Network 1000

Access to information, services and support for people with visual impairment

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Executive summary

This report presents findings from Network 1000 Survey 2. The data was collected during interviews with 884 visually impaired people between November 2006 and January 2007. All the participants were registered as either blind or partially sighted and lived in Great Britain. Sampling and analysis accounted for the age distribution of the visually impaired population.

The report focuses upon data relating to access to information, services and support. More specifically the report presents data in relation to:

1) Current experience of eye clinics and low vision clinics.
2) Experience in the eye clinic at time of certification as blind or partially sighted.
3) Experience of services in the year following registration as blind or partially sighted.
4) Experience of services in the last year.
5) Services offered to the family of the visually impaired person.

1 Current experience of eye clinics and low vision clinics

Eye clinics in the UK are generally located in hospitals, and, along with other eye health professionals, are staffed by ophthalmologists who diagnose and treat various eye conditions and diseases through medication or surgery. Fifty percent of people were visiting an eye clinic at the time of the survey (that is, they had had an appointment within the last six months or had an arranged appointment in the future). The majority of these told us that they were visiting the eye clinic for a check up (92%), and 77% told us they were there to visit the ophthalmologist.

Low vision clinics or centres in the UK exist to help people make the best use of their remaining sight and are often (but not always) based within or near an eye clinic. In low vision clinics it is often optometrists who carry out assessments of functional vision, dispense magnifiers and other low vision aids to visually impaired people, as well as providing advice about lighting and other aspects of vision. Twenty percent of registered visually impaired people said they were currently visiting a low vision clinic (a further 30% had visited one in the past).

2 Experience in the eye clinic at time of certification as blind or partially sighted

This part of the research focussed upon a sub-sample of participants who had been registered as blind or partially sighted in the preceding eight years. Given the timings of the Network 1000 surveys, the 395 participants who were asked questions in relation to this part of the survey had been registered as blind or partially sighted between 1999 and 2005.

Participants were asked to think about the time at the eye clinic when they were first certified as visually impaired by their ophthalmologist. Care was taken to ensure that participants understood the difference between certification and registration of visual impairment.

Of people registered as blind or partially sighted in the previous eight years:
- 45% said they did not receive an explanation of the registration process at the time of certification in the eye clinic.
- 17% received no help or information in the eye clinic other than medical diagnosis and treatment.
- Most of the advice received was about Talking Books, Low Vision Aids, and general information about social services (all recalled by over 40%).
- Generally, a greater proportion of people of retirement age said they received help and information in the eye clinic compared with those of working age.
- 70% were satisfied with the service they received, though this proportion was relatively low for those of working age (56% compared with 72% of those of retirement age reporting satisfaction).

A follow-up open question collected views about why people expressed their levels of satisfaction. Four overlapping themes emerged:

- Emotions:
  People expressed a variety of emotions when recalling their experiences. The most frequently reported one being that of shock and confusion.

- Expectations and timing:
  Unsurprisingly, many of those who were satisfied said they were happy with the support they received or felt that they did not need any. However, with the benefit of hindsight and newly acquired experience of visual impairment, when people looked back to that time they also expressed dissatisfaction with the services they had received. Similarly, many people also noted that they did not know what to expect and had nothing to compare the experience with. Linked to this is that information often needs to be given in a staged approach (particularly given the shock people may be feeling and the complex situation in which they find themselves).

- Contact with the medical profession at the eye clinic:
  People described both positive and negative interactions with staff within eye clinics. Positive comments included the helpfulness of doctors, nurses, and optometrists. Negative comments included examples of insensitivity and difficulty understanding medical language.

- Support or information at the eye clinic:
  Some participants described the kind of help that they thought had been or would be most useful. Many referred to services such as leaflets/booklets

on medical information, what happens next, LVAs, and the need for emotional support and counselling. There were many comments which highlighted that some people felt dissatisfied that the eye clinic did little beyond diagnosis. Nevertheless, other examples highlight that when implemented sensitively and appropriately eye clinics and social support services can link together effectively. Such services are present in many different configurations in some eye clinics in the UK and have a variety of titles such as ‘help desks’, ‘eye clinic support services’, and ‘eye clinic liaison officers’. The research presents clear evidence of the value of such services.

3 Experience of services in the year following registration as blind or partially sighted

As with the previous section, this part of the research focussed upon a sub-sample of participants (N=395) who had been registered as blind or partially sighted in the preceding eight years.

The influential ADSS publication 'Progress in Sight' notes that adults who are certified as being blind or partially sighted should be contacted within 10 working days of receiving their ‘Certificate of Visual Impairment’. Participants were asked the length of time it took after registration for someone from social or welfare services to come and see them:

- 36% said that they were seen in less than six weeks.
- This rose to 47% who were seen within three months.
- 20% did not recall such a visit at all.
- People of working age were seen more quickly than people of retirement age.
- There is clear evidence of regional differences in speed of visits and general satisfaction with services.

Participants were asked a series of questions about the people they had seen and the services they had received in the year following registration:

- 52% of visually impaired people reported having seen either a social worker or specialist social worker (63% of working age people and 51% of retirement age people).
- 17% of people reported receiving no services at all.
- Advice about using technical aids, LVAs, and talking books were most commonly recalled (all by 50% or more of people).
- People of working age reported receiving advice about mobility, travel, and employment and education more commonly than people of retirement age.
- 75% of people reported they were satisfied with the services they received in the year following first registration.
- There was a difference across the age groups (59% satisfied amongst working age groups compared with 77% for retirement age groups).
- There was a difference between men and women (87% satisfied amongst men compared with 68% amongst women).

A follow-up open question collected views about why people expressed their levels of satisfaction. Four overlapping themes emerged:

- Expectations and need for support:
  - Many of those who were satisfied with the services they received simply reported that they did not need services at that time.
  - Some offered more detailed explanations, e.g. referring to personal characteristics (e.g. 'independent', don't like to 'fuss'), their level of vision, activities and abilities (e.g. 'I can still get out'), and other sources of support (especially family).
  - Many had little or no expectations of the services they could receive. Often this was expressed in fairly neutral terms simply saying they did not know, or that they assumed no help was available or nothing could be done.
  - Others appeared to express negative expectations which were fulfilled, and a number of others expressed dissatisfaction because they had since learnt about things they had missed, or they had had to find things out for themselves.

- Support given:
  - Many of those who were satisfied with the support they received described some of these services. They typically spoke positively about people and services (e.g. mobility, benefits advice, low vision advice, and talking books).
  - Unsurprisingly, those who were not satisfied with the services they received often described things they required or would have appreciated. These included advice about benefits, emotional support and counselling, mobility training, support with employment, general information, and having to wait too long for services.

- 'Point of contact':
  - Many participants (who were generally satisfied with the service they received) highlighted the importance of having contact details of people who could offer them support or advice if they needed it in the future. This reassurance of having a 'point of contact' was particularly highlighted by people over 65 years of age.
  - For some, not having such a point of contact was a source of their dissatisfaction with the services they received.

- Services and professionals:
  - Many participants made references to professionals and organisations (e.g. national and local voluntary sector organisations, social services departments). References were positive and negative and generally in line with their general satisfaction with the services they had received. Many local and national voluntary sector organisations were mentioned by name.
  - The boundaries between organisations and the funding mechanisms in the sector are complex. There were a number of instances where participants were confused by the contractual relationships between

statutory social services departments and voluntary sector organisations.

4 Experience of services in the last year

This part of the research focussed upon all participants with the exception of those who had only been registered as blind or partially sighted in the year prior to the interview. Given the timings of the Network 1000 surveys, the 838 participants who were asked questions in relation to this part of the survey had the following characteristics:

- They were registered as blind or partially sighted before the year 2005.
- They were all answering questions about the preceding year which approximated to the calendar year of 2006.

Participants were asked a series of questions about the people they had seen and the services they had received in the previous year.

- 17% of visually impaired people reported having seen either a social worker or specialist social worker.
- 53% of people reported receiving no services at all.
- Advice about using technical aids, LVAs, and talking books were most commonly recalled (all by around 20% of people).
- Advice on benefits as well as employment and/or education were also commonly recalled (both 15% of people).
- 71% of people reported they were satisfied with the services they had received in the previous year.
- There was a difference across the age groups (64% satisfied amongst working age groups compared with 73% for retirement age groups).

