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Network 1000

**Opinions and circumstances of visually
impaired people in Great Britain:
report based on over 1000 interviews**

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Foreword

Welcome to the first main report from the Network 1000 project. This project is the first of its kind to be conducted with major sector wide involvement. It has been undertaken by the Visual Impairment Centre for Teaching and Research (VICTAR) at the University of Birmingham and funded by the Big Lottery Fund through VISION 2020 UK on behalf of sector organisations. It began in March 2004 and will finish in February 2007.

Its key aims are to establish a sample of 1000 people who are registered as blind or partially sighted which is as far as possible representative of the visually impaired population in the UK, and then to begin to consult them on a range of issues. The sample has been built up using a rigorous statistical approach (stratified random sampling – weighted in relation to age to ensure a spread of participants across different age groups) to give authority to the results and enable them to be generalised.

A first working report presented selected results from a baseline survey of the first 700 people. This report now presents more extensive results from the full sample of over 1000 people. The results have been carefully presented to help the reader interpret the data. The results are generally split into different age groups reflecting that people's circumstances are often linked to their age. Also, when different age groups are combined together, the data is 'weighted' to account for the greater proportion of older people in the visually impaired population. By adopting this reporting approach we are better able to get an insight into the circumstances and opinions of the visually impaired population as a whole while still capturing the more detailed picture of differences across age groups.

The results shown here clearly indicate the vast range of issues, findings and further questions that are emerging from this project. For example:

- People's perceptions of employment and employability;
- The wide range of educational attainment and subsequent life experiences;
- The high occurrence of disabilities and long term health issues in addition to visual impairment;
- Role of visually impaired people as carers;
- Use of computers;
- People's perceptions of barriers to going out and about.

The report also presents two additional and equally important analyses. Firstly, a qualitative analysis of what participants identified as important issues in their lives in a response to an open question. This is extremely significant because it gives a more direct insight into issues that visually impaired people themselves think are important. Secondly, a section of the report relates to a sub-sample of 'key informants' who describe the circumstances of visually impaired people with learning and/or communication difficulties whom they know. Again this is a significant analysis because it presents an insight into the lives of a group of people who are rarely represented in surveys.

This report will now be followed by further data collection and analysis of selected themes. Discussions continue to assess how this valuable project can be sustained long term. The management panel welcome ideas and feedback on these results and the project as a whole. We are proud of this important piece of research and hope it informs and supports your work.

The Network 1000 Management Panel, Summer 2006

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Ann Bristow	Association of Directors of Social Services
Kevin Carey	Humanity
Mark Drury	National Library for the Blind
Sue Keil	RNIB
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1 Executive summary

This report presents a summary of data collected through 1007 interviews with visually impaired people in Great Britain. The interviews were carried out between spring 2005 and spring 2006. The research has been carried out by the Visual Impairment Centre for Teaching and Research (VICTAR) within the University of Birmingham in partnership with VISION 2020 UK and was funded by the Big Lottery Fund. Each telephone interview took an average of 40 minutes and was carried out by researchers within VICTAR. The project forms one of the biggest surveys of its kind ever undertaken and the first survey to be conducted with major sector wide involvement.

This report is divided into four sections:

- Introduction and description of the Network 1000 sample
- Main survey findings
- Analysis of open ended question
- Findings from the Key Informant interviews

1.1 Introduction and description of the Network 1000 sample

The 1007 research participants are all registered blind or partially sighted people who live in Great Britain. This sample was taken from the registers of blind and partially sighted people held by 20 social services departments in England, Wales and Scotland. The participants were recruited by sending out information packs containing details of the project in print and tape format to approximately 6,000 people.

This sampling process was carefully designed to generate a 'random sample' stratified and weighted for age. This means that the sample is statistically robust ('unbiased'), while still containing a range of people of different ages. The sample contains approximately equal numbers of participants in five different age groups: 18-29 year olds; 30-49 year olds; 50-64 year olds; 65 to 74 year olds; and 75 years and upwards. The sampling means that the information gathered from the sample can be statistically generalised to the visually impaired people on the registers of blind and partially sighted people in England, Wales and Scotland (approximately 360,000 people).

The sample is split between 960 visually impaired people we interviewed directly and a further 47 people who had learning and communication difficulties such that our interview schedule was inappropriate for them. To illicit the opinions and information for these people we carried out similar interviews with 'key informants'. Key informants were people who were close to the visually impaired person and were able to answer questions as best they could on their behalf. The results are presented separately for these two sub-groups.

Prior to interviewing participants a substantial amount of time was spent designing the interview schedule (questionnaire). Three key areas informed the questionnaire design. Firstly, the team aimed to involve visually impaired people in the design process and this included a series of interviews and focus groups at the design and piloting stages. Secondly, the World Health Organisation's 'International Classification of Functional Disability and Health' (WHO, 2001) was used as a useful framework and vocabulary for many of the questions. Finally, a literature review identified a number of other surveys which provided valuable sources of questions; of particular significance was the RNIB Adults Needs Survey (Bruce, McKennell and Walker 1991). The resulting questionnaire covered a wide range of topics.

1.2 Executive summary of main survey findings

The following summarises the findings from interviews with 960 visually impaired people. This sub-sample has the following age characteristics: 18-29 (n=180); 30-49 (n=204); 50-64 (n=223); 65-74 (n=184); 75+ (n=169). Throughout, figures are weighted to account for the age characteristics of the visually impaired population.

Participants and their homes

Unsurprisingly, the visually impaired people lived in a variety of circumstances at a variety of stages of their lives. Forty-two per cent of the visually impaired population were widowed; many of these were in the older age groups. Related, people who were single and never married tended to be younger. Forty-five per cent of visually impaired people lived alone. Again this was closely linked with age, being more common amongst older people.

Younger people (18-29) were often living with parents in their family home, frequently with brothers and sisters. It was also common for this age group to be living with a spouse or partner, sometimes with children. This pattern was followed for 30-49 year olds, who were often living with a spouse (56%), and had children under 16 as part of the household (33%). Across the age range 50-74, the likelihood of living with children under 16 dropped, though patterns of living alone (around 30%) and with a spouse (around 65%) remained approximately fixed. It was over the age of 74 years when the frequency of living alone increased (54%) and the likelihood of being a widow or widower increased.

Some 10% of people said they were living with someone who was sick, disabled or elderly. In many of these cases this sick or disabled person was the visually impaired person's spouse/partner, and it was very often the visually impaired person who provided all or some of the support.

Vision and communication

The participants were approximately evenly split between those who were registered blind and those who were registered partially sighted. As would be expected, visually

impaired people had a range of reported functional vision. When wearing glasses and/or contact lenses, but not using a magnifier of any kind, 18% said they could read ordinary newspaper print, while 52% said they could see well enough to read a newspaper headline or large print. Thirty per cent of people could not read any kind of print without a magnifier. Related, 30% of people said they did not communicate in writing at all.

In terms of other reported levels of vision: 4% of the population had no light perception; the majority (91%) could see the shapes of furniture in a room (or better); only 10% could see well enough to recognise a friend across a road.

Participants were asked if the difficulty with their sight was greater or less than a year earlier. Thirty-nine per cent thought it was about the same, though 56% felt it was worse. Older people were much more likely to report worsening vision.

Less than half of visually impaired people (43%) said they read ordinary print with or without a magnifier, rising to 57% who said they read large print. Five per cent of visually impaired people read braille (the majority of whom became visually impaired in childhood).

Seventy-one per cent of people said they used magnifiers for reading, and this was more common in older age groups. Handheld magnifiers were most commonly owned, though some sophisticated low vision aids were also described by many, such as a magnifier mounted in/on spectacles, and a considerable number had electronic aids including CCTVs.

Visual impairment, health and hearing

People described a variety of different visual conditions which caused their visual impairment. As would be expected, these reflect how different conditions are linked to age. Forty-nine per cent of people reported having macular degeneration, and this was the most commonly reported condition amongst those of retirement age (59%). The next most commonly reported conditions were glaucoma (18%) and cataract (15%). Other conditions reported by between 5% and 3% of people were diabetes-related eye conditions, detached retina, retinitis pigmentosa, and eye injury. Thirty-two per cent also named other eye conditions or symptoms of their visual impairment (often in addition to conditions named above).

Perhaps the clearest 'social' (non-medical) observation is that many people did not know the name of their eye condition when questioned (11%). Of those who did name their eye condition, many had to be prompted when they did not spontaneously give the name of their eye condition. Combined, this gives a conservative estimate that 23% of the population do not know, or are unsure of, the name of the eye condition that is responsible for their visual impairment.

Almost three quarters (70%) of visually impaired people reported that they had long term health problems or disabilities, other than their visual impairment. The likelihood of this increased with age, and as would be expected some of the conditions described were linked with age (e.g. heart problems and arthritis). In particular, 43%

of visually impaired people reported having difficulty with their hearing. Again, this increased with age, and the incidence of hearing loss was as high as 53% for the 75+ age group.

Employment

When asked to describe their employment status, the majority of people (80%) described themselves as retired from paid work altogether. This is not surprising considering the age characteristics of the visually impaired population. More relevant is the employment status of people of working age. Thirty-four per cent described themselves as being employed, self-employed, or employed and a student. Twenty per cent of those of working age described themselves as unemployed, 22% long term sick or disabled, 7% as looking after family and 12% described themselves as being retired from paid work altogether (most of whom were aged 50 or over).

Even within the working age population, people's self-described employment status was linked to age. The overall employment rate was 34%, but was higher for the 30-49 age group (45%). Not surprisingly, those in the 18-29 age group had a lower employment rate (33%), which can be partly attributed to the 22% who described themselves as being a student. The 50-64 age group had the lowest employment rate at just 21%. Interestingly, 25% of people in this age group described themselves as being retired (although they were not old enough to receive a state pension). Also, 26% described themselves as long term sick or disabled (this was higher than in any other age group).

