blind and partially sighted people. We had someone who wanted to learn Braille but there is nothing locally. There was only a distance learning RNIB course”. (Southampton Sight Staff 4)

5) Client outcomes

This section analyses the outcomes for clients who used the Sight Loss is not Life Loss service. It draws on data from the semi structured in depth interviews with a sample of service users and volunteers. Quotes from the interviews have been used to bring life to the research findings but have been anonymised and each service user interview identified by a code. The majority of the research participants were the 'oldest old' and had experienced sight loss for a number of years, but some were of working age.

The interviews with clients show positive outcomes and individual benefits to the people who have used the services.

5.1 Impact of sight loss

The interviews showed the impact that sight loss can have on peoples' lives. It can, for example, lead to depression.

"I attended one or two lectures at the hospital about it. I got rather depressed on account of that – there is no cure or help for macular degeneration." (Service user 2)

"I could previously see to do a lot of things, but I can't do gardening anymore because I can't see the flowers. I can see the outline of the tree but not the detail. It depresses you a little bit, because the things you enjoy doing you can't do any more. (Service user 9)

The project provided support for people when they were first diagnosed, a particularly difficult time for people, and helped them to cope.

"I don't think I would have coped so well – it was a lifeline, when it all happened. It was somewhere to go, and meet other people." (Service user 4)

"When you're losing your sight it is a shock, and you need help and that's where I got the help". (Service user 6)

Sight loss can make life very challenging and can be very frustrating.

"A lot of the time, you almost forget about it... somebody else in the Macular Society has, like me, been short-sighted all the time. I suppose for us it's not so bad. Occasionally you could absolutely scream because it's so infuriating, but it doesn't happen very often." (Service user 3)

It impacts on whole families and the loss of employment, the change in financial circumstances and the need to rely on others can be distressing.

"My wife is my full time carer. I feel very sad for her. She is retired and I expected to be working for another fifteen years and looking after her. I find that very sad for her. It is not what she should be doing at this time in her life". (Service user 8)

5.2 Support in coping with sight loss

When people contacted or were referred to the centre it was often a very difficult time and people needed information.

“I was a bit bewildered, I suppose. When I saw the consultant for the last time, it was just a ‘poor you’... I was looking for some information about where I stood... I thought I’ll have to sort myself out here.” (Service user 10)

“My first reaction was panic, because I’m very independent and I like to do things myself. It’s quite depressing as well. But if you go to the centre there’s a lot of people you can talk to; you learn a lot just through chatting. And you think really I’ve just got to pull my socks up and get on with it.... It just gives you a background in how to deal with things. I have met people who have been an inspiration.” (Service user 11)

The camaraderie and support provided by others in a similar situation at the centre can be a source of comfort and support.

“It is really nice to know other people with the same complaint. It’s a funny sort of thing, and it’s very hard to explain to other people sometimes. Just the general support, and knowing they’re there if I did want any help”. (Service user 3)

“It’s been useful because it reminds you you’re not the only one with a problem, and there’s a lot of people much worse off than I am”. (Service user 10)

Research participants said that the services from Southampton Sight had changed their situation for the better.

“Yes, yes I think so. Going and meeting people in the same boat, who haven’t got sight, you learn a lot from each other.” (Service user 4)

“Without it, it would have been a very lonely frustrating life. You could have eventually mentally deteriorated”. (Service user 6)

“Yes, like everybody, when you first get sight loss you worry yourself to death because you can’t see things... if you go and meet people who say you could use this, or you could do this, and you get talks about various aspects of your sight, from people like doctors, it’s good. I never knew I could get the Talking Echos and I wouldn’t be without it now... as I can’t read any newspapers, I wouldn’t know what was going on.” (Service user 9)

“I think by now I’d be feeling very depressed and probably rather frightened.” (Service user 11)

5.3 Range of services

The wide range of services available at Southampton Sight is appreciated. People use the service for different reasons and to access different services.