A follow-up open question collected views about why people expressed their levels of satisfaction. Four overlapping themes emerged (which had similarities with the views expressed in relation to services in the year after registration reported above):

- Expectations and need for support:
  - General satisfaction with services (as reported by over two thirds of the sample) was often coupled with participants having relatively low expectations of the services available, although others felt frustrated by this.
  - The feeling that support was not needed was very common amongst those who were satisfied with the services they received. Many referred to support they had received in the past and that no more support was needed now. Others indicated that they had ‘adapted’ to their sight loss in some way.
  - It was very common for participants to refer to the support they received from their friends and family. This was most common amongst people of retirement age (especially women).

- Changing needs:
  - Another strong theme was that of changing needs over time, and people feeling that their situation was stable so nothing was needed. This is clearly linked with the previous theme. Others speculated that if changes came about then they would seek help, and some described how this had already happened.

- ‘Point of contact’ and ‘passive’ services:
  - In line with this, many highlighted that having a contact point was important – this was very common and many said they were reassured by this (well over 100 participants made reference to it).
  - As was noted in previous sections, participants who were less satisfied with the service also highlighted that they either did not have such a contact point or that this seemed insufficient for them. Some of this dissatisfaction was linked to some participants feeling that services were often passive, bureaucratic, inefficient, or under resourced. Participants who were not satisfied with the services they received commonly felt that they had to find things out for themselves and then contact the services in question.
  - In contrast, a number of participants described the positive impact of being contacted once a year to check whether they needed any support (e.g. a phone call).

- Support and services:
  - Participants highlighted lots of different types of support they had or had not received in the previous year. Participants who were not satisfied with services often felt that the services were either absent, delayed or of poor quality. In some cases these participants explicitly compared their situation to how they believed it to be better for others who lived elsewhere.
  - Contrasting experiences expressed by participants suggests that they have different expectations of services but also that the availability of services differs across the country.
  - Services referred to included support in relation to: ICT and computers; travel passes; holidays and day trips (often older people); library for the blind, talking books, newspapers and newsletters; benefits; support in the home (e.g. cleaning), and devices (e.g. liquid level indicators); shopping; meals on wheels; ‘Access to Work’ and employment services; education services; housing services; magnifiers; and mobility training. Participant’s contrasting experiences are presented in the report.

5 Services offered to the family of the visually impaired person

We asked all those taking part in the survey if their families had been offered any support. Overwhelmingly we were told that families had not been offered any support (87%). When examining the findings by age it appears that families of those in the 18-29 age group received more support than those at the older end of the age spectrum.

Overall, 70% of visually impaired people indicated that they were satisfied with the level of support they received. Nevertheless, people of working age were less satisfied than those of retirement age – 23% said they were not satisfied compared with 12% of those of retirement age.

Follow-up open questions collected views about what types of support participants thought their family might have needed (and in some cases the support that was received). It is not surprising that large numbers of people felt that their family did not need support (over half the participants) or were unsure / had no view (a further 20%). Nevertheless, participants did highlight some areas they thought important, and these broadly fell into the following overlapping categories:

- ‘Visual Training’ and general understanding of visual impairment:
  - A number of participants highlighted that their family would benefit from improving their general understanding of visual impairment. These were often very practical things, for example related to mobility, sighted guide techniques, or general visual awareness.
  - Others talked about issues beyond the practical, focussing more on family understanding and empathy towards the circumstances of the participant.
  - A number of participants suggested some support which could help (and in some cases had helped) to overcome some of these challenges, for example attending courses for family members.

- Counselling / emotional support:
  - The potential benefits of family counselling and emotional support were identified by many. The focus of this was sometimes with reference to helping family members understand the visually impaired person’s situation, but it was often linked to helping family members deal with their own reaction to the situation and changes to their lives in unexpected ways.
  - In some cases, participants who were visually impaired from an early age described how their parents and siblings had struggled to come to terms with the visual impairment. Some participants also discussed the importance of ‘genetic counselling’.
  - Some participants felt that family members might sometimes need an outlet to talk about the impact upon their life. Some talked about family members potentially benefiting from respite care.

- Direct and indirect support for family members:
  - Participants often described how their family (often making reference to wives and husbands) would benefit from support with practical activities – e.g. shopping, transport, form filling, cleaning, and gardening. Sometimes this was described as something which would help give the family members a rest or a break. Sometimes reference

  was made to teaching family members new skills such as cooking and home maintenance.
  - A number of participants who were visually impaired when children described the support their parents received or should have received. Some talked about parent groups and specific voluntary organisations.

- General advice and financial support:
  - Many participants described how their family would have benefited from more information generally, often referring to information about the eye condition and its prognosis, methods of supporting visually impaired people (e.g. mobility, sourcing equipment and books), and financial support and benefits.
  - A number of participants talked in general terms about requiring financial support for family members. Others were more specific, e.g. referring to the cost of travel. The ‘Carer’s Allowance’ was mentioned by a few participants.
  - As has been highlighted elsewhere in this report, some participants thought about the future and the type of support their family might need then.

1 Introduction

Background

In March 2004, Vision 2020 UK and the Visual Impairment Centre for Teaching and Research (VICTAR) at the University of Birmingham were commissioned by the Big Lottery Fund to carry out the research project “Network 1000: Surveying the changing needs of visually impaired people”. The initial funding was for three years and covered ‘Phase 1’ of the broader Network 1000 project. Network 1000 Phase 2 started in April 2007 and has been funded by Thomas Pocklington Trust, RNIB and GDBA. Phase 2 aims to further analyse the data gathered in Phase 1 as well as maintain the Network 1000 sample.

The project has four key aims. The first was to establish a consultation network of over 1000 visually impaired people aged 18 and over. The second aim was to adopt a more longitudinal approach to data collection that would enable the project to report and record changes in circumstances over time and enable further comparative data to be evaluated. This report presents some of the *second* round of this data collection.

Thirdly, the project is underpinned by a commitment to consult with visually impaired people. To this end the research team have adopted a collaborative approach to ensure that people with a visual impairment have had an input into the design process.

Finally, the project aims to provide statistically useful data on the changing views, experiences and needs of visually impaired people that can be used to influence service development and provision. Our aim is to report not only the voices of those who have taken part in the survey, but also to ensure that the statistics produced from the survey will enable these voices to be generalised to the wider visually impaired population.

This report draws upon the data collected from 884 visually impaired people. The report focuses upon data relating to access to information, services and support. More specifically it focussed upon participants experiences of: services in eye clinics (now and at the time of registration as blind or partially sighted); services in the year following registration as blind or partially sighted; services in the year preceding the interview; and services offered to the family of the visually impaired person.

Description of the sub sample of directly interviewed participants (n=884)

At the time of the Network 1000 Survey 1, the sample consisted of 1007 visually impaired adults split across five age groups (see Douglas, Corcoran and Pavey, 2006). All the participants were on the registers of blind and partially sighted people held by 20 social services departments in England (15), Scotland (4) and Wales (1). This sample of 1007 was split between 960 visually impaired people who were interviewed directly, and a further 47 Key Informant interviews (in which we interviewed people who were close to the visually impaired person who had learning or communication difficulties). 884 participants were interviewed directly in Network 1000 Survey 2 (a drop of 76). It is the results from these interviews in relation to 'Access to services, information, services and support' which are presented in this report. In addition, 38 Key Informants were also interviewed in this phase of work, though this data is not reported here.

The weighting used in the analysis in this report is based upon the age distribution of people on the 20 registers used in the sampling. This distribution is almost the same as estimates taken from the official registration figures for England (Department of Health 2003), Scotland (Scottish Executive 2003), and Wales (National Assembly for Wales 2003, note figures are for 2001-2). These figures combined enable an approximate base population and population distribution to be calculated. The Network 1000 survey results can be statistically generalised to this base population.

Table 1: Distribution of the sample across the five age groups of participants in Network 1000 Survey 2 by sex and distribution of population. Base: whole sample of directly interviewed participants (N=884).

Age group	Male	Female	Total sample (N)	Base population
18-29	(57)	(76)	(133)	9,000
30-49	(98)	(104)	(202)	28,000
50-64	(100)	(105)	(205)	31,000
65-74	(70)	(90)	(160)	37,000
75+	(65)	(119)	(184)	255,000
Total	(390)	(494)	(884)	* 360,000

*Based upon estimates taken from official registration figures for England (Department of Health 2003), Scotland (Scottish Executive 2003), and Wales (National Assembly for Wales 2003).

As with the Network 1000 Survey 1, the distribution of participants in the Network 1000 Survey 2 remains broadly even in terms of sex (but, as expected, when weighted it suggests a higher proportion of women to men in the population – particularly in older age groups). Due to the migration of some participants from one age group to another, along with the drop-out of some participants, the distribution of participants across the age groups has changed.

The weighting applied in the analyses in this report is the same as that used in Network 1000 Survey 1 analyses, with slight adjustment to scale for the different sample size.