Finance

Detailed information is presented in relation to visually impaired people's reported finances. For example, the analyses give some insight into the take-up of benefits/entitlements (such as the Disability Living Allowance). Seventy-six per cent of people reported having some savings, and the majority felt they were "just about getting by" or better. Nevertheless, some people felt that they were finding it financially difficult (e.g. keeping up payments with mortgage or rent), and some additional information is reported about what some people felt that they had gone without.

Independent living skills

In terms of independent living skills, 'preparing a meal' and 'household cleaning' were most commonly identified by visually impaired people as being particularly challenging tasks (33% and 43% respectively). While less often identified as being challenging, 'personal care' (19%) and 'getting about the home' (17%) were still identified by many as difficult.

For those who lived with someone, 84% received help with these types of daily living tasks. This figure was higher for those who were over 50 years of age. People who

helped often included the spouse or partner, particularly for those aged over 30 (although the number of responses was low for the 75+ age group). Similarly, parents often gave support, particularly to those under 30 years old.

Fifty-eight per cent of people (including those who lived alone) reported getting help from people outside the household. Again, these were often relatives, such as parents amongst younger age groups, and children amongst older age groups. A further 17% said that they were helped by friends or neighbours (the highest being the 30-64 year olds). A significant number of people (52%) reported employing paid help, the likelihood of which increased with age.

Travel

Participants were asked a number of questions about travel and going out beyond their homes. Forty-five per cent of visually impaired people said that they left their home every day, and this rose to 80% of people who left their home several times a week or more. Going out was linked with age – older participants were less likely to leave their homes every day (for example, an estimated 67% of working age people left their home every day compared with only 40% of people of retirement age). Nearly half of visually impaired people felt they would like to leave their home more often if they were able to. These people identified a variety of barriers to leaving home more often – some of these were individually-based issues (e.g. the person's visual impairment was perceived as the barrier) and some were socially-based issues (e.g. general issues related to transport were perceived as barriers).

A variety of modes of transport were described. Fifty-six per cent of people described travelling by private car and 18% by taxi. Nevertheless, public transport was used by many (e.g. 41% told us they used the bus), and walking was one of the most common methods described (46%). Mode of transport also appears to be linked to age; private car was more commonly named as a mode of transport by people of retirement age, whilst people of working age were more likely to walk and use public transport.

Computer use

A high proportion of the sample appeared to be split between those who used computers often and those who did not use them at all. Patterns of computer use were clearly linked to age - younger participants were more likely to use computers than older participants. The resultant weighted frequencies reflect this: an estimated 77% of the population never use a computer (88% of those of retirement age, 32% of those of working age). The use of computers did not appear to be linked to registration type.

The majority of people aged 18-29 and 30-49 had a computer at home (82% and 77% respectively). These numbers decreased with age (22% in the 75+ age group). Word processing, emailing, and use of the internet were the most commonly cited uses of computers (by those who used them). Using the internet and emailing was more common amongst the younger age groups.

Thirty four per cent of people wanted to use computers more than they currently did. As with transport, people identified a variety of barriers to using computers more often – some of these were individually-based issues (e.g. the person's visual impairment was perceived as a barrier) and some were socially-based issues (e.g. accessibility of equipment was perceived as a barrier).

Education

Forty-nine per cent of visually impaired people described themselves as having a qualification and 12% had achieved a first degree or higher qualification. Approximately 38% had an ordinary level (GCSE) or higher qualification. Taking the population overall, the older the participant was, the less likely they were to have any qualifications, for example only 11% of 18-29 year olds did not have a qualification compared to 59% of people aged over 75. This pattern was repeated throughout the sample, although it was more likely that older participants would have a qualification in the category 'other qualifications' than their younger counterparts.

Participants who were visually impaired as children were asked questions about the type of educational establishments they had attended. Responses showed that participants had experienced a variety of different educational settings, including special and mainstream schools.

For participants whose onset of visual impairment was after school age, 13% had since been involved in formal education. The majority had attended adult education classes, although some had also attended some form of higher education establishment, a special college for those with a visual impairment, or mainstream colleges of further education.

When asked, 80% of visually impaired people did not want to do any further formal education. Those of working age were more likely to want to carry out some form of education, in particular those in the 18-29 age group (who were also more likely to be currently engaged in education).

Leisure

Participants were asked a series of questions about what they did in their spare time when at home and outside the home. Unsurprisingly, a large variety of different leisure activities were reported. Common activities within the home included listening to the radio and music, and television, videos and DVDs (reported by 91% and 87% of visually impaired people respectively). Reading and listening to talking books was also commonly reported (77% of people) as was gardening (35%). Other relatively common activities were arts and crafts, knitting/needlework, crosswords, cooking and computers/internet (particularly amongst the young). Common activities beyond the home included: shopping; meetings with local clubs; participating in religious services; and pubs, clubs and restaurants. All these activities were reported by 30% or more of visually impaired people. Other commonly reported activities included walking (28%), attending specialist clubs or groups for visually impaired people

(16%), doing unpaid voluntary work (14%), and attending leisure activities such as evening classes (12%).

1.3 Executive summary of the analysis of the open ended question

To provide the participants an opportunity to talk about other themes of personal importance which were not covered elsewhere in the survey, we included a final 'catch-all' question that invited participants to talk about any issue that they felt was important to them in relation to their visual impairment. Rather than having a pre-defined list of possible responses as in the earlier questions, the participant was encouraged to describe this issue in their own words, which could be a negative or positive experience or an observation regarding the past, present or future. In short, the question gave the participants an opportunity to emphasise and elaborate upon themes already discussed or to introduce new themes.

Twenty-four themes were identified in the subsequent analysis, 14 of which clearly overlapped with themes covered earlier in the survey. The remaining 10 "new themes" more clearly stood alone. The following summary highlights 11 of the 24 issues, listed in order of most cited, that were each raised spontaneously by more than 100 participants.

The data generated by the open question is important not only to the research team and other researchers in the field, but also to policy makers and service providers, as it highlights the issues that visually impaired people feel are important.

Travel, transport and mobility

This included issues relating to various aspects of moving around (including within the home and outside). There are four sub-groups of this theme relating to 'mobility on foot' (including mobility, mobility training, and physical obstacles), 'public transport', feelings of 'independence and flexibility' (both positive and negative), and references to 'driving'.

Independent Living Skills

This covered a range of skills necessary for independent living, including housework tasks, meal preparation, personal care and hygiene, getting around the home, basic DIY, and shopping. It also included comments regarding a perceived lack of independence and dependence on others, and the need for training or devices to facilitate participants' independence.

Family issues

This covered issues relating to participants' family members. For example, the support provided by participants' families, the changing roles within the family since losing their sight, support for family members to help them cope and adapt to the loss

of their loved one's sight, and support for visually impaired parents in caring for their children.

Social and emotional issues

This included aspects of visual impairment that people felt impacted upon things such as being able to socialise, communicate with others, understand body language, social conventions, being able to ask others for help, having self-confidence.

Communication and reading

This included both positive and negative issues relating to reading. It includes comments about print, the use of low vision aids, braille, talking books/newspapers, the management of mail and ability to read labels on grocery items and medication, and the use of technology such as mobile phones for communicating both verbally and via text messaging.

Counselling, emotional needs and adjustment

This included people's reflections upon emotional needs and support they have had or would like to have had, including references to counselling services and emotional adjustment to sight loss.

Leisure activities - outside of the home

This related to activities that participants did in the past but were now unable to do for various reasons, as well as activities that they were participating in at the time of interview. Comments included how easy or difficult such participation was, and activities that participants would like to do either now or in the future.

Employment

This covered a number of issues relating to employment. In some cases participants simply described the work they did or wanted to do, whilst others described the support which helped them to attain or stay in a job, or the difficulty they have faced in attaining/keeping a job due to various barriers.

Agencies and user groups

This included issues relating to statutory and voluntary agencies that support visually impaired people, and self-help groups/organised groups for people with visual impairment.

Sighted people's awareness of visual impairment

This related to participants' perceptions of the awareness of the general public about issues relating to visual impairment and how awareness can affect visually impaired people.

Attitudes of others

This is related to the theme above, and included descriptions of occasions where participants have encountered both positive and negative attitudes regarding their visual impairment and circumstances. The attitudes were attributed to other people, including family and friends, work colleagues, medical and other agency staff, and the general public.

Other themes

The themes described above were each mentioned by more than 100 participants. The remaining 13 themes, whilst being less prevalent, are by no means less significant, and are listed below (in order of most cited):

- Leisure activities at home
- Medical and other issues related to visual impairment
- Education
- Other disabilities and health difficulties
- Low vision aids and lighting
- Finances
- Technology and gadgets
- Laws and policy issues
- ICT and computers
- Visual impairment awareness of visually impaired people
- Voluntary work
- Housing
- Religion.

Conclusion

The inclusion of such an open question was vital in order to allow participants to describe the issues that were of most importance to them. Firstly, it was important to ensure that participants could raise issues that had not been pre-conceived by the research team and previously covered in the survey. Secondly, a key aim of this initial research was to identify the participants' own opinions of what issues are important. The open ended question was an essential tool to encourage and facilitate the participants' involvement in setting the 'themes' for subsequent data collection in the forthcoming second survey.

The data generated by the open question is important not only to the research team and other researchers in the field, but also to policy makers and service providers, as it highlights the issues that visually impaired people feel are important.