“I go to the speaker sessions. They are excellent and the speakers are free....They have coffee mornings, book clubs, you name it, they do it. They have afternoon tea and things like that. I get the magazine they send me; you get loads of information from them, which is very good”. (Service user 9)

5.4 Reducing social isolation

The research shows that the project is successfully tackling social isolation. The research participants who attended the social activities found it a way to make friends and to take part in different events and activities.

“The talking book group, it’s excellent, we all love it.... we all feel that the book group has evolved into a very friendly little group of us who know each other quite well.” (Service user 3)

“Oh yes, I have made lots of friends. Through going to the activities you get to know them. Several of us, we have each other’s telephone numbers, and in between times we have a little chat on the telephone.” (Service user 4)

“Oh yes, [I have met] loads and loads. We all do different things; I do Tai Chi on a Monday, and we had a group this afternoon. We went for an outing yesterday; we don’t do that very often because of transport. Tomorrow there’s a lunch club. We had Wimbledon Tea, St. George’s Day party. They’ve got creative writing, a reading group, children’s groups, teenage groups, for people of working age.” (Service user 6)

Although many of the service users are older people, there are a range of age groups who use the centre.

“I do tai chi classes and I do a mini form of bridge in the afternoon, and once a month an excellent book club. I’m not so interested in the tea and cake. I’m at the younger end....There are younger people involved though, even teenagers and children’s groups. I don’t feel like the baby so much anymore.” (Service user 10)

Without the social programme at the centre some people said that they would not be able to go anywhere else.

“I wouldn’t go anywhere I don’t think. I did have a friend who took me out, but she’s ill, I mean she’s 88. My son takes me out, but apart from that I wouldn’t get out. Or I can ring them up and chat to them on the phone.” (Service user 6)

Even people who when sighted would not have considered taking part in group social activities find the support of being in a group beneficial.

“And it is frustrating to say but I would have said I was not a person who likes to take part in groups but I find that being part of a group with people with sight loss is a good way to get out and about and help each other”. (Service user 8)

People are appreciative of the contact with others and the social interaction and described their fear of being isolated.

“I don’t feel so isolated, which I think is the number one priority, because it is quite frightening. I know there’s help available, as and when I need it. And if I want a chat, sometimes you just need that little bit of time.” (Service user 11)

5.5 Equipment to enable independent living

People who have used the centre have received support to help maintain independent living, particularly through being able to access specialist equipment that they are able to try in the resource centre.

“I did learn a lot about sight loss, what I could do and what I could get. They were very helpful”. (Service user 1)

“I couldn’t see my watch; and I went to Southampton Sight to see about magnifying glasses and watches and various implements they had to help. The lady said would I like to join Southampton Sight, so I agreed.... I use their lights and various other things for highlighting anything that’s in low light. You can move the lamp and so on; I can take it wherever I am. That’s a great help.... But Southampton Sight I’ve been to see the stuff, I’ve told them what I wanted, and they’ve sorted it for me. And it arrived in two days, usually.” (Service user 2)

“They have a resource centre there and you can try these things out. I’ve just bought a mobile phone from them; they’ve now got a new kitchen in the centre, they’ve got all new gadgets so we can try them out ourselves.” (Service user 6)

The practical support with seemingly small issues provided by the project can make a big difference to the everyday life of someone with sight loss.

“I have had sight loss for a few years, it was about 2002 when they told me. I was registered partially sighted the year before last and that makes a difference as it gave me contact with the Sight organisation. You can get involved in groups, ask questions, there are lectures by doctors and you can get things like lighting. It deals with all the things partially sighted people have problems with. You can get watches and they will change the batteries. It is the little things that are a problem for a person who cannot see. For example, you can’t tell the time”. (Service user 7)

“At the resource centre my wife has spoken to them on birthdays etc to see if there is anything I can use. I use the talking library. I have done well with gadgets really. Today is my birthday and my wife has bought me the greatest thing, it is an A4 card with lines for writing.....I have a talking clock and watch, pocket scanner and recorder. It is little things that help you get through. Now I am gadget man”. (Service user 8)

5.6 Practical support, information and advice

The project provides practical support such as dealing with administration and housing.