Access to information, services and support

The Network 1000 Survey 1 report presented many themes which were identified as important by participants. Several of these themes fall under the broad category of ‘Services’. This comprises a varied group of topics including: current and past experiences in the eye clinic, experiences of the process of certification as blind or partially sighted, the support and services received soon after registration, support and services received currently, and the support and services offered to the family of the visually impaired person. In response to this, Network 1000 Survey 2 included sets of questions in relation to these topics:

1) Current experience of eye clinics and low vision clinics (Base: whole sample, N=884).
2) Experience in the eye clinic at time of certification as blind or partially sighted (Base: those who were first registered in the previous eight years, N=395).
3) Experience of services in the year following registration as blind or partially sighted (Base: those who were first registered in the previous eight years, N=395).
4) Experience of services in the last year (Base: whole sample except those who were very recently registered (in the last 2.5 years), N=837).
5) Services offered to the family of the visually impaired person (Base: whole sample, N=884).

In this report data is presented in relation to each topic in turn.

We intersperse the report with quotations from our participants in order to give a personal context to the figures being presented. These are *verbatim* where possible and are recorded in italics; where this is not possible and depending on the method employed by the interviewer, the quotations have been paraphrased to capture the meaning of the quotation and are reported in ordinary print. In all cases, the response has been checked and confirmed as a correct reflection of the comment at the time of interview.

2 Current experience of eye clinics and low vision clinics

Eye clinics in the UK are generally located in hospitals, and, along with other eye health professionals, are staffed by ophthalmologists who diagnose and treat various eye conditions and diseases through medication or surgery. Fifty per cent of people were visiting an eye clinic at the time of the survey (that is, they had had an appointment within the last six months or had an arranged appointment in the future). These proportions were approximately the same across all five age groups.

Table 2: Reasons for visiting the eye clinic by working/retirement age group (options prompted). Base: Those currently visiting an eye clinic. (N=449), weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
To see the eye doctor / ophthalmologist	83%	76%	77%	(357)
For a check up	93%	92%	92%	(416)
Low vision clinic	30%	26%	27%	(130)
For treatment relating to the eye condition that is the cause of your registration	24%	18%	19%	(99)
For treatment not related to the eye condition that caused your registration	4%	5%	5%	(16)
Other	5%	6%	6%	(24)
Don't know	0%	1%	1%	(1)
Number interviewed	(252)	(197)	-	(449)

The majority told us that they were visiting the eye clinic for a check up (92%), and 77% told us they were there to visit the ophthalmologist. There was generally little differences between responses of working age and retirement age groups.

Low vision clinics or centres in the UK exist to help people make the best use of their remaining sight and are often (but not always) based within or near an eye clinic. In low vision clinics it is often optometrists who carry out assessments of functional vision, dispense magnifiers and other low vision aids to visually impaired people, as well as providing advice about lighting and other aspects of vision. Twenty percent of registered visually impaired people said they were currently visiting a low vision clinic (split between 13% in eye clinics and 7% outside eye clinics). A further 30% had visited a low vision clinic in the past.

3 Experiences in the eye clinic at time of certification as blind or partially sighted

At the time of Network 1000 survey 1 interview, all the participants had been registered as either blind or partially sighted for a variety of lengths of time (ranging from less than a year to over 50 years). In Network 1000 survey 2, we were interested in people's experiences at time of initial certification as blind or partially sighted (in the eye clinic) and their experience of services in the year following registration. It was felt most useful to focus upon the experience of people who had been registered in the preceding eight years. This was for two broad reasons: firstly participants may find it too difficult to recollect experiences more than eight ago; and secondly we were most interested in people's experiences of relatively contemporary services.

Given the timings of the Network 1000 surveys 1 and 2, the 395 participants who were asked questions in relation to this part of the survey had the following characteristics:

- They were registered as blind or partially sighted between 1999 and 2005.
- All had been registered between one and eight years prior to the interview.

Participants were asked to think about the time at the eye clinic when they were first certified as visually impaired by their ophthalmologist. Care was taken to ensure that participants understood the difference between certification and registration of visual impairment.

Table 3: In the eye clinic, did anyone explain to you what would happen as a result of being registered as blind or partially sighted? (by working age/retirement age). Base: those registered within the previous 8 years (N=395), weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
Yes	41%	49%	48%	(184)
No	51%	44%	45%	(182)
Don't know	1%	1%	1%	(5)
Can't remember	6%	7%	7%	(24)
Number interviewed	(183)	(212)	-	(395)

Overall, just under half of visually impaired people (48%) said they had received some form of explanation of what would happen as a result of being registered. A slightly smaller proportion of people of working age described receiving an explanation than those of retirement age i.e. 41% compared to 49%. Overall, nearly a half of visually impaired people (45%) registered as blind or partially sighted in the previous eight years said they did not receive an explanation of the registration process at the time of certification in the eye clinic. We then asked participants what kind of help/information was offered followed by a series of prompted options.

Table 4: What kind of help/information was offered in the eye clinic (by working age/retirement age). Base: those registered within the previous 8 years (N=395), weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
General information about social services	36%	44%	43%	(160)
Specific contact details for social services	28%	26%	26%	(119)
Information on any Low Vision Aids (LVAs)	40%	45%	45%	(174)
Information on talking books	31%	49%	46%	(149)
Information on helpful gadgets and equipment	30%	39%	38%	(138)
Details of a home worker / carer services	12%	16%	15%	(55)
Details of any voluntary organisations	37%	23%	25%	(133)
Counselling either at the time or later	9%	7%	8%	(31)
Leaflets about your visual impairment	31%	35%	35%	(136)
Appropriate information to help the family	14%	9%	10%	(47)
Any nutritional advice	6%	6%	6%	(26)
Other	2%	4%	4%	(13)
Nothing	32%	15%	17%	(83)
Don’t know	1%	2%	2%	(4)
Can’t remember	3%	4%	4%	(16)
Number interviewed	(183)	(212)	-	(395)

Most of the advice received was about Talking Books, Low Vision Aids, and general information about social services (all over 40%). Generally, a greater proportion of people of retirement age recalled receiving help and information in the eye clinic compared with those of working age (though a clear exception to this was information about voluntary organisations). This is further reflected in the higher proportion of working age people reporting receiving ‘nothing’ compared to those of retirement age (32% compared with 15%). Indeed, this may also be reflected in perceived satisfaction with the help and information received in the eye clinic around the time of registration. While overall satisfaction was relatively high (70% of those registered in the previous eight years saying they were satisfied), this proportion was relatively low for those of working age (56% compared with 72% of those of retirement age reporting satisfaction).

Table 5: Overall, were you satisfied with the help/information you were offered in the eye clinic around the time of registration? (by working age/retirement age). Base: those registered within the previous 8 years (N=395), weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
Yes	56%	72%	70%	(256)
No	23%	18%	18%	(80)
Partially satisfied	12%	4%	5%	(29)
Can’t remember	1%	1%	1%	(5)
Don’t know / Unsure	8%	5%	6%	(25)
Number interviewed	(183)	(212)	-	(395)

Participant explanations

A follow-up open question collected views about why people expressed their levels of satisfaction. Analysis of this qualitative data revealed a number of overlapping themes, which can be usefully summarised under the following headings:

- Emotions.
- Expectations and timing.
- Contact with the medical profession at the eye clinic.
- Support or information at the eye clinic.

Emotions

People expressed a variety of emotions when recalling their experiences. Shock and confusion were common:

No help or information was offered and she was in shock so she didn't ask any questions. She looks back at it with horror. Female, retirement age, not satisfied.

"I was in such a state of shock I accepted it when they sent me home." Female, retirement age, unsure of her satisfaction.

It was a shock at first. But they helped him and it really helped to calm him. Male, working age, satisfied.

Expectations and timing

Unsurprisingly, many of those who were satisfied said they were happy with the support they received or felt that they did not need any. Interestingly, many who were satisfied with the service simply said that the eye clinic staff had done all they could and there was nothing more that could be done, ie. they discussed their satisfaction in terms of the medical treatment they received.

However, with the benefit of hindsight and newly acquired experience of visual impairment, when people looked back to that time they also expressed some reservations, even dissatisfaction, with the services they had received:

"You don't really know what there is and what you need to know – it's things you find out later that makes you wonder why you weren't told things." Male, working age, unsure of his satisfaction.

Similarly, many people also noted that they did not know what to expect and had nothing to compare the experience with:

"When you don't know what to expect you don't know if you haven't received what you should have." Female, retirement age, satisfied.