1.4 Executive summary of the findings from the Key Informant interviews

A number of visually impaired people were unable to take part in the project personally due to additional health, communication or learning difficulties. To ensure that these people could still be included in the project, the research team devised an alternative approach that involved inviting a third party who was 'close' to the visually impaired person, to speak for and on their behalf. In practice this was a relative, friend, or someone who was caring for the participant in a professional capacity. We refer to this third party as a Key Informant (KI) and to the visually impaired person that they were speaking on behalf of as the 'co-participant'.

The key informants were interviewed using a survey which, although similar to the main survey, included re-worded questions that allowed the KI to give their opinion of the needs and circumstances of the co-participant. This enabled us to include the details of their lives and circumstances within the project, using the key informant's knowledge of the visually impaired co-participant.

The data generated from the survey are more qualitative than that relating to the main (n=960) sample, due to the small numbers of KIs and co-participants involved (n=47). Due to the probable response bias in terms of sampling and the subjective nature of the data collected, it is not valid to generalise statistically the findings relating to the key informants and co-participants to the wider visually impaired population. The summary below describes the key characteristics of the sample of 47 co-participants, as provided by the key informants.

Overview

The visually impaired co-participants in the sample were from a variety of backgrounds and different ages. All had some form of visual impairment severe enough for registration. Nevertheless, a variety of different levels of functional vision were reported by the key informants. All of the co-participants also had some level of learning and/or communication difficulty. Again this varied across the sample. Nevertheless, the co-participants tended to fall into those whose onset of learning and/or communication difficulty was congenital or post-natal (i.e. during childhood) and those whose onset was in adulthood.

Co-participants with onset of learning and/or communication difficulty in childhood

The co-participants whose age of onset of learning and/or communication difficulty was in childhood tended to have the following characteristics:

- were younger (generally between 18-49 years old);
- onset of visual impairment was in childhood;
- had a range of childhood and genetic conditions that caused their visual impairment;

- often lived with a parent (who usually provided at least some of the care, if not all);
- sometimes lived in individual, supported accommodation;
- was often described as being single/never married;
- was often registered as disabled;
- had a variety of additional health problems or disabilities including (in particular) hearing impairment, and conditions related to the skeletal and nervous system;
- in terms of employment status were often described as long-term sick or disabled, or unemployed, or sometimes as students;
- were sometimes studying on courses for people with special needs covering various life skills;
- usually received one or both components of Disability Living Allowance (DLA);
- received additional special educational needs support at school;
- usually went outside their homes at least once a week;
- sometimes used a computer, mainly to play games or for fun activities;
- often took part in a variety of activities beyond the home.

Co-participants with onset of learning and/or communication difficulty in adulthood

Co-participants whose age of onset of learning and/or communication difficulty was in adulthood tended to have the following characteristics:

- were older (50+ years of age, and usually older);
- onset of visual impairment was usually in adulthood;
- often had age-related visual conditions;
- often lived in institutional accommodation, for example a residential home;
- sometimes lived with a spouse or grown-up child (who usually provided at least some of the care);
- were often widowed;
- had a variety of additional health problems or disabilities which were often age-related (e.g. arthritis, heart condition, hearing impairment);
- were sometimes described as having dementia;
- a distinct exception was a co-participant whose learning/communication difficulty and visual impairment were the result of an accident;
- were often described as retired from paid employment (though had worked in the past);
- were often in receipt of Attendance Allowance;
- never used a computer;
- did not leave their home very often, if at all;
- rarely took part in activities beyond the home.

Open question: what is important to the co-participant?

As with the main sample, the majority of questions encouraged the KI to express their personal opinion about the co-participant and their circumstances in relation to a

number of pre-determined topics. A 'catch-all' question, similar to that used with the main sample, was therefore posed to the KI. This question asked them to try to describe the co-participant's thoughts regarding their visual impairment and how it affected their life, thus allowing the KI to talk about any issues that they thought were of importance to the co-participant.

A variety of illuminating responses were given, as summarised below:

- a number of KIs talked about the practical difficulties that co-participants faced in their everyday life, which often led the co-participant to feel frustration; this seemed to affect co-participants regardless of the age of onset of their learning and/or communication difficulty;
- co-participants who acquired their learning/communication difficulty in adulthood were often said to miss doing things that they used to do before the onset of their condition, e.g. reading and other activities;
- a number of KIs said it was important not to change the co-participant's daily routines;
- some KIs felt unable to answer the question, either because it was impossible to tell what the co-participant felt due to their learning/communication difficulty (including co-participants with both adult and childhood age of onset of learning/communication difficulty), or because the co-participant had never experienced life before their visual impairment (specifically co-participants with childhood age of onset of their learning/ communication difficulty).

Open question: effect of the co-participant's circumstances upon the key informant

The analysis of the open-ended question posed to the main sample, in particular the emerging theme of "Family Issues", suggests that visual impairment and its consequences can affect not only the life of the visually impaired person, but also the lives of their family members. Where the key informant was either related to or the main non-professional carer of the co-participant, the research team felt it was important to allow the KI to describe how the co-participant's circumstances had affected their own life, and in some cases, that of their family. The question was posed to all key informants who were not involved with the co-participant in a purely professional capacity (n=42).

The key informants of co-participants whose onset of their learning and/or communication difficulty had been in childhood (who were mainly their parents) talked about a number of practical and emotional implications that the co-participant's needs and circumstances had had upon their lives:

- those who were the main carer of the co-participant described how their lives revolved around the full-time care of the co-participant, with only infrequent respite;
- it often significantly affected the lives of the rest of the family, particularly the co-participant's siblings, by restricting social opportunities and 'normal' family activities;

- many KIs expressed concerned about future care arrangements for the co-participant in the event that they would be unable to care for them one day (i.e. due to their old age, ill health or death);
- the KIs often remarked that, whilst sometimes difficult, caring for the co-participant had enriched their lives.

The key informants of co-participants whose onset of their learning and/or communication difficulty was in adulthood were mainly the children of the co-participants, but occasionally their partner or friend. These KIs also talked about the practical and emotional implications that the co-participant's needs and circumstances had had upon their lives:

- some KIs (mainly children of the co-participants) talked about how the co-participant's circumstances had significantly changed their life, for example by needing to move nearer to the co-participant or having the co-participant move in with them;
- others spoke about having had to change their working practices or curtailing social activities in order to devote more time to the care of the co-participant;
- some of the KIs spoke of how they had become very aware of the practical needs of the co-participant, and how they tried to organise their homes or the home of the co-participant, and sometimes change the practices of others, in order to make the environment safer for them.

2 Introduction and description of the Network 1000 sample

2.1 Introduction

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”. Funding was initially granted for three years. The project is now in its final year of funding.

The project has four key aims. The first was to establish a consultation network of over 1000 visually impaired people aged 18 and over. In the event, the survey recruited and interviewed 1007 people with a visual impairment – making it the largest survey of its kind in the United Kingdom.

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 (see Corcoran, Douglas, Pavey, Fielding, McLinden and McCall, 2005 for a fuller account). This report represents the first 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 every stage of the design process (see Corcoran, Douglas, Pavey, Fielding, McLinden and McCall, 2005).

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 document is a report based upon the data collected from 1007 visually impaired people. This sample was taken from the registers of blind and partially sighted people held by 20 social services departments in England, Wales and Scotland; by these we mean departments that provide statutory services for adults with a visual impairment. The 1007 participants were recruited by sending out information packs containing details of the project in print and tape format to approximately 6,000 people.

Each person who gave their consent to participate, took part in a telephone interview between the Spring of 2005 and Spring 2006. Each interview took an average of 40 minutes and covered a broad range of topics such as transport, leisure, education and employment.

An overview of the sample and description of the reporting protocol is described below. After that section, the report is divided into three substantial sections which report the results of the survey:

- Main findings
- Analysis of open ended question
- Findings from the Key Informant (KI) interviews.

2.2 Overview of sample and reporting protocol

This section gives an overview of the sample and sample design, and the weighting process used in the analysis. The sampling process was designed carefully to generate a 'random sample' stratified and weighted for age (see below). The sampling design has made every effort to create a sample which is statistically robust ('unbiased'), while still containing a range of people of different ages.

The section begins with a detailed description and explanation of the sampling and weighting process before discussing the rationale behind the survey design, describing the participants and the variables used to analyse the data.

Design weighting

In this report, we describe the responses from the sample of the 1007 participants who took part in the survey.

In most cases, the figures presented have been weighted to aid generalisation to the wider visually impaired population. The process of weighting begins at the initial sampling stage. When we designed the sampling strategy, we purposefully set out to recruit equal numbers of people from five different age groups: 18-29 year olds; 30-49 year olds; 50-64 year olds; 65 to 74 year olds; and 75 years and upwards. This is a very useful strategy as it gives us data about the whole adult population. However, as we know that there are more people who are older in the visually impaired population, this strategy can become problematic if we seek to get aggregate frequencies and percentages for the entire sample and then incorrectly generalise to the wider visually impaired population. Such incorrect generalisations would result in over representing the circumstances and opinions of younger people with impaired vision, and give a false overall picture. We needed to account for this through design weighing that correctly proportions our sample to the known visually impaired population.

Weighting takes two forms: design weighting and response weighting. The first accounts for the design of the sample as indicated above and is described in more detail in the project's working document on sampling (Corcoran, Douglas, Pavey, Fielding, McLinden and McCall, 2005). Response weighting is more complex and seeks to understand and compensate for differences between the population and those who respond to the project (i.e. accounting for those who *did not* take part in the survey as well as those who did). In this report we implement the simpler design

weighting that takes into account the age distribution of the wider visual impairment population.

As an illustrative example, we present some design weighting that accounts for numbers across age groups in the registered population. The actual process is somewhat technical and not described here. However, the presented frequencies (presented as percentages) illustrate the effect of weighting well.

Table 1: Illustration of unweighted versus weighted frequencies (%). Base: whole sample (N=960).