“We had help with housing. We got a volunteer at Southampton Sight to talk to social services for us. She got some forms for us. They’ve helped us sign forms and things – when we got our new blue badges, we got somebody to help us from there. We’ve used the resource centre”. (Service user 5)

The project is a source of information on a wide range of topics for people with sight loss, who would otherwise find it difficult to access information.

“Mainly to start with it was meeting other people, socially. And then I did get on to the committee for a while; but also they could find out stuff for you, if you wanted something to help in the home and so on. If you don’t know they can find out for you. Things I can use to help me, for example, a colour detector. Electronic labels for food to explain how to cook it. Also paperwork, they can find things out. They look things up on the computer for me, so they’re very helpful for things I’m not sure about”. (Service user 6)

“If they don’t know they find out reasonably quickly, in minutes rather than weeks. They always know what’s going on and they keep you informed... The doctors are good at the hospital, but they are very very busy”. (Service user 11)

5.7 Subsidised transport and affordability

Service users are no longer able to drive and this has an impact on their independence.

“I could see enough to drive until about 10 years ago, your independence goes. We live in a rural area. It’s a mile and a half to the nearest village”. (Service user 9)

Using public transport can be daunting and difficult but taxis can be unaffordable. The subsidised transport enables people to access the project affordably.

“They brought to light Southampton Dial-a-Ride, which picks people up from home and is a lot cheaper than using taxis...A taxi would cost £17 there and back... if I go via Southampton Sight it’s £3-4.” (Service user 1)

Southampton Sight organises outings for service users that are greatly valued. Most service users are unable to take such trips on their own and/or cannot afford to do so.

“I have also been out on trips. They have some fantastic days out. They are all totally free. For people like us on benefits and out of work to get out and do these things is fantastic. I recently went to Stonehenge. I wouldn’t have gone without them. It was an amazing day out. We had the privilege of being the first people inside the new round houses. It was phenomenal. And we had a top archaeologist with us. You couldn’t pay for a day like that. It is just me and my wife now and a lot of things we wouldn’t consider because of our financial circumstances”. (Service user 8)

5.8 Lack of other support options

Most research participants were unaware of other services that could offer similar support and assistance and felt that Southampton Sight was the only place that could provide this.

“No, I don’t think I would....I really think Southampton Sight could help with almost anything.” (Service user 3)

Particularly with cuts to statutory service there are no other support options for some people.

“There is no one else in Southampton to pick up the pieces. With the councils having government cut backs there is nothing else, only the charities to pick up the slack. Without them people like me would be hung out to dry”. (Service user 8)

5.9 Confidence building

Being involved with the project can help people to cope with their initial diagnosis but over time can also enable their confidence to grow so that they are able to support other people with sight loss.

“When you first know that you’re going to lose your sight... I’ll never forget that day, after that I went into shock. And I find now I’m helping other people who lose their sight, because I can relate to them. I do talks – at Southampton Sight but also for social services, at the university.” (Service user 6)

The ability to volunteer with Southampton Sight is greatly valued. It helps to build people’s confidence and provides an environment that is like going to work for people who would like to be in employment.

“I was registered blind five years ago just before my 50th birthday and until then had been in full time employment all my life. Since then it has been a very different environment as I have been out of work since. I volunteer at the eye clinic. I look upon Southampton Sight as rehabilitating me. It has helped me to get my confidence back. I treat it like going to work and particularly asked to do the Monday morning shift so it is like going back to work after the weekend”. (Service user 8)

5.10 Feedback on satisfaction with the service

The feedback from service users was very positive. People found the staff helpful and efficient.

“The fact that they seem very very on the ball and very useful. I could rely on them for a lot of things, when I’ve asked for information she’s always answered my phone call. I find them very reliable”. (Service user 2)

“They do an extremely good job... all the time they’re trying to improve their services.” (Service user 3)

The project is described as friendly, supportive and welcoming.