Linked to this is that information often needs to be given in a staged approach (particularly given the shock people may be feeling and the complex situation in which they find themselves):

"Initially I felt they had tried to explain, but then when I needed answers later on it was difficult to get hold of somebody." Female, working age, satisfied.

Contact with the medical profession at the eye clinic

People described both positive and negative interactions with staff within eye clinics. Positive comments included the helpfulness of staff including doctors, nurses, and optometrists. Participants made reference to the style of interaction (e.g. ‘friendly’, ‘sympathetic’, and ‘understanding’), as well the content and outcomes of the meetings:

“I thought they were really good. The woman there was really good, she understood what I was saying which is everything. People don’t often understand.” Female, retirement age, satisfied.

“The staff made me feel comfortable and happy with the service.” Female, working age, satisfied.

“I thought they were very good - especially the nurse who told me about it all.” Female, working age, satisfied.

Negative comments included examples of insensitivity and difficulty understanding medical language.

“The first doctor I went to on my own – I couldn’t understand the big words they used.” Male, working age, partly satisfied.

The medical staff were quite rude [..]. Poor awareness of the nurse at the time of registration. Female, working age, not satisfied.

Support or information at the eye clinic.

Some participants described the kind of help that they thought had been or would be most useful. Many referred to types of services presented in Table 4, e.g. leaflets/booklets on medical information, what happens next, and life changing consequences of visual impairment, LVAs, the need for emotional support and counselling:

“They helped me get LVAs” Female, working age, satisfied.

[She was satisfied because] because they put her in touch with [Local Association of Visually Impaired People] and they have helped her a lot. Female, working age, satisfied.

“The main things that helped me were given to me then – e.g. magnifier with a light built in.” Male, working age, satisfied.

There were many comments which highlighted that some people felt dissatisfied that the eye clinic did little beyond diagnosis (which contrasted with others who appeared content with this), with some making reference to information and services they wish they had received:

“I didn’t really have any help from the hospital, just diagnosed the condition and said there wasn’t much to be done.” Female, retirement age, not satisfied.

“I don’t feel I was offered enough. Particularly counselling would have been helpful as it was a huge shock.” Female, retirement age, not satisfied.

Overview

Participants clearly had varying levels of satisfaction for the services they received in the eye clinic at time of registration. Their range of experiences and expectations expressed in their comments gives some insight into the reasons for this.

Many participants highlighted the *way* they were spoken to as a key issue – some feeling that staff were cold or dismissive, other feeling that they found it hard to understand what was being described. This poor communication experienced by some may be linked to the observation that many visually impaired people do not know, or are unsure of, the name of the eye condition that is responsible for their registration (an estimated 23% - see Douglas, Corcoran and Pavey, 2006)

Another key issue highlighted was the importance of the eye clinic in providing visually impaired people with a broad range of information *in addition* to clear details about their medical condition. Depending upon timing, this information might include information about other services such as low vision services, voluntary and statutory social care services, information about equipment, and emotional support. It is encouraging that many people were satisfied with the services they received in the eye clinic, but others were clearly dissatisfied. Registration as blind or partially sighted is one of the formal ways of linking medical services to social care services and it is important that the ophthalmologist understands and communicates this. Clearly many people (45%) did not recall such an explanation. Indeed one person felt that registration was actively discouraged:

The doctor’s attitude was very dismissive. [The doctor] actually said that there was no point in him being registered but he pushed to be registered - he was flabbergasted. Male, working age, not satisfied.

Certainly for some the process of registration was not one that they had expected or hoped for, and to this extent it may be somehow a symbolic moment that good intentioned doctors wish to avoid putting their patients through:

“It’s difficult to accept the registration.” Female, working age, satisfied.

“[..] I was shocked at being registered – I thought I could see enough.” Female, working age, not satisfied.

However, even if it does not seem so at that time, the process of registration should ultimately be a positive action rather than a negative endpoint (even if people are not always clear about the sources of the support they receive):

She was happy to be registered, [..] the help was satisfactory but she isn't entirely sure who organised it all. Female, working age, satisfied.

"Went quite quickly to social services and they were very good." Male, working age, satisfied.

"When [I lost my eyesight I was all on my own], but social services and the eye clinic were marvellous." Female, retirement age, satisfied.

Importantly, in addition to the formal process of registration there are other less standard processes such as signposting patients to information and support services. Such services are present in many different configurations in some eye clinics in the UK and have a variety of titles such as 'help desks', 'eye clinic support services', and 'eye clinic liaison officers' (e.g. see Browne, 2002; Sinclair and Ryan, 2008). There are clear advantages of such services – e.g. they are available at the time and in a location convenient for the patient, other eye clinic staff can refer patients on to people who have greater knowledge of social support services, and they can link patients to social support services quickly. Another important factor is that many patients will have repeated visits to eye clinics and this provides multiple opportunities for people to seek appropriate support when they feel ready and as their needs and circumstances change. This is clearly demonstrated by the high figures of participants currently attending an eye clinic (Table 2). Some of the points raised by the participants highlight that relatively small and simple developments could make big differences to what is a complex and challenging time for them:

"I would have liked to have a little bit more information and offered more support, but with the time allowed in the eye clinic there isn't time for them to do anything. It would have helped if there had been an eye clinic help desk." Female, working age, not satisfied.

"They didn't do anything. My sister has same condition and she has complained and campaigned to get the eye clinic to give people leaflets about their eye condition." Female, retirement age, not satisfied.

4 Services received in the year following registration as blind or partially sighted

As previously described, 395 participants were asked a series of questions in relation to the services they received in the year following first registration as blind or partially sighted. These participants had the following characteristics:

- They were registered as blind or partially sighted between 1999 and 2005.
- All had been registered between one and eight years prior to the interview.

The influential ADSS publication 'Progress in Sight' notes:

> "Adults who are certified as being blind or partially sighted should be contacted within 10 working days of receiving their BD8 certificate [now 'Certificate of Visual Impairment' or CVI] and offered an assessment of their social care needs. (Note: This is a requirement of the Department of Health as set out in its letter to all directors of social services in October 2000)" (ADSS 2002, p32).

There is some ambiguity as to the details of this requirement, and for this reason the participants were asked a broad question related to the length of time it took after registration for someone from social or welfare services to come and see them. The most common length of time after registration people recalled waiting to see someone was 'less than six weeks' (36%). This rises to 47% for within three months (although there appears to be a difference between those of working age and those of retirement age, 57% and 45% respectively).

Nevertheless, 20% did not recall such a visit at all. The question posed to participants asked specifically about someone coming to see them rather than simply being contacted. Therefore it is conceivable that people received a telephone call or letter from their social services but no 'visit'. It is also possible that people did not recall such a visit – unsurprisingly, given the question required participants to recall events from between one and eight years previously, 20% of people could not remember (and this was more common amongst those of retirement age compared with those working age, 22% and 9% respectively).

However, these figures tend to tally with recollections of services received in the year after registration and general perceptions of satisfaction reported in the following sections.

The Network 1000 sample was drawn from 20 social service department registers, which allows comparison across different parts of the country. It is important to be cautious about any conclusions drawn because numbers of participants from each department is relatively small. Nevertheless, we can observe large differences when comparing areas of the country, although there does not seem to be patterns (e.g. comparing city-based authorities to geographically larger county-wide authorities). The percentage of people reporting receiving a visit within six weeks ranged from 88% for the best local authority to 14% for the worst (both figures unweighted). Similarly, percentage of people reporting never having such a visit ranged from 0% for the best local authority to 50% for the worst (both figures unweighted). The two best figures were from the same county (a Scottish county-wide authority), and the two worst figures were also from the same county (an English city-based authority). It is also notable that the same city-based authority had the lowest proportion of people who were satisfied with the services they received in the year following registration.

Table 6: How long after registration did someone from the social or welfare services come to see you? (by working age/retirement age). Base: those registered within the previous 8 years (N=394), weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
Less than six weeks	34%	36%	36%	(143)
Six weeks to three months	23%	9%	11%	(56)
Three to six months	7%	9%	9%	(33)
Six to twelve months	4%	1%	2%	(11)
More than a year	3%	3%	3%	(9)
Don’t know / can't remember	9%	22%	20%	(60)
Never had such a visit	19%	20%	20%	(80)
I'm still waiting for a visit, but do expect one any day	1%	0%	0%	(2)
Number interviewed	(182)	(212)	-	(394)

Participants were asked a series of unprompted and prompted questions about the people they had seen and the services they had received in the year following registration. The most common professionals reported to have been seen were social / welfare workers (32%), specialist social workers of visual impairment (30%) and benefits advisors (22%). All these figures are based upon prompted questions (ie. participants were asked directly if they had seen these professionals). Combining the variables we find that 52% of visually impaired people reported having seen either a social worker or specialist social worker (or both) in the year following registration (63% of working age people and 51% of retirement age people).