	Sample %	Weighted %	Total (n)
Employed people of working age	33%	34%	(561)
Onset of visual impairment after 50 years of age	32%	66%	(960)
People who are widowed	16%	42%	(960)
People living alone	30%	45%	(960)
People who use braille	10%	5%	(960)

The table illustrates the role of weighting. In terms of employment rates amongst those of working age, differences are subtle, and in fact unweighted and weighted frequencies are similar at 33% and 34% respectively.

However, compare this to frequencies for the entire sample on issues which we would expect to be highly influenced by age group, for example, the frequency of people who are widowed. Sixteen per cent of the sample are widowed, but with the weighting (which effectively gives greater weight to older people in our sample) we have an aggregate of 42% widowed. It is these weighted figures that give the best population estimates. In other words we estimate that 42% of the visually impaired population are likely to be widowed.

Nevertheless, in most cases we present data split into different age groups. These are either the five age groups used in sampling (18-29 year olds, 30-49 year olds, 50-64 year olds, 65-74 year olds, or 75+) or the useful split between those of retirement age and those of working age. We have defined working age as 18-59 for women and 18-64 for men; that is the age when people in the sample are eligible, in principle, for their state pension. This takes into account the prevalence of older people (particularly older women) in the survey for whom recent changes to the State Pension Age do not apply (Directgov 2006). Such a split is generally useful because age has such an important impact upon how people live and plan their lives.

In order to clarify the interpretation of the weighted tables, we are using the example of the table relating to marital status and household composition, reproduced later in the body of the text, to exemplify the weighted process:

Table 2: Illustrative table. Marital status and household composition. Base: whole sample (N=959), weighted.

	Age group					Total weighted %	Total sample (n)
	18-29 %	30-49 %	50-64 %	65-74 %	75+ %		
Marital status							
Single / never married	72%	29%	11%	6%	5%	10%	(232)
Living as a couple	10%	7%	4%	1%	2%	3%	(46)
Married	17%	49%	60%	64%	31%	39%	(432)
Widowed	0%	0%	8%	22%	57%	42%	(156)
Divorced	1%	12%	15%	7%	4%	6%	(78)
Separated	1%	2%	3%	1%	1%	1%	(15)
Household composition							
Living alone	19%	24%	29%	28%	54%	45%	(289)
Living with children*	16%	40%	20%	10%	9%	13%	(187)
Living with children <16	13%	33%	6%	1%	2%	5%	(109)
Living with grandchild	0%	1%	1%	2%	3%	2%	(15)
Living with siblings	24%	2%	0%	1%	1%	1%	(50)
Living with parents**	41%	14%	4%	0%	0%	3%	(111)
Living with spouse	30%	56%	64%	66%	34%	43%	(491)
Living sick/disabled person	11%	12%	17%	12%	9%	10%	(120)
Number interviewed	(180)	(204)	(223)	(183)	(169)	-	(959)

* includes children, step children, foster children, and children-in-law;

** includes parents, step-parents, and parents-in-law.

The tables are generally divided into three main columns. The first column contains the descriptor and may contain sub-descriptions as above (e.g. '**Marital status**, Single / never married' etc.). The second contains the variable by which the data has been split. In this case it is the five 'Age groups' but could also be 'Working age / retirement age' or by registration status e.g. 'blind / partially sighted'. The figures here are the weighted figures that can be applied to the wider population within that variable. The third column gives the totals of the weighted sample and adjacent to that the number of participants interviewed in our survey. The 'Total Sample' figures relate to numerical frequencies and are always given in brackets e.g. the number (232) was the actual number of participants who gave that answer.

As an example, looking at the 'Widowed' descriptor in the left column, we can see that 0% of visually impaired people aged between 18-29 have been widowed whereas 57% of people aged over 75 have. This, when combined, gives an aggregate percentage of 42% for the wider visually impaired population. The adjacent 'Total Sample' column tells us the number of people within our survey who told us they were widowed was (156).

The very bottom section of the table gives the total response frequency for our sample. This is a useful device to calculate the percentage of responses from

participants *within* the survey. For example, taking a different example of 'Living with spouse' we know that (491) people within the survey from a base sample of (959) said they were living with a spouse – this equates to 51% of our sample. Again this demonstrates the value of weighting as this figure is larger than the 43% of the total weighted sample. It is the figure of 43% that is safe to use as a generalisation of the population of visually impaired people.

Rationale behind the survey design

In terms of Network 1000 there are three key frameworks, or principles, that informed the rationale behind the survey design (see Pavey, Douglas and Corcoran 2005 for fuller details):

- involving participants in the research;
- World Health Organisation (WHO) International Classification of Functioning, Disability and Health (WHO, 2001).
- and other surveys and research found in the literature.

The research team have already made reference to the importance they attach to including people with a visually impaired in the construction of the survey instrument (see Corcoran, Douglas and Pavey 2004 unpublished). In accordance with this approach focus group discussions were held with different groups and individuals with a visual impairment, and the issues raised from these were included within the topics of the questionnaire (Corcoran, Douglas, McCall, McLinden, and Pavey 2005). Another strategy to promote input into the survey design, is the use of some open-ended questions in the survey to encourage the participants to generate topics and issues of relevance to them, rather than just responding to the researcher's agenda.

In addition, the team's position is also aligned to the WHO (2001) framework that builds upon WHO (1980) which made the (now classic) distinction between 'impairment', 'disability', and 'handicap'. This has now been modified with a greater emphasis upon an inclusive agenda and social participation through the following key terms (amongst others):

- Impairment – problems in the body function or structure;
- Activity – concerned with performances in activities at an individual level;
- Participation – concerned with involvement in life situations on a society level;
- Environmental factors – concerned with variables which can be manipulated (whether physical, social, or attitudinal) which might improve performance on activities and/or increase participation;
- Barriers – general term describing environmental factors, which may cause 'activity limitations' and 'participation restrictions'.

In terms of implications for the survey design, we consider that this provides an extremely useful framework and vocabulary for categorising the questions we have asked participants. For example, we have asked questions about an individual's *impairment* (e.g. the nature and severity of their visual impairment), *activity* (e.g. what they are able to see, able to do), *participation* (e.g. read a book, join libraries, read a

gas bill), and *environmental factors* and *barriers* (e.g. presence and absence of accessible formats).

The survey instrument was also informed by other surveys within the field, which were useful in formulating question design and at a later date will enable comparisons with other studies to be made.

The sample

The Network 1000 total sample size is 1007. This is split between 960 visually impaired people we interviewed directly and a further 47 people who had learning and communication difficulties such that our interview schedule was inappropriate for them. For these people we carried out similar interviews with 'key informants'. Key informants were people who were close to the visually impaired person and were able to answer questions as best they could on their behalf. All the interviews provided extremely valuable data about the lives of visually impaired people, but in the most part the data is more usefully considered as two separate sub-groups (n=960 visually impaired people and n=47 key informants). For this reason, the report has separate sections for each sub-sample. However, the next short section about the whole sample presents some data in relation to all of the data combined (n=1007).

Description of variables relating to the total sample (n=1007)

The sample of 1007 is split across five age groups. All the participants were on the registers of blind and partially sighted people held by 20 social services departments in England (16), Scotland (3) and Wales (1).

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 to be calculated. The Network 1000 survey results can be statistically generalised to this base population.

Table 3: Sample distribution across the five age groups and distribution of population

Age group	Sample (n)	Base population
18-29	201	9,000
30-49	211	28,000
50-64	224	31,000
65-74	185	37,000
75+	186	255,000
Total	1007	* 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).)

Two other key variables available at the time of sampling were registration status (blind or partially sighted) and sex. We recorded information on both these variables from the registers at the time of sampling; weighted frequencies from the sample reflect the expected distribution i.e. more women than men, and an approximately equal split between those registered partially sighted and those registered blind. It is interesting to note, although not surprising, that a number of people did not know their registration status or were not aware that they were registered. Also, of those who were registered blind, 45% thought they were registered partially sighted beforehand.

A third variable of significance during recruitment was that related to learning and/or communication difficulties, for example speech, comprehension or hearing difficulties. As anticipated, in the case of some people we had invited to participate in Network 1000, we were informed (often by a carer or member of the family) that the visually impaired person was not able to take part in the project because they found it difficult to communicate. Following further consultation, 47 people (acting as key informants) agreed to take part in the project and give us information about the visually impaired person that they knew. This group forms an estimated 7% of the visually impaired population, although we suspect that this is a low estimate because many people may have assumed the research was not relevant. It should also be noted that many of the visually impaired people we interviewed directly had health problems and disabilities other than a visual impairment (including learning and communication difficulties). This is discussed elsewhere in the report (see section 5: Findings from the key informant interviews).

Table 4: Distribution of the registration status, sex, and participant type of the sample. Base: whole sample (N=1007), weighted and unweighted.

Characteristic	Sample (unweighted) %	Weighted %
Registration status		
Blind	47%	43%
Partially sighted	51%	54%
Unknown status	1%	1%
Unaware of registration	1%	1%
Sex		
Men	44%	38%
Women	56%	62%
Participant type		
Key informant	5%	7%
Visually impaired person	95%	93%
Number interviewed	1007	(1007)

Other key variables in relation to the sample were ethnic group, country of birth, religion and marital status. In terms of ethnic group, 93% of the sample (96% weighted) described themselves as White UK. This was higher than anticipated and may be a result of under-representation of other ethnic groups on the registers or a response bias (or most likely both). Related to this, 95% of the sample (96% weighted) were born in the UK. In terms of religion, 18% described themselves as having no religion (11% weighted), 78% Christian (87% weighted), and 5% (2% weighted) another religion (including Hindu, Jewish, Muslim, and Sikh). We were unable to stratify by ethnic origin as such data is not recorded across all registers. The likely under-representation of ethnic and religious minority groups in the sample warrants further investigation and consideration in future analysis and potential re-sampling.