“It’s a very friendly place. I’m really glad it was there for me. I always look forward to going.” (Service user 4)

“They’ve always been very efficient in my opinion. We’re also on the focus group there, we try to give opinions and so on, what we thought of it, and trying new things out. I think especially for elderly people, they’re very good, but for us, we enjoy going to the social functions.... We’ve got some lovely volunteers, some lovely drivers, people in the office are lovely and helpful, take us out to the transport, they just help us all the time. They really really work hard for us up there, they really really do.” (Service user 6)

“They’re very welcoming. Even when I just go across to change the battery on my watch, which they do free of charge, they sit you down and you have a tea or a coffee. There’s always something there.” (Service user 9)

The staff are experienced in working with people with sight loss and are able to provide an environment that is supportive but not patronising.

“I don’t think I’m blind, I just can’t see. The staff are marvellous and they treat you normally. When you become disabled people treat you like you are a child, even though they are well meaning, I am still an adult. They are wonderful. They have a great understanding and a wealth of experience. They are able to connect with people....They provide such a wide range of services from kids to people like me with one foot in the grave and everyone in between. And they do it so lovingly”. (Service user 8)

“I suppose I feel they treat you as a person, not an eye problem. You’re a person with a difficulty, not just a problem. And if you’re a bit frustrated they’re a pretty tolerant and understanding lot, and you certainly never feel unwelcome..... But it’s really nice to go to a place where you haven’t got to explain yourself. You’re just accepted for what you are. Having to explain your situation can get awfully tiring. It is much harder to participate in groups; people try to help and do a pretty good job on the whole, but it’s quite wearing compared to people who understand and who actually listen to what you’re saying” (Service user 10)

“They’ve always got time for everybody, no matter who you are”. (Service user 11)

6) Conclusions

6.1 Client satisfaction

There is clearly demand for the service and it is meeting a local need. The project exceeded two of its key target outcomes and almost reached the third. Service users are very positive about the service and for some it is a lifeline that they could not do without.

6.2 Outcomes for service users

An important part of the project is the provision of support in coping with sight loss from staff at the time of diagnosis when it is a shock but also ongoing support from other people with sight loss facing the same issues. The project is reducing social isolation; many people do not have other opportunities to leave the house or to socialise. The resource centre and access to equipment is regarded as invaluable and helps people to find appropriate solutions to enable independent living. There is also access to information, advice and guidance on a range of issues.

6.3 Confidence building and volunteering

Service users described the difference that Southampton Sight had made to their lives. Many said that they felt more confident, that with support they had been able to cope with the shock of sight loss and go on to help other people in the same situation. The opportunity to volunteer is very valued, particularly by people of working age who would like to be in employment.

6.4 Lack of other support and social opportunities

Both agencies referring people to the project and service users said that there was nowhere else providing either information and support or social activities for people with sight loss. The opportunity to try equipment to help with everyday living was greatly valued.

6.5 Service user involvement

The project involves service users as volunteers, as trustees and in focus groups to get feedback on the service and shape its future direction. The opportunity to participate in such a way is valued. Service users find the service supportive but not patronising.

6.6 Awareness raising

The project raises awareness of health issues related to sight loss, of how to manage different conditions, how to access different types of support, and of medical advances in the field.

6.7 Summary

Overall the project is meeting its objectives and is providing a service to people with sight loss that is regarded as invaluable.

7) Contacts

For more information about this report please contact:

Dr Gemma Burgess
Cambridge Centre for Housing and Planning Research
Department of Land Economy
University of Cambridge
19 Silver Street
Cambridge
CB3 9EP

01223 764547
Glb36@cam.ac.uk

For more information about Southampton Sight please contact:

Jeff Page
Chief Executive Officer
Southampton Sight
3 Bassett Avenue
Southampton
Hampshire
SO16 7DP

023 8076 9882
0772 5039 088
jeff@southamptonstight.co.uk
www.southamptonstight.co.uk