Also, a relatively high 30% of people reported they had seen someone from their local blind society / organisation. Considering that this was not prompted, it suggests that voluntary organisations are one of the most common providers of support workers in the first year after registration. However, it should be noted that voluntary organisations (both local and national societies of visually impaired people) are commonly contracted by statutory local authorities to provide some services.

Following clarifying questions, 17% of people reported receiving no services at all in the year after they were first registered as blind or partially sighted.

It is notable that there appears to be reported differences across the age group in relation to which professionals were seen (beyond the more obvious finding that employment officers were more likely to be seen by people of working age). Working age people were more commonly seen by social workers and especially specialist social workers of visual impairment (43% compared with 28% for retirement age people). This suggests a differentiated service for different age groups and this is reflected in the types of practical advice and support reported (see tables on the following pages). It is advice with mobility, travel, and employment and education which people of working age reported receiving more commonly than people of retirement age. It appears to be relatively equally common for both age groups to have received advice about using technical aids (50%), coping at home (e.g. cooking, 29%), advice with LVAs (56%), and advice on benefits (39%). Advice on talking books was more commonly received by people of retirement age (59% compared with 46% of working age), and receipt of emotional support was rarely reported by any age group (15%).

Table 8 presents a list of the practical advice and support participants recalled receiving when prompted by the interviewer (the full wording of the prompts is provided in the Appendix). The interviewer also noted unprompted recollections of support participants received (again, details of the categories are provided in the Appendix). Very few participants described receiving this type of support: four described support in relation to braille or Moon; five described support in relation to lighting; 12 described support in relation to ICT; two described support in relation to guide dogs; and two reported being put in touch with other visually impaired people.

Table 7: Who offered you support in the year after registration? (by working age/retirement age). Base: those registered within the previous 8 years (N=395), weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
PROMPTED:				
Social worker / welfare worker	37%	31%	32%	(137)
Specialist social worker for visual impairment	43%	28%	30%	(140)
Benefits advisor	19%	22%	22%	(94)
Care Manager	8%	2%	3%	(23)
Home Help / Home care worker	8%	10%	9%	(34)
Counsellor (e.g. someone offering emotional support)	7%	1%	2%	(19)
Employment officer	19%	0%	3%	(34)
UNPROMPTED:				
Other from Social Services	3%	1%	2%	(10)
Voluntary helper from the local blind society/organization	29%	31%	30%	(117)
Another person with a visual impairment	1%	0%	0%	(1)
Other voluntary helper	0%	2%	2%	(5)
Friends / family	6%	6%	6%	(22)
Other	19%	14%	14%	(66)
Other: Support from health service	1%	7%	7%	(31)
Don’t know	1%	1%	1%	(5)
Can’t remember	6%	10%	10%	(31)
Received **no** services at all*	13%	17%	17%	(64)
Number interviewed	(183)	(212)	-	(395)

Note: *Following interviewer clarifying prompt “In the year after registration did you receive any services at all?”

Table 8: Types of practical advice and training received in the year after registration (by working age/retirement age). Base: those registered within the previous 8 years (N=395), weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
Training to get about outside (e.g. mobility training)	40%	21%	23%	(124)
How to get and use some technical aids (e.g. talking clock)	51%	50%	50%	(195)
How to cope at home (e.g. prepare food, cook)	31%	27%	29%	(114)
Offered a talking book machine / tape services	46%	59%	53%	(210)
Advice on LVAs	52%	59%	56%	(220)
Emotional support	17%	13%	15%	(60)
Advice on travel (e.g. travel card, or dial-a-ride)	45%	30%	37%	(146)
Advice on benefits	39%	40%	39%	(156)
Advice on education/training and/or employment	32%	3%	16%	(65)
Number interviewed	(183)	(212)	-	(395)

Notes: Responses based upon percentages who said they received this advice and training when prompted. Majority of remaining participants either said they did not receive the given service or said they had not received *any* service in a previous question. A small number (between 0% and 4% for a given question) either could not remember or did not know. Full wording of these prompted questions is presented in the Appendix.

Participants were asked if they were satisfied with the services they received in the year following first registration – 75% of people reported they were satisfied, while 14% said they were not satisfied and 8% said they were partially satisfied (a further 3% could not remember or were unsure). Again there appears to be a difference across the age groups (59% satisfied amongst working age groups compared with 77% for retirement age groups). Satisfaction appeared also to be linked with gender: a greater proportion of men being satisfied with the services received in the first year after registration than women (87% compared with 68%).

Table 9: Overall, were you satisfied with the services you received in the year after registration? (by working age/retirement age). Base: those registered within the previous 8 years (N=393), weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
Yes	59%	77%	75%	(271)
No	18%	13%	14%	(58)
Partially satisfied	15%	7%	8%	(43)
Can’t remember	2%	0%	0%	(5)
Don’t know / Unsure	5%	3%	3%	(16)
Number interviewed	(182)	(211)	-	(393)

Participant explanations

A follow-up open question collected views about why people expressed their levels of satisfaction. Analysis of this qualitative data revealed a number of overlapping themes, which can be usefully summarised under the following headings:

- Expectations and need for support.
- Support given.
- Point of contact.
- Services and professionals.

Expectations and need for support

Many of those who were satisfied with the services they received simply reported that they did not need services at that time. Some said no more than this, though others offered more detailed explanations. For example, sometimes participants referred to personal characteristics (e.g.

‘independent’, don’t like to ‘fuss’), their level of vision, activities and abilities (e.g. ‘I can still get out’), and other sources of support (in particular the presence of family members especially partners). In these cases participants felt that this meant that they did not need support at that time (the year after registration).

“I don’t want people getting too involved - coming round every week or wanting me to go somewhere every week.” Male, retirement age, satisfied.

“I do not need anything at home. My wife was a district nurse so can do things for me if I need it. But I have not needed it.” Male, retirement age, satisfied.

“I’m a fairly independent person. Perhaps things were suggested and I didn’t take them up.” Male, retirement age, satisfied.

“I could have had more if I had of asked. I know they are there if I need them. I want to keep my independence.” Female, retirement age, satisfied.

“I’m not a moaner. I’m as happy as I can be under the circumstances as long as I can get out places.” Male, working age, satisfied.

Many had little or no expectations of the services they could receive. Often this was expressed in fairly neutral terms simply saying they did not know, or that they assumed no help was available or nothing could be done:

“I thought it was normal. I didn’t expect anybody to come because my brother never got anybody.” Female, retirement age, satisfied.

“There was nothing they could do.” Female, retirement age, satisfied.

“I wasn’t expecting any help so I was happy and surprised [when] they came out to see me at home.” Male, working age, satisfied.

Others appeared to express negative expectations which were fulfilled, and a number of others expressed dissatisfaction because they had since learnt about things they had missed, or they had had to find things out for themselves.

“Looking back I realise how much advice they didn’t give me.” Female, working age, partially satisfied.

Typical of what she would expect from this country. Female, working age, not satisfied.

Support given

Many of those who were satisfied with the support they received described some of these services. They typically made positive reference to some of the people and services described in the tables earlier in this section, but often people described less specific advice and support:

"I did get some advice generally how to do things like crossing roads." Male, retirement age, satisfied.

"[There's] always someone to come in with advice. They put [me] on the right road and then you have to go from there." Female, retirement age, satisfied.

"[I] had talking books and a reader." Female, retirement age, satisfied.

"The magnifiers [..] were so helpful. Also the DLA." Female, working age, satisfied.

[..] she got the white cane training which was really helpful as she had no confidence to go outside. Female, working age, satisfied.

"[I am satisfied] because feel I had quite a bit done, rails out up on the path, light in the porch, walk in shower put in, hand rails put up for the bath, had a window pull to pull the windows shut. Things to help me stay in my home." Female, retirement age, satisfied.

Some referred to more involved programmes of support:

"I found the hospital was very supportive. I went for therapy classes after the stroke so I understood my limitations. I have been able to adjust my lifestyle. My wife is my carer." Male, retirement age, satisfied.

"They were good [..] and they used to come and take me to my courses." Female, retirement age, satisfied.

Unsurprisingly, those who were not satisfied with the services they received often described things they required or would have appreciated. These included advice about benefits, emotional support and counselling, mobility training, support with employment, general information, and having to wait too long for services.

"I had to ask neighbours and friends to help with everything, and found this hard - giving personal information to neighbours... No help from social services. [..] No advice from anyone." Male, working age, not satisfied.

"Service [was] good when [it] came around. But took a long time to get help." Female, retirement age, partially satisfied.