In terms of marital status, the two biggest groups were those who were married (37%) and those who were widowed (43%). This second figure links to the high number of visually impaired people who lived alone, which will be discussed later (see section 3.1 The visually impaired participants and their home).

Table 5: Distribution of the marital status of the sample. Base: whole sample (N=1007), weighted and unweighted.

Marital status	Sample (unweighted) %	Weighted %
Single / never married	26%	10%
Living together as a couple	5%	3%
Married	43%	37%
Widowed	17%	43%
Divorced	8%	7%
Separated	1%	1%
Number interviewed	1007	(1007)

In this report we have a separate section for data gathered from key informants (n=47). Percentages presented in most of the following sections are based upon the sub-sample of visually impaired people who participated directly (n=960).

Reporting style and protocol

Results (tables, figures, and quotes) are reported in sections relating to topics (usually sections of the questionnaire). In many cases the tables presented are not based upon the entire sample. One reason for this is that not all questions are posed to all participants as not all questions are applicable to all participants. For example, people who were employed were *not* asked questions about unemployment or *vice versa*. Secondly, there are some cases of ‘missing data’ for particular questions. This is where, for example, participants may have felt that the question was inappropriate or they did not know the answer and therefore were unable to answer a question. The strategy adopted here is to use all the data available, and change the sample size for each table accordingly – base sample sizes are given in the table headings e.g. N=959 or N=106.

Given the complex nature of the design weighting, we have also taken considerable care over the language of the report. We refer to the ‘population’ or ‘people’ as those who are representative of the wider visually impaired population (those who are registered as blind or partially sighted). We refer to ‘the sample’ or the ‘participants’ when we are referring specifically to those who took part in the survey.

We also intersperse the report with quotations from our participants in order to give a personal context to the figures being presented. These quotations are taken from responses to one of the final open questions in the questionnaire, and fuller analysis of this data is presented in a later section of this report. 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.

3 Main findings (based on 960 interviews)

3.1 The visually impaired participants and their home

Relationships and household

In this section we build upon the descriptions of the participants presented in the previous section (i.e. details related to sex, marital status, ethnicity, and religion), though this time based upon the sample of visually impaired people we interviewed directly (n=960).

As already discussed, reported marital status was closely linked with age. While 42% of the visually impaired population were widowed, many of these were in the older age groups. Similarly, people who were single and never married tended to be younger. In terms of household composition, 45% of visually impaired people lived alone. Again this was closely linked with age, being more common amongst older people. Similarly, people who lived with their parents tended to be younger.

Table 6: Marital status and household composition. Base: whole sample (N=959), weighted.

	Age group					Total weighted %	Total sample (n)
	18-29 %	30-49 %	50-64 %	65-74 %	75+ %		
Marital status							
Single / never married	72%	29%	11%	6%	5%	10%	(232)
Living as a couple	10%	7%	4%	1%	2%	3%	(46)
Married	17%	49%	60%	64%	31%	39%	(432)
Widowed	0%	0%	8%	22%	57%	42%	(156)
Divorced	1%	12%	15%	7%	4%	6%	(78)
Separated	1%	2%	3%	1%	1%	1%	(15)
Household composition							
Living alone	19%	24%	29%	28%	54%	45%	(289)
Living with children*	16%	40%	20%	10%	9%	13%	(187)
Living with children <16	13%	33%	6%	1%	2%	5%	(109)
Living with grandchild	0%	1%	1%	2%	3%	2%	(15)
Living with siblings	24%	2%	0%	1%	1%	1%	(50)
Living with parents**	41%	14%	4%	0%	0%	3%	(111)
Living with spouse	30%	56%	64%	66%	34%	43%	(491)
Living sick/disabled person	11%	12%	17%	12%	9%	10%	(120)
Number interviewed	(180)	(204)	(223)	(183)	(169)	-	(959)

* includes children, step children, foster children, and children-in-law;

** includes parents, step-parents, and parents-in-law.

The figures in the table reflect different stages of people's lives. Younger people (18-29) were often living with parents in their family home, often with brothers and sisters. It was also common for this age group to be living with a spouse or partner, sometimes with children. This pattern was followed for 30-49 year olds, who were often living with a spouse (56%), and had children under 16 as part of the household (33%). Across the age range 50-74, the likelihood of living with children under 16 dropped, though patterns of living alone (around 30%) and with spouse (around 65%) remained approximately fixed. It was over the age of 74 years when the frequency of living alone increased (54%) and the likelihood of being a widow or widower increased.

Some 10% of people said they were living with someone who was sick, disabled or elderly. This was most commonly the case in the 50-64 age group (17%), although it was relatively common for all age groups. In many of these cases this sick or disabled person was the participant's spouse/partner (65%). This was more likely in the older 50+ age groups. Visually impaired people often provided all (40%) or some (34%) of the support. Again, this was most often the case in the 50-64 age group.

Table 7: Frequencies of the level of support provided by participants to persons living in their household who are sick, disabled or elderly and in need of special help. Base: those living with people who are sick, disabled or elderly and require special help (N=118), weighted.

	Age group					Total weighted %	Total sample (n)
	18-29 %	30-49 %	50-64 %	65-74 %	75+ %		
All of support	10%	28%	53%	36%	40%	40%	(42)
Some of support	35%	52%	39%	45%	27%	34%	(48)
No support	55%	20%	8%	18%	33%	26%	(28)
Number interviewed	(20)	(25)	(36)	(22)	(15)	-	(118)

Tenure and accommodation

A high proportion (62%) of visually impaired people lived in a home that was owned outright. Not surprisingly, the majority of these participants were aged 50 and over. A further 10% were buying their home with the help of a mortgage or loan. Overall 21% said they were renting. While this was more common in younger age groups, a considerable number of people aged 75+ also rented (18%).

Table 8: Home tenure. Base: whole sample (N=959), weighted.

	Age group					Total weighted %	Total sample (n)
	18-29 %	30-49 %	50-64 %	65-74 %	75+ %		
Own outright	8%	18%	46%	67%	72%	62%	(398)
Buying with mortgage	21%	43%	24%	7%	4%	10%	(196)
Part rent / part mortgage	0%	0%	0%	0%	1%	0%	(3)
Renting	39%	30%	27%	21%	18%	21%	(259)
Rent-free (incl. relative's)	8%	2%	2%	3%	5%	4%	(36)
Lives with parents	15%	4%	1%	1%	1%	2%	(42)
Unknown	9%	2%	0%	1%	1%	1%	(25)
Number interviewed	(180)	(204)	(223)	(183)	(169)	-	(959)

The most commonly reported types of accommodation were detached houses or bungalows (33%), semi-detached houses or bungalows (28%), and end of terrace and terraced houses (16%). Many people with a visual impairment were living with family as discussed above (e.g. 9% of 75+ age group were living with children). Even so, the reported size of the properties, coupled with high outright ownership, suggests that we might consider these aspects of the sampling in future analyses. This is because that the younger people (18-29) who said they owned their own homes may actually have been living with their parents, and were therefore describing their parents' situation rather than their own. Nevertheless, there is a wide range of other accommodations that people reported they lived in including purpose-built flats and maisonettes as well as sheltered and institutional accommodation, both of which were relatively common amongst those of retirement age (5% and 4% respectively).

Table 9: Type of accommodation in which people live. Base: whole sample (N=957), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Detached house / bungalow	21%	36%	33%	(243)
Semi-detached house/bungalow	33%	27%	28%	(303)
Terrace / end terrace	23%	14%	16%	(188)
Flat / maisonette (<10 dwellings)	12%	6%	7%	(103)
Flat / maisonette (10+ dwellings)	7%	6%	6%	(54)
Sheltered accommodation	1%	5%	4%	(19)
Institutional accommodation	0%	4%	3%	(13)
Various other*	3%	3%	3%	(34)
Number interviewed	(562)	(395)	-	(957)

* Including: various types of converted flats and bed-sits as well as mobile homes, caravans, and houseboats.

3.2 Vision and visual impairment

Seventy-four per cent of people told us that they wore glasses or contact lenses at least some of the time. The most commonly reported reason given for wearing them was for distance vision e.g. walking around (69%), and reading (66%), followed by other close-up uses (58%), and shielding against bright lights (20%). Only 10% wore them to protect their eyes, and fewer still for cosmetic reasons (3%). There did not appear to be any notable differences between age groups.

We asked the participants whether they could see well enough to read different sizes of print when wearing glasses/contact lenses, *but not using a magnifier of any kind*:

- 18% said they could read ordinary newspaper print;
- 52% said they could see well enough to read a newspaper headline or large print;
- 30% of people could not read any kind of print without a magnifier.

Participants were also asked six questions (see Table 9 below) regarding how much they could see, as used in the 1991 RNIB Adults Needs Survey (Bruce, McKennell and Walker 1991):

- 4% of the population reported having no light perception;
- the majority (91%) could see the shapes of furniture in a room (or better);
- only 10% could see well enough to recognise a friend across a road.

The six questions enabled the 'scoring' of participants' level of functional vision on a seven point scale (0-6) which is summarised in the table below.

Table 10: Frequencies of participants' functional vision scores. Base: whole sample (N=958), weighted.

	Age group					Total weighted %	Total sample (n)
	18-29 %	30-49 %	50-64 %	65-74 %	75+ %		
0. No light perception	7%	5%	8%	4%	3%	4%	(51)
1. Can tell by the light where the windows are	7%	10%	11%	7%	3%	5%	(74)
2. Can see the shapes of furniture in a room	6%	11%	17%	16%	27%	23%	(144)
3. Can recognise a friend if close to their face	9%	12%	13%	11%	20%	17%	(126)
4. Can recognise a friend at arm's length away	25%	26%	16%	32%	20%	22%	(225)
5. Can recognise a friend across a room	28%	24%	23%	20%	18%	20%	(217)
6. Can recognise a friend across a road	18%	12%	13%	11%	9%	10%	(121)
Number interviewed	(179)	(204)	(222)	(184)	(169)	-	(958)

These self-reported levels of vision appear to be linked to registration status. As would be expected, partially sighted people were much more likely to be able to see well enough to recognise a friend across a road (functional vision score 6) than people who were registered blind (16% compared with 2% respectively).

Participants were asked how old they were when they (or others) first noticed that their visual impairment was affecting everyday things:

- 18% reported that it was during their childhood (from birth to 16 years of age inclusive);
- 89% of those aged 18-29 first noticed the effect of their visual impairment during their childhood compared to 56% of those aged 30-49, 35% of those aged 50-64, 17% of those aged 65-74, and only 8% of those aged 75+;
- most commonly, people first noticed the effect of their visual impairment during their adult years, particularly between the ages of 65-74 (23%) and 75+ (26%).

Forty-two per cent reported that they first noticed they had a serious problem with their eyes themselves. Following that, vision loss was first noticed by opticians/optometrists, followed by family members (28% and 10% respectively).

When asked how much of the time they worried about their eyesight, only 40% of participants said 'none of the time'. The majority (60%) said that they worried about it to a greater or lesser extent: 20% said 'a little of the time'; 21% said 'some of the time'; 11% said 'most of the time'; and 8% said 'all of the time'.

Participants were also asked how much pain or discomfort they had in and around their eyes. A large proportion (54%) reported no pain or discomfort at all, whilst 25% reported having had mild pain or discomfort, 14% moderate pain or discomfort, and 7% had suffered severe or very severe pain or discomfort.

Table 11: Is the difficulty you have with your sight greater or less than it was a year ago? Base: Whole sample (N=960), weighted.

	Age group					Total weighted %	Total sample (n)
	18-29 %	30-49 %	50-64 %	65-74 %	75+ %		
Greater than a year ago	21%	37%	41%	52%	63%	56%	(407)
Less than a year ago	5%	3%	6%	7%	4%	5%	(50)
About the same	72%	60%	52%	41%	33%	39%	(499)
Don't know	2%	0%	0%	1%	0%	0%	(4)
Number interviewed	(180)	(204)	(223)	(184)	(169)	-	(960)

Under half of visually impaired people (39%) felt that the difficulty they had with their sight was about the same as a year ago. In contrast, 56% reported that the difficulty was now greater, whilst the remaining 5% felt it was less of a difficulty. There was an interesting pattern in terms of age, where younger participants were more likely to say it was “about the same” compared to older participants who were more likely to report that the difficulty was greater than it had been a year ago.

Visual impairment and eye conditions

People described a variety of different visual conditions which caused their visual impairment. As would be expected, these reflect how different conditions are linked to age. Forty-nine per cent of people reported having macular degeneration, and this was the most commonly reported condition amongst those of retirement age (59%). The next most commonly reported conditions were glaucoma (18%) and cataract (15%). Diabetes-related eye conditions were reported by 5% of people. Retinitis pigmentosa was reported by 4% of the population although this was higher amongst people of working age (12%), reflecting the early onset of the condition. Thirty-two per cent also described other eye conditions, as well as 11% who did not know the name of their eye condition. Both these groups combined (43%) were asked follow-up questions about the nature of their condition and were asked to describe in their own words what was wrong with their eyesight.

Table 12: Reported eye conditions. Base: whole sample (N=960), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Macular degeneration	9%	59%	49%	(227)
Glaucoma	10%	20%	18%	(119)
Cataract	9%	16%	15%	(109)
Diabetic related	9%	5%	5%	(81)
Retinitis pigmentosa	12%	2%	4%	(84)
Injury	4%	2%	2%	(26)
Detached retina	4%	3%	4%	(40)
Other	57%	26%	32%	(454)
Don't know	13%	11%	11%	(127)
Number interviewed	(563)	(397)	-	(960)

An analysis of this additional information was carried out with the support of a qualified optometrist. The descriptions people gave of their eye conditions enabled categorisation into some recognised visual conditions, but more commonly into 'symptoms' and 'signs' of visual impairment.

Table 13: Post-hoc analysis of additional descriptions of visual condition provided by participants. Base: participants who described their condition as 'other' or 'don't know' (N=581), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Field loss				
Related to stroke / tumour	8%	4%	5%	(35)
General	6%	3%	4%	(34)
Anterior eye disease				
Uveitis	3%	1%	1%	(12)
Aniridia	2%	1%	2%	(12)
Corneal	1%	4%	3%	(12)
Optic atrophy				
Leber's amaurosis	3%	0%	1%	(15)
Tumour	5%	2%	3%	(21)
General	9%	2%	5%	(48)
Other				
High myopia	6%	6%	6%	(34)
Other retinal	17%	15%	15%	(92)
Nystagmus	11%	1%	4%	(60)
Ocular albinism	4%	0%	1%	(21)
Retinoblastoma	1%	0%	0%	(6)
Other eye conditions	6%	5%	5%	(34)
Unclear and don't know	9%	12%	11%	(60)
Number interviewed	(416)	(165)	-	(581)

Perhaps the clearest 'social' (non-medical) observation is that many people did not know the name of their eye condition when questioned (11%). Of those who did name their eye condition, 20% had to be prompted when they did not spontaneously give the name of their eye condition. Combined, this gives a conservative estimate that 23% of the population do not know, or are unsure of, the name of the eye condition that is responsible for their registration.

Case studies related to vision and visual impairment

The following examples are accounts of three visually impaired people's experience of encounters/interaction with hospital staff.

Age 63

Male

Lives alone

Working age (Not working)

Registered partially sighted

"I find that at the moment when my eyes went, one doesn't believe until it happens to you how much you rely on your eyesight. The way I am now, it's worse than having a heart attack - you use your eyes for everything, I just can't get used to it. When I ask questions about it nobody gives me answers. My doctor is very arrogant, he doesn't pay attention to what you're asking him. I ask him, 'Will my eyes get better? Will I need glasses? Will I be able to go and do any kind of work?' but it seems to fall on deaf ears. The only thing I get is, 'Your next appointment's in five months time' and that's another five months I'm locked up in the house waiting for the next appointment to be told nothing. I tell them, 'I don't mean to be rude, but I'm the type of guy that if anything's bad, just tell me.' It's like a secret - I would rather know the worst. At the moment I don't know what's going to happen."

The following is an interesting contrast to the excerpt above:

Age 69

Male

Does not live alone

Retirement age

Registered blind

"[I] moved hospitals and the doctors there are great. They haven't been able to cure my condition but they are really helpful and I know the prognosis."

Another participant highlighted the importance of being given information about their condition at the time of diagnosis or as early as possible:

Age 74

Female

Does not live alone

Retirement age

Registered partially sighted

"When I was diagnosed with Macular degeneration I didn't have a clue what it was and it was very worrying. People could do with more information at the beginning."

3.3 Reading and access

When asked about the different ways in which people read:

- just under half of visually impaired people (43%) reported that they read ordinary print either with or without a magnifier. When broken down by registration status, a much greater proportion of people registered partially sighted read ordinary print than those who were registered blind (55% compared with 28% respectively);
- 57% said they read large print (with or without a magnifier);
- some 5% said that they read braille, the majority of whom were aged between 18-64;
- only 1% of the reading population used Moon;
- the most popular method of reading was by listening to recorded tapes, with 72% of people reporting that they read in this way. This method appeared to increase in usage with age;
- 44% of people described having someone who read to them.

A much higher proportion of registered blind participants listened to tapes than those registered partially sighted (90% compared with 59%). Although the proportions are low, a higher proportion of those registered blind (10%) used computer speech output compared to 5% of those who were registered partially sighted.

Of those who read braille, 67% became visually impaired during their childhood (aged from birth to 16 years).

Table 14: Frequencies of methods of reading by registration status (excluding those who did not know their status). Base: those who knew their registration status (N=933), weighted.

	Registration status		Total weighted %	Total sample (n)
	Blind %	Partially sighted %		
Ordinary print *	28%	55%	43%	(497)
Large print *	45%	67%	57%	(583)
Braille	9%	3%	5%	(98)
Moon	1%	1%	1%	(18)
Do you listen to tapes	90%	59%	72%	(616)
Someone reads to you	58%	33%	44%	(388)
Computer speech output	10%	5%	7%	(156)
None of these	0%	1%	1%	(8)
Number interviewed	(438)	(495)	-	(933)

* Reading with or without a magnifier.

Some 16% used a computer to communicate in writing (compared with 7% of people who used a typewriter). People aged between 18 and 49 were most likely to use a computer to communicate in writing; in contrast only 4% of people aged 75+ used a

computer in this way. Similarly, younger participants were much more likely to communicate using text messages on a mobile phone.

Over half of the population (57%) communicated with sighted people through handwriting. However, a greater proportion were registered partially sighted (67%) compared with 41% of all registered blind people.

Eleven per cent said someone else helped them communicate in writing, whilst 30% said they did not communicate in writing at all. Participants who were registered blind were more likely to say that they did not communicate in writing at all (40% compared with 24% of participants registered as partially sighted). Interestingly, they were as likely to communicate using text messages on a mobile phone as partially sighted participants.

Case studies related to reading and access

Many people spoke of how much they missed reading print books, both practically and the wider choice of material that is available in print:

Age 39

Female

Lives alone

Working age (Not working)

Registered blind

"I miss reading books, [I] find it very hard to get used to talking tapes, some people do enjoy them. I have given up some things I used to do because [it] strains my eyes."