"Some of the people I saw I felt just weren't trained to deal with the emotional side of things. I came to my home, alone, no family nearby and I was mourning the loss of my sight - trying to deal with the mental upset of it everyday and there was nobody I could talk to about it. I even went to the doctor's and the counsellor there said they couldn't help. The [local society for visually impaired people] also wouldn't help. There was no one at social services trained to deal with younger people with visual impairments." Female, working age, not satisfied.

"I wasn't really offered any [support] – e.g. I was not offered any rehabilitation training or counselling. I found out afterwards that there is training I could have to read using my peripheral vision but I was never offered this." Female, retirement age, not satisfied.

"I didn't get any real help apart from the stickers to tell the temperature. Nobody has given any advice about going out on the road, travelling." Male, retirement age, not satisfied.

"When I was first registered, the year after and even to this day I am very frightened of going outside. I could have done with having help outside but there was none of that and even the rehabilitation I could have done with some of that around the house. You can see all your life and then all of the sudden you're not going to see - it's a big drop. I seem to have done most of it myself - I still haven't been told about going outside on my own [..]. and not one person has asked me about how I feel." Female, working age, not satisfied.

"Would've been better if someone had sent out a package listing everything that was available rather than having to find it out yourself." Female, working age, partially satisfied.

It was also relatively common (albeit to a lesser extent) for some of those who *were* generally satisfied with the service they received to also identify such missing or delayed services.

"As far as I can recall I had no complaints about the help offered by [local society for visually impaired people]. They never said anything about benefits [..]." Male, retirement age, satisfied.

"Social services were great. I would have liked to have had more counselling." Male, working age, satisfied.

"I was new to this [and] I appreciated the help that I got. I was satisfied and happy with what I was given. [But when I] joined a group with ladies from different parts of England I found out about things I should have been offered through this group. For example, assistance with banking, talking computers. But one needs to pay for everything and it's expensive, and there is no where one can apply to get help." Female, retirement age, satisfied.

'Point of contact'

Many participants (who were generally satisfied with the service they received) highlighted the importance of having contact details of people who could offer them support or advice if they needed it in the future. This reassurance of having a 'point of contact' was particularly highlighted by people over 65 years of age.

"I'm more than satisfied. Whatever I need I can get in touch. I have no need to worry." Female, retirement age, satisfied.

Indeed, for some, their dissatisfaction seemed to be linked to not having such a point of contact (or feeling that was not enough):

"It would have been nice to see someone but I didn't know if there was anyone. No one told me who I could see." Male, working age, not satisfied.

"After the first month they just said 'if you need us, phone us' and that was it." Male, working age, not satisfied.

"I seem to have been forgotten." Male, working age, not satisfied.

Services and professionals

Many participants made references to professionals and organisations (e.g. national and local voluntary sector organisations, social services departments). References were positive and negative and generally in line with their general satisfaction with the services they had received. Many local and national voluntary sector organisations were mentioned by name (e.g. RNIB, GDBA, Action for Blind People). Here are some positive examples:

"Social services were fantastic." Male, working age, satisfied.

The RNIB were really great - they put him in touch with guide dogs. Male, working age, satisfied.

"[Local voluntary society for visually impaired people] were very helpful and kind." Female, retirement age, satisfied.

“My rehab officer was really helpful and helped me overcome a lot of the challenges. [It] helped me to adapt to being blind. He was also blind and of a similar age. Anything I wanted to know that he didn’t know he would go away and look into it and get back to me.” Working age, satisfied.

The boundaries between organisations and the funding mechanisms in the sector are complex. There were a number of instances where participants criticised statutory social services departments while contrasting them with excellent support they had received from voluntary sector organisations. Certainly in some of these cases the voluntary sector organisation in fact held the contract to carry out work on behalf of the local authority.

5 Services received in the last year

At time of the Network 1000 Survey 1 interview, all the participants had been registered as either blind or partially sighted but for a variety of lengths of time. In Network 1000 Survey 2, we were interested in people's experience of services in the *preceding* year (i.e. the 12 months before the interview). These questions were asked of all participants within the sample excluding those who had most recently been registered as blind and partially sighted. (The survey also collected data about experiences of services in the year after registration – see previous section. For some participants recently registered (n=45), 'the previous year' and 'the year after registration' constituted the same year. These participants were excluded from this section of the survey.) This gave a sample of 838 participants who answered questions about the services they had received in the previous year.

Given the timings of the Network 1000 surveys 1 and 2, the 838 participants who were asked questions in relation to this part of the survey had the following characteristics:

- They were registered as blind or partially sighted before the year 2005.
- They were all answering questions about the preceding year which approximated to the calendar year of 2006.

Unsurprisingly, the proportion of people who received services in the previous year was lower than the proportion who received services in the year after registration. The most common professionals reported to have been seen were social / welfare workers (12%), specialist social workers of visual impairment (9%) and benefits advisors (10%). All these figures are based upon prompted questions (ie. participants were asked directly if they had seen these professionals). Combining the variables we find that 17% of visually impaired people reported having seen either a social worker or specialist social worker (or both) in the previous year (20% of working age people and 16% of retirement age people).

As with services received in the year after registration, a relatively high 20% of people reported they had seen someone from their local blind society / organisation. Considering that this was not prompted, it again suggests that voluntary organisations are one of the most common providers of ongoing support for people with who are registered with a visual impairment. However, it should be noted that voluntary organisations (both local and national societies of visually impaired people) are commonly contracted by statutory local authorities to provide some services.

Following clarifying questions, 53% of people reported receiving no services at all in the previous year.

There was little reported difference between age groups regarding the professionals that had been seen in the previous year (with the exception of employment officers – reported as having been seen by 11% of working age people).

Table 10: Who offered you support in the last year? (by working age/retirement age). Base: whole sample, except those who were very recently registered (in the last 2.5 years), N=838, weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
PROMPTED:				
Social worker / welfare worker	12%	13%	12%	(102)
Specialist social worker for visual impairment	15%	7%	9%	(92)
Benefits advisor	11%	10%	10%	(97)
Care Manager	3%	2%	2%	(32)
Home Help / Home care worker	5%	7%	7%	(50)
Counsellor (e.g. someone offering emotional support)	2%	1%	1%	(22)
Employment officer	11%	0%	2%	(61)
UNPROMPTED:				
Other from Social Services	4%	2%	3%	(27)
Voluntary helper from the local blind society/organization	20%	20%	20%	(186)
Another person with a visual impairment	0%	0%	0%	(1)
Other voluntary helper	3%	4%	4%	(27)
Friends / family	4%	7%	6%	(52)
Total ‘Other’	23%	11%	14%	(180)
Other: Support from education	2%	0%	1%	(26)
Other: Support from health service	5%	6%	6%	(47)
Other: Other employment related support	4%	0%	1%	(21)
Don’t know	1%	0%	0%	(7)
Can’t remember	0%	0%	0%	(4)
Received **no** services at all*	44%	55%	53%	(376)
Number interviewed	(482)	(356)	-	(838)

Note: *Following interviewer prompt “In the last year did you receive any services at all?”

Table 11: Types of practical advice and training received in the last year (by working age/retirement age). Base: whole sample except those who were very recently registered (in the last 2.5 years), N=838, weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
Training to get about outside (e.g. mobility training)	12%	9%	9%	(101)
How to get and use some technical aids (e.g. talking clock)	17%	20%	19%	(156)
How to cope at home (e.g. prepare food, cook)	9%	8%	8%	(75)
Offered a talking book machine / tape services	20%	24%	23%	(188)
Advice on LVAs	19%	23%	22%	(178)
Emotional support	8%	5%	6%	(63)
Advice on travel (e.g. travel card, or dial-a-ride)	18%	7%	9%	(131)
Advice on benefits	17%	14%	15%	(143)
Advice on education/training and/or employment	17%	14%	15%	(96)
Number interviewed	(482)	(356)		(838)

Notes: Responses based upon percentages who said they received this advice and training when prompted. Majority of remaining participants either said they did not receive the given service or said they had not received *any* service in a previous question. A small number (between 0% and 1% for a given question) either could not remember or did not know.

Participants were asked if they were satisfied with the services they received in the previous year – 71% of people reported they were satisfied, while 13% said they were not satisfied and 10% said they were partially satisfied (a further 6% could not remember). Again, there appears to be a difference across the age groups (20% not satisfied amongst working age groups compared with 11% for retirement age groups). There appears to be no strong link between reported satisfaction and gender or length of registration.