Age 43

Female

Does not live alone

Working age (Not working)

Registered blind

"The other thing is just being able to get hold of material that's normally in print - would be lovely to have a wider choice in things on braille and tape. When you stand in front of shelves in a bookshop, you think wow, it must be great to be able to have that much choice."

Below is an example of how one participant fought for 'equal access':

Age 46

Male

Does not live alone

Working age (Working)

Registered blind

Over last two to three years he has got things onto alternative formats – this has become both a personal challenge and also a challenge at work to promote opportunities of alternatives to others, e.g. the Nationwide [bank/building society] send statements and the Council send information in audio-format. There have been teething problems with timing the arrival of tapes / timing of bills - for first three months he was charged by the bank. Things are better now, and they are more understanding.

3.4 Low vision aids

Whilst 71% of the population said they used magnifiers for reading, 29% indicated that they did not (this figure includes 8% of the population who told us that they did not read at all). The likelihood of using a low vision aid (LVA) increased with age (53% in 18-29 age group to 73% in 75+ age group). Those with the poorest and best reported functional vision (Vision Score) were less likely to use LVAs. Those who are registered as partially sighted are a little more likely to use LVAs than those registered blind.

Of the LVAs that people had, the most popular were hand-held magnifiers and hand-held magnifiers with a light. Some of the participants had sophisticated LVAs, e.g. a magnifier mounted in/on spectacles, and a considerable number had Closed Circuit Televisions (CCTV). CCTV was taken to include cameras attached to a television, and small scanners with a screen for reading labels, as well as more traditional CCTVs.

Table 15: Types of LVA people reported having. Base: people who reported using an LVA (N=596), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Magnifier – hand-held	50%	50%	50%	(292)
Hand-held magnifier with a built-in light	40%	59%	56%	(281)
Pocket magnifier (often used for 'outdoor' tasks)	19%	12%	13%	(115)
Magnifier – on a stand with light	5%	9%	8%	(36)
Magnifier – on a stand without light	5%	4%	4%	(26)
Magnifier – attached to spectacles	3%	1%	2%	(15)
Magnifier mounted in / on spectacles	8%	5%	6%	(39)
Binoculars – monocular or hand-held telescope	15%	7%	9%	(86)
CCTV	23%	20%	20%	(136)
Other	25%	20%	21%	(133)
Number interviewed	(322)	(274)		(596)

Although there is an interesting range of LVAs, it should be noted the above table refers to the kinds of LVAs that the participants reported that they *had access to*, not necessarily ones that they *used*.

Of those who did *not* use LVAs, 22% had never tried using them. Those who reported having the best functional vision ('Can recognise a friend across a road' based upon functional vision score – see above) were most likely to have never tried using an LVA. Those who were registered blind were more likely to have tried using LVAs in the past.

Of those with functional vision and who could read, 73% said that they used better lighting for reading tasks. This did not appear to be linked with age, although there was a slightly increased prevalence of 86% for those aged 65-74, compared to 74% and 70% for those aged 50-64 and 75+ respectively. It appears that people with better reported vision are generally more likely to use additional lighting.

Case studies related to Low Vision Aids

The following quotations were examples given by participants where an LVA had enabled more independence:

Age 37

Male

Lives alone

Working age (Not working)

Registered blind

"It was difficult to start with, because I was reliant on others before I got my magnifier. People used to have to read my bills out to me and I didn't like people reading my bills, [I] feel more independent since I have a magnifier."

Some participants felt that information about low vision aids (amongst other services) was not readily available, or that services were sparse. There was also concern about the cost of equipment:

Age 59

Female

Does not live alone

Working age (Not working)

Registered blind

"The only thing that annoys me is that you never hear about any help - nobody ever told me about CCTV - it was just by chance that someone rang and told me about it. It happened she had a son with visual impairment and [he] is doing A Levels and I asked how he manages it, and she told me that he had a CCTV. So I rang RNIB and got one and it's been such a help ... Lack of information is the main thing... Whenever I meet someone with a visual impairment I always try to tell them about things that might help. Special equipment is also so expensive - [you] have to weigh up how much you'd use it. [There's] nothing wrong with [the] current CCTV - [it] just doesn't do as much as modern ones."

Age 58

Male

Does not live alone

Working age (Not working)

Registered partially sighted

"Having moved from one district to another I've found it very difficult to transfer things from there to here. (Interviewer: "What kinds of things?") Social worker for the blind - in four and a half years I've met him once. When you contact him all you get is a recorded message. No facilities for visual aids in the [area where he lives], they just give you a catalogue that you have to send away and you have to get somebody to explain what there is in the catalogue - it's stupid."

3.5 Health, other disabilities, and hearing

Twenty-eight per cent of the visually impaired population reported being registered disabled, the greatest proportion of whom were in the 50-64 age groups (45%) whilst those in the oldest age group (75+), reported the lowest level of registration at 23%. A further 6% did not know whether or not they were registered as disabled. Almost three quarters (70%) reported that they had long term health problems or disabilities, other than their visual impairment. The likelihood of this increased by age, with 73% of those aged 65 and upwards reporting additional health problems or disabilities compared with 44% in age groups 18-29 and 46% for those aged 30-49. This did not appear to be linked to registration status. Those who said they had additional health problems or disabilities, other than their visual impairment, were asked to describe them, and their responses were later coded. This is presented in the table below. Some of the conditions were clearly linked with age as would be expected (e.g. heart problems and arthritis).

Table 16: Describe your long term health problem or disability (post hoc coding). Base sample: all those who said they had a long term health problem or disability other than their visual impairment (N=581), weighted.

	Age group					Total weighted %	Total sample (n)
	18-29 %	30-49 %	50-64 %	65-74 %	75+ %		
Heart problems	8%	9%	19%	25%	34%	29%	(117)
Strokes	3%	6%	11%	8%	6%	7%	(43)
Arthritis	5%	6%	13%	28%	31%	27%	(106)
Diabetes	11%	22%	27%	31%	8%	13%	(122)
High blood pressure	4%	13%	15%	18%	16%	16%	(81)
Circulatory system	3%	6%	5%	13%	6%	6%	(40)
Skeletal system	14%	15%	23%	14%	22%	21%	(106)
Nervous system	23%	22%	13%	7%	5%	7%	(74)
Respiratory system	15%	9%	7%	10%	9%	9%	(54)
Digestive system	0%	5%	9%	7%	7%	7%	(37)
Urinary tract / kidney	4%	15%	9%	4%	4%	5%	(41)
Other	39%	21%	19%	16%	7%	11%	(110)
Cancer	5%	1%	3%	3%	6%	5%	(20)
The ear / hearing	5%	6%	8%	5%	5%	5%	(35)
Number interviewed	(79)	(94)	(150)	(134)	(124)	-	(581)

All participants were asked whether they had difficulty with their hearing; just under half (43%) said that they did. This increased with age, as high as 53% for the 75+ age group. Of these, 62% had a hearing aid, the greatest proportion of which (67%) were those aged 75 and over, although a significant number (36%) of the youngest age band (18-29) also used a hearing aid. When asked whether the difficulty they had with their hearing was greater or less than it was a year ago, the majority (59%) felt it was 'about the same'. Of the remaining cohort who reported difficulty with their hearing, 35% felt the difficulty was greater than it was a year ago.

Case studies related to hearing, health and other disabilities

Some participants felt that their other health difficulties or disabilities were more of a problem than their visual impairment:

Age 57
Female
Does not live alone
Working age (Not working)
Registered partially sighted
"Again, I could deal with the visual impairment as it's been over 15 years, but it's the arthritis in my knee that holds me back more."

For some participants, their visual impairment made it difficult for them to manage their other disabilities:

Age 71
Female
Lives alone
Retirement age
Registered partially sighted
"With my diabetes, it's very difficult injecting [myself] – [I] talked to my GP, and at the moment it's ok. But if it gets worse I may have to have someone come and do it, or go into a home."

Below is an example of a participant who suffered with mental health difficulties:

Age 58
Male
Does not live alone
Working age (Not working)
Registered blind
"[My visual impairment] had a great impact on me. Losing my driving licence, I went through clinical depression because of this and I'm still on medication for my nerves. ... to be truthful, since 1977 I have been living a life of fear. I lost a young wife in 1977 and it took time for me to meet another woman. Little things become big things because I'm scared - so I worry about little things."

3.6 Employment

When asked to describe their employment status, the majority of people (80%) described themselves as retired from paid work altogether. This is not surprising considering the age characteristics of the visually impaired population. More relevant is the employment status of people of working age. Thirty-four per cent described themselves as being employed, self-employed, or employed and a student. Twenty per cent of those of working age described themselves as unemployed, 22% long term sick or disabled, 7% as looking after family and 12% described themselves as being retired from paid work altogether (most of whom were aged 50 or over).

Table 17: Frequencies of participants' self-reported employment status by working/retirement age group. Base: whole sample (N=958), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Self employed	5%	0%	1%	(27)
Paid employment (inc. part-time)	28%	0%	6%	(163)
On maternity leave	0%	0%	0%	(2)
Unemployed	20%	0%	4%	(123)
Retired	12%	97%	80%	(420)
Looking after family or home	7%	1%	2%	(38)
Student (full or part-time)	4%	0%	1%	(44)
Long term sick or disabled	22%	1%	5%	(117)
Paid employment and a student	1%	0%	0%	(6)
Something else	2%	1%	1%	(18)
Number interviewed	(561)	(397)	-	(958)

Even within the working age population, people's self-described employment status was linked to age. The overall employment rate was 34%, but was higher for the 30-49 age group (45%). Not surprisingly, those in the younger 18-29 age group had a lower employment rate (33%), which can be partly attributed to the 22% who described themselves as being a student. It is the older 50-64 age group which had the lowest employment rate of 21%. Interestingly, 25% of people in this age group described themselves as being retired (although they were not old enough to receive a state pension). Also, 26% described themselves as long term sick or disabled (this was higher than in any other age group).