Table 12: Overall, were you satisfied with the services you have received in the last year? (by working age/retirement age). Base: whole sample except those who were very recently registered (in the last 2.5 years), N=838, weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
Yes	64%	73%	71%	(569)
No	20%	11%	13%	(133)
Partially satisfied	11%	9%	10%	(87)
Can’t remember	6%	6%	6%	(46)
Don’t know / Unsure	0%	0%	0%	(0)
Number interviewed	(482)	(353)		(835)

Participant explanations

A follow-up open question collected views about why people expressed their levels of satisfaction. Analysis of this qualitative data revealed a number of overlapping themes which unsurprisingly had many similarities to those raised in relation to services in the year after registration. Nevertheless, this group contained participants with a much more varied experience of sight loss (over half having been first registered as either blind or partially sighted more that eight years earlier).

- Expectations and need for support.
- Changing needs.
- ‘Point of contact’ and ‘passive’ service.
- Support and services.

Expectations and need for support

General satisfaction with services (as reported by over two thirds of the sample) was often coupled with participants having relatively low expectations of the services available, although others felt frustrated by this:

“I don’t think they can do much else for me - especially at my age. I don’t need any advice on education and employment.” Male, retirement age, satisfied.

“I’ve given up on hoping to receive help as I don’t know what is available.” Female, retirement age, not satisfied.

The feeling that support was not needed was very common amongst those who were satisfied with the services they received. Sometimes this is linked to expectations, personal qualities (such as being ‘independent’, ‘not demanding’) or other sources of support (especially family). Many referred to support they had received in the past and that no more support was needed now. Others indicated that they had ‘adapted’ to their sight loss in some way.

“I suppose I am managing quite well and don’t need anything.” Male, retirement age, satisfied.

“I’m just used to being blind. [I’ve] been blind about 10 years.” Male, retirement age, satisfied.

“Every time I have needed help I have been able to get it. My condition hasn’t changed so I have not needed any retraining.” Female, working age, satisfied.

It was very common (over 50 cases) for participants to refer to the support they received from their friends and family. This was most common amongst people of retirement age (especially women).

Changing needs

Another strong theme was that of changing needs over time, and people feeling that their situation was stable so nothing was needed. This is clearly linked with the previous theme. Others speculated that if changes came about then they would seek help, and some described how this had already happened.

“[I’m] satisfied at the moment. If things change [I] might think differently in future.” Female, working age, satisfied.

“I feel like I can do a lot. I don’t feel like I am dependent on others. I don’t have to ask too many people for too many things. When it worsens I can get some help. I am sure the help will be available. I am quite happy at the moment [because] I know what help is available from my visits to the clinic.” Male, working age, satisfied.

“I’m managing fine - I work full time, I’ve managed to adapt my life around my circumstances. Its over 5 years since the stroke – I’m completely adapted. It does bother me occasionally but you forget what it was like beforehand.” Female, working age, satisfied.

‘Point of contact’ and ‘passive’ services

In line with this, many highlighted that having a contact point was important – this was very common and many said they were reassured by this (well over 100 participants made reference to it).

“If I wanted something I can go to [local society for visually impaired people resource base].” Male, retirement age, satisfied.

“I think we are extremely lucky - if I need help I know who I can contact. If I need help I can be pointed in the right direction. [Local society for visually impaired people] and the social worker are there if I need them. [For example, I] asked for some braille labels and the social worker did this for me and sent me some labels in the post.” Female, retirement age, satisfied.

“I am satisfied because I know the services are there if I need them. [Local society for visually impaired people] stay in touch so I know they are there if need them.” Female, working age, satisfied

As was noted in previous sections, participants who were less satisfied with the service also highlighted that they either did not have such a contact point or that this seemed insufficient for them. Some of this dissatisfaction was linked to some participants feeling that services were often passive, bureaucratic, inefficient or under resourced. Participants who were not satisfied with the services they received commonly felt that they had to find things out for themselves and then contact the services in question.

“[I] rang social services about two months ago and they haven’t called back.” Female, retirement age, not satisfied.

“I find all these services tend to be extremely slow – e.g. arranging appointments takes time for them to get back to you. I always have to do the chasing which I don’t think is acceptable.” Female, working age, partially satisfied.

“Once they’ve seen you in [county] you're left to your own devices. [My county] are always last to get anything that comes out new.” Female, retirement age, not satisfied.

“The council employs somebody to deal with blind people. In the last few years this person has changed numerous times and I’ve never met them. [I] feel ignored - they have lots of aids they could give me but I’ve never had access to this kind of help. [You] feel very much on your own because you are blind in this area.” Male, retirement age, not satisfied.

“It would be nice if the council or other bodies used the list of those registered then they should make contact with me not leave it up to me to contact them. It would be nice for them to contact us. I am pretty independent and have learnt to cope but would be nice once a year to be rung and told what services were available.” Female, retirement age, not satisfied.

“They are very reactive rather than proactive.” Male, working age, not satisfied.

In contrast, a number of participants described the positive impact of being contacted once a year to check whether they needed any support (e.g. a phone call).

The people at the blind society have been very good - they ring him up every year to keep in touch. In fact, next week he's picking up a talking watch from them. Male, retirement age, satisfied

“The lady from the blind centre comes about once a year - or when I need any help.” Female, retirement age, satisfied

Support and services

Participants highlighted lots of different types of support they had or had not received in the previous year. Participants who were not satisfied with services often felt that the services were either absent, delayed or of poor quality. In some cases these participants explicitly compared their situation to how they believed it to be better for others who lived elsewhere. This type of data does not allow precise comparisons but it is noticeable that in some case participants who appeared to be in similar situations clearly had contrasting views about the adequacy or appropriacy for support they received. It is likely some of the different views of the services are linked to different people’s personal characters, needs and expectations. It is also likely that the different experiences reflect the differing availability of services (whether from voluntary or statutory sector) across the country.

Some of the services people referred to included support in relation to: ICT and computers; travel passes; holidays and day trips (often older people);

library for the blind, talking books, newspapers and newsletters; benefits; support in the home (e.g. cleaning), and devices (e.g. liquid level indicators); shopping; meals on wheels; ‘Access to Work’ and employment services; education services; housing services; magnifiers; and mobility training. Some contrasting experiences are presented:

Shopping

“I think help for elderly people is a bit thin on the ground. If there is a club you can join it is difficult to get to without transport. It becomes very difficult to do things like shopping - there isn’t anyone from social services that can help with things like this.” Female, retirement age, not satisfied.

“One thing that has been helpful is 'brighter futures for the elderly' they take us shopping once a fortnight and we have lunch and they then bring us home. All for £5. They have also offered us a party on Boxing day.” Female, retirement age, satisfied.

Employment, isolated

“[I’m] still unemployed, alone and without a social life and isolated.” Male, working age, not satisfied

“Access to Work is superb, couldn't work without it.” Male, working age, satisfied

Benefits

“[The Job Centre] don’t tell you [anything] about the benefits you can receive.” Male, working age, not satisfied.

“[I have had] some computer training which has filled a few gaps. Job search and benefits advice also helpful. All help from Action for Blind People.” Male, working age, satisfied

Around the home

“Offered no help in finding braille teacher nor with help cooking or help around the house. Only the support received has been friends and family.” Male, working age, not satisfied.

She has a very supportive family and she has not needed a lot of outside help. The only outside help is a home cleaner who she has arranged and she receives an allowance from the health service to pay for that. Female, retirement age, satisfied.

Computers

“Social services could do more – e.g. [..] had to take out a loan to pay for specialist equipment. [I] asked them and people at work for funding but was refused.” Male, working age, not satisfied.

Even more [satisfied] than the year before - this is the year when the doors have opened even wider, equipment "thrown" at him [..]. British Legion has bought him a complete scanner, computer etc. Male, retirement age, satisfied.

“The social services [..] have also got me onto a computer course.” Male, working age, satisfied.

Mobility

“I have been asking for a carer to do some of the work for me and also for mobility training. I have been waiting for years so I have given up on this.” Male, working age, not satisfied.

[They] answered her questions and gave her the mobility support she needed. Also said that they would be there for her if she needed it. Female, working age, satisfied.

Equipment

“[I’ve] not got any contacts [to] get in touch with to get help with gadgets and LVAs.” Female, working age, not satisfied.

“Whatever I need to know I can get through contacting the blind society. They also supply a lot of the gadgets to help me.” Female, retirement age, satisfied.

Education and leisure

She has help at college – the lady who helps her is really good but she would like more help. Would like to go out without her mum and dad. She needs someone [of] her own age to do things with. Female, working age, not satisfied.

“Generally the support they provide is what I want – i.e. helping me to go out to cinemas etc. Allows me a life of my own rather than always going out with my parents.” Female, working age, satisfied.

Student support were helpful in giving general advice about life in [the city]. Then at the end of the year he borrowed equipment from them, which they also discussed with him. They saw him really quickly too. Male, working age, satisfied.

6 Support for the visually impaired person's family

We asked all those taking part in the survey if their families had been offered any support (here 'support' was meant loosely rather than specifically 'carer's assessment'). Overwhelmingly we were told that families had not been offered any support (87%). When examining the findings by age group it appears that families of those in the 18-29 age group received more support than those at the older end of the age spectrum i.e. 23% compared to 1% for those aged 75+ years.

Table 13: Has your family ever been offered any support? (by working age/retirement age). Base: whole sample (N=882), weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
Yes	9%	2%	3%	(69)
No	84%	88%	87%	(748)
Don't know	2%	2%	2%	(20)
Can't remember	1%	0%	0%	(6)
Has no family	4%	8%	8%	(39)
Number interviewed	(503)	(379)	-	(882)

Overall, 70% of visually impaired people indicated that they were satisfied with the level of support they received. Nevertheless, people of working age were less satisfied than those of retirement age – 23% said they were not satisfied compared with 12% of those of retirement age.

Table 14: Overall, are you satisfied with the support your family were offered? (by working age/retirement age). Base: visually impaired people with family, (N=833), weighted.

	Working Age %	Retirement Age %	Total Weighted %	Total Sample (n)
Yes	62%	72%	70%	(557)
No	23%	12%	15%	(149)
Partly satisfied	4%	3%	3%	(35)
Can’t remember	0%	0%	0%	(3)
Don’t know / Unsure	10%	13%	13%	(89)
Number interviewed	(481)	(352)	-	(833)

Participant explanations

Follow-up open questions collected views about what types of support participants thought their family might have needed (and in some cases the support that was received). Given the general levels of support received and satisfaction reported in this section of the report, it is not surprising that large numbers of people felt that their family did not need support (over half the participants) or were unsure / had no view (a further 20%). Nevertheless, participants did highlight some areas they thought important, and these broadly fell into the following overlapping categories:

- ‘Visual Training’ and general understanding of visual impairment.
- Counselling / emotional support.
- Direct and indirect support for family members.
- General advice and financial support.

‘Visual Training’ and general understanding of visual impairment

A number of participants highlighted that their family would benefit from improving their general understanding of visual impairment. These were often very practical things, for example related to mobility, sighted guide techniques, or general visual awareness:

“Some help on how to guide me.” Female, working age.

“They need some training in how to look after someone who can’t see so they can know how to deal with people with visual impairment, e.g. why they shouldn’t leave things laying about or move things.” Male, working age.

“How to walk me across roads. How to hand me cups. Help to understand what support I need.” Woman, retirement age.

Others talked about issues beyond the practical, focussing more on family understanding and empathy towards the circumstances of the participant:

“Understanding that although my sight is getting worse I can lead an independent life. And some emotional support – especially when it happened. They need help to realise it is not the end of [my] life. I need their support, but I also need to get on with my life.” Female, working age.

“I think understanding - I can only tell them how I'm feeling but there's a lot really going on with my life [..]. They don't really know what's what. I can only tell them what the doctor says and they don't really know or understand. My sister [..] gets annoyed and worried and I think she could do with sitting down with the doctors and nurses and finding out what's going on.” Female, working age.

A number of participants suggested some support which could help (and in some cases had helped) to overcome some of these challenges, for example attending courses:

“When I did the ‘insight’ course my son came with me to some sessions and was offered information and help to increase his awareness about the problems I have.” Female, retirement age.

“[My family need] advice on how to support me because sometimes I feel belittled and maybe if they heard from someone else they would have a better understanding.” Female, working age.

Counselling / emotional support

The potential benefits of family counselling and emotional support were identified by many. The focus of this was sometimes with reference to helping family members understand the visually impaired person’s situation, but it was often linked to helping family members deal with their own reaction to the situation and changes to their lives in unexpected ways.

“My family need counselling. They don’t understand what I’m going through. They don’t understand the frustration.” Female, working age.

“Some emotional support for my family. My husband was very scared I would fall over he became overprotective. My husband had to train himself domestically as he had to care for me.” Female, retirement age.

In some cases, participants who were visually impaired from an early age described how their parents and siblings had struggled to come to terms with the visual impairment. Some participants also discussed the importance of ‘genetic counselling’.

[Participant] thinks her mum needed to talk to somebody as she feels guilty about it. Thinks her brother needed to talk to somebody as well, as he too was affected by her losing her eyesight. Female, working age.

“In the future we may need some [support] as I am expecting a baby. It is likely they will have the same condition so we will need help explaining how it will affect the child.” Female, working age.

Some participants felt that family members might sometimes need an outlet to talk about the impact upon their life. Some talked about family members potentially benefiting from respite care.

“It would have been needed early on and then maybe a year later –someone to talk to without me being there so they could talk about things.” Female, working age.

“I think it’s a case of what your spouse thinks they can do for you. All the time they’re available they do what they can, therefore you rely on your spouse but the spouse are never offered help. [My wife] needs cheering up – maybe an association for carers where they can all talk and get some support. Unburden herself.” Male, retirement age.

Direct and indirect support for family members

Participants often described how their family (often making reference to wives and husbands) would benefit from support with practical activities – e.g. shopping, transport, form filling, cleaning, and gardening. Sometimes this was described as something which would help give the family members a rest or a break. Sometimes reference was made to teaching family members new skills such as cooking and home maintenance.

“A cleaner for example, not even paid for, just some help finding one. [My] husband currently has to do everything.” Female, retirement age.

“Someone to come in and help me so they can go away on a holiday.” Female, working age.

"Help with learning to cook. Help how to cope with living with someone with a visual impairment." Female, working age.

A disabled sticker for her husband's car. Female, retirement age.

A number of participants who were visually impaired when children described the support their parents received or should have received. Some talked about parents groups and specific voluntary organisations.

"Now I'm 25 I don't [think] they need any at the moment. They needed more when I was younger. Better advise on school and what help I could get at school." Female, working age.

Her mum did need it when she was first registered as blind. Possibly someone to talk to. [..] How to handle the situation and things in the home. Female, working age.

"They used to get support from a group I used to attend. It was called LOOK." Female, working age.

General advice and financial support

Many participants described how their family would have benefited from more information generally, often referring to information about the eye condition and its prognosis, methods of supporting visually impaired people (e.g. mobility, sourcing equipment and books), and financial support and benefits.

"Someone to explain government forms." Male, retirement age.

A number of participants talked in general terms about financial support for family members. Others were more specific, e.g. referring to the cost of travel. The 'Carer's Allowance' (see, for example, Directgov, 2008) was mentioned by a few participants, some describing how family members received the benefit and others describing how they did not.

"[They received a] carer's grant to take me on holiday and get me out and about." Female, working age.

As has been highlighted elsewhere in this report, some participants thought about the future and the type of support their family might need then.

"They will need help coping when I do go blind." Male, working age.

In the future maybe [they'll need support]. Someone to come and show her husband how he could best help her to get on with her life." Female, working age.

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8 Appendix

The following table provides the wording used for the question about the types of practical advice and training received in the year after registration as blind or partially sighted.

Interviewer: “Thinking about the support you received, what sort of practical advice or training did you get?”

Notes to interviewer:
DO NOT PROMPT. Wait 15 seconds for spontaneous responses (you will be able to prompt on some later). If no response after a few seconds probe "can you remember anything?"

Tick all that apply

1	Training to get about outside (eg mobility training, long or white cane)	
2	How to get and use some technical aids/gadgets, (e.g. talking clock or watch. Liquid measures/level indicators).	
3	How to cope at home (eg rehabilitation: prepare food, cook, use kitchen, household movement)	
4	Offered a talking book machine / tape services	
5	Advice on magnifiers/ Low Vision Aids (LVAs) (e.g. magnifiers, magnifying glasses)	
6	Emotional support through letting you talk about your concerns	
7	Advice on travel (e.g. travel card, or dial-a-ride)	
8	Advice on benefits	
9	Advice on education/training and/or employment (NB: training leading to a qualification or new work skills, not rehabilitation)	
10	Taught / recommended Braille/Moon as a reading media	
11	Advice on lighting and colour contrast	
12	Put you in touch with others with a sight problem	
13	Meals on wheels	
14	Advice on computers / software	
15	Information or training about guide dogs	
16	Can't remember	
17	Other – specify	

The question was not prompted. If participants did not say that they had received the relevant practical advice or training without prompting the interviewers would prompt each in turn. This was only carried out for categories 1 to 9 in the above table.