Table 18: Frequencies of participants' self-reported employment status by age group. Base: people of working age (N=561), weighted.

	Age group			Total weighted %	Total sample (n)
	18-29 %	30-49 %	50-64 %		
Self employed	2%	4%	6%	5%	(22)
Paid employment (inc. part-time)	28%	40%	15%	28%	(158)
On maternity leave	1%	0%	0%	0%	(2)
Unemployed	25%	20%	20%	20%	(120)
Retired	0%	2%	25%	12%	(50)
Looking after family or home	5%	8%	5%	7%	(35)
Student (full or part-time)	22%	1%	1%	4%	(44)
Long term sick or disabled	11%	22%	26%	22%	(110)
Paid employment and a student	2%	1%	0%	1%	(6)
Something else	4%	1%	2%	2%	(14)
Number interviewed	(179)	(204)	(178)	-	(561)

Employed or self-employed participants

Thirty-four per cent of working age visually impaired people were in some kind of employment. Of these, the vast majority (94%) described their work as being permanent rather than temporary. Sixty-eight per cent said that they worked full-time. Of those who worked part-time, 26% said it was mainly due to their visual impairment.

In terms of self-reported registration status, people who were registered partially sighted were much more likely to be employed or self-employed than those who were registered blind (43% compared with 25% respectively).

Participants were asked about the type of industry in which they worked, their job title and the nature of their work; a wide range of occupations was reported, with examples from all nine categories of the Standard Occupational Classification (SOC 2000 – see National Statistics, 2006) ranging from:

- Managers and Senior Officials (e.g. Service Manager for voluntary organisation, Branch Managers);
- Professional Occupations (e.g. Teachers, Software Designer, Social Worker);
- Associate Professional and Technical Occupations (e.g. Nurses);
- Administrative and Secretarial Occupations (e.g. Accountants, Secretary, Receptionist, Clerical Worker);
- Skilled Trades Occupations (e.g. Bakers, Telecommunications Engineer);
- Personal Service Occupations (e.g. Care Assistants);
- Sales and Customer Service Occupations (e.g. General Retail Assistant);
- Process, Plant and Machine Operatives (e.g. Bridle Stitcher, Assembler of valves);

- Elementary Occupations (e.g. Warehouse Assistant, Cleaners).

Of those who were employed and of working age, 37% said that they had formal responsibility for supervising the work of other employees. Not surprisingly, the likelihood of this increased with age. Of the people who described themselves as self-employed, the majority (72%) worked alone or with a partner(s). The remainder had employees.

The majority of working people (82%) said that, overall, they were happy with their job.

Non-working people - reasons for leaving last paid job

Of our sample who were not working at the time of the interview (n=760, an estimated 93% of the visually impaired population), 411 people said that they were visually impaired when they left their last paid job (35% of the wider visually impaired population). When asked about the main reason for leaving their last job, 27% said it was mainly due to the onset or deterioration of their visual impairment. Other reasons included health (16%), retirement (30%), and redundancy (7%).

Of the non-working participants of working age, 42% had not worked for more than 10 years. Unsurprisingly, the majority of these were aged 30-49 or 50-64. A further 24% of the total working age population said that they had not worked for between five and 10 years. Those people who were registered blind were much more likely to have been out of paid work for more than 10 years than those who were registered as partially sighted (52% compared with 28%).

Unemployed people

Of the people of working age who described themselves as unemployed (20% of working age visually impaired people), 24% said they were seeking paid employment, 28% were not seeking work but said they would like it, and 48% were not seeking work and did not want it. Of visually impaired people who described themselves as unemployed, some 76% felt it was unlikely or very unlikely that they would begin a paid job within the next year. This pattern was pronounced in the unemployed 50+ year olds (60% not wanting work), and this is reflected in an almost universally held belief amongst this group that they were unlikely to get employment in the next year. The longer that people had been unemployed the more likely they were not to want to work.

Unemployed participants who had said that they would like to work were asked what, in their opinion, would help them to get a job and conversely, what stops them. The most frequently reported barriers to getting a job were general social explanations such as a lack of jobs in the area or jobs which were relevant to their visual impairment and/or qualifications, a lack of or need for training, and difficulty in finding out about jobs. Transport related issues and attitudes of employers were also cited by some. Some people also felt their visual impairment and/or health was a significant barrier.

The participants who did not want to work were asked why they felt that way. The most common reasons given were related to their visual impairment or to their general health or other disability. Fewer of this group suggested social explanations for their situation compared to those who wanted to work.

Long-term sick or disabled people

An estimated 22% of working age visually impaired people described themselves as long term sick or disabled. Of these, 76% were visually impaired when they left their last paid job. The majority (69%) said that they left their last paid job because of either their health or their visual impairment.

Of all those who described themselves as long term sick or disabled, forty nine per cent said that they had not worked for over 10 years, with a further 24% not having worked for between 5–10 years.

Case studies related to employment

The following three cases illustrate the contrasting experiences of people at the beginning, middle, and end of their working life:

Age 24

Female

Does not live alone

Registered partially sighted

Working age (Student, Not working)

"My main issue to do with my visual impairment is I personally find it hard to know how much to tell people when you are applying for a job. And although the new DDA [Disability Discrimination Act] says people have to provide you with things, I still don't know how much you should tell people. Do you wait till you've got a foot in the door and then tell them, if you haven't stated it in your job application? I'm applying for jobs in [the] civil service at the moment - partly because they're keen to employ people [with disabilities]. In terms of university, attitudes are changing a lot, but I think there's still staff, individual people who can be difficult ... Some people think you're getting an advantage by asking for things - they don't realise it's because you really need it - you don't want to think you got it unfairly."

Age 46

Female

Does not live alone

Working age (Working)

Registered blind

"Access to work has been brilliant. Without them I couldn't carry on working at all. They came and assessed my work situation, [and] provided [a] magnifier at work."

Age 59

Male

Does not live alone

Registered blind

Working age (Not working)

"The only thing that annoyed me when I got early retirement and couldn't get another job was having to tell people you're blind. Just because you can't see, you can still do things by feel. I would have liked to carry on working but didn't get the opportunity. This did annoy me a bit, but you can't let it get you down. When I was at 'Blogg's', there was another old boy there who couldn't see and our boss said we was the best two people there ... I'm older now and wouldn't have time for it now."

3.7 Finance

Participants were asked about the different types of income that they received, including: pensions; disability allowances, benefits and tax credits; benefits and payments for unemployment; family benefits and allowances; housing benefits and allowances; and a range of other types of income.

Participants were not prompted on individual types of income unless they were unsure of the name of the benefit or payment that they received. Therefore, the number of people who actually received the various payments and allowances described below could be higher, particularly in the case of some of the less well-known types of income or benefit that may not have readily come to mind when the participants were asked these questions.

Pensions

Table 19: Frequencies of those receiving pensions (grouped by people of retirement/working age). Base: whole sample (N=960), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
State Retirement Pension	0%	94%	76%	(374)
Pension from previous employer	13%	40%	35%	(221)
Pension from spouse's employer	1%	17%	14%	(58)
Private Pension / Annuity	2%	8%	7%	(50)
Widow's / War Widow's Pension	0%	2%	2%	(9)
War Disability Pension	0%	4%	3%	(10)
Pension Credit	0%	15%	12%	(66)
Other	1%	2%	2%	(16)
Don't know	0%	0%	0%	(3)
Refused to answer	1%	1%	1%	(8)
No, none of these	82%	1%	17%	(490)
Number interviewed	(563)	(397)	-	(960)

The majority of people of retirement age (94%) said that they received the State Retirement Pension. A further 40% received pensions from a previous employer, compared to only 8% of those of retirement age who said they received income from another type of private pension.

Disability allowances, benefits and tax credits

A common benefit received was Disability Living Allowance (DLA), with 30% of people reporting that they received at least one of the two components (mobility and

care). Only people under 65 years of age can apply for DLA, although it is possible to continue to receive the benefit beyond this age. Therefore it is not surprising that the numbers in receipt of DLA over the age of 65 were lower than that of those under 65 (18% compared with 79%). It is possible to look at people who were registered blind or partially sighted before they were 65 years old, and establish whether they received DLA at the time of interview. Taking into account when DLA was introduced in April 1992, 27% of those who could have received DLA before they were 65 did not do so. This suggests that approximately 3,000 people in England, Scotland and Wales who are registered as visually impaired missed out on claiming DLA.

Attendance Allowance can only be received by people aged 65 or over, and 40% of those aged 65+ said that they received Attendance Allowance.

Table 20: Frequencies of those receiving disability allowances, benefits or tax credits (grouped by people of retirement/working age). Base: whole sample (N=960), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Severe Disablement Allowance	10%	1%	3%	(59)
Industrial Injury or Disablement Allowance	0%	0%	0%	(2)
Disability Living Allowance – mobility component	72%	15%	26%	(516)
Disability Living Allowance – care component	62%	15%	24%	(463)
Disability Living Allowance – care and/or mobility component	79%	18%	30%	(583)
Attendance Allowance (if aged 65+)	0%	40%	32%	(112)
Carer's Allowance (formerly Invalid Care Allowance)	2%	3%	2%	(22)
Incapacity Benefit (formerly Invalidity Benefit)	31%	0%	6%	(158)
Working Tax Credit *	5%	0%	1%	(32)
Blind Person's Tax Allowance	5%	3%	4%	(44)
Don't know	2%	5%	5%	(36)
Refused to answer	1%	1%	1%	(8)
No, none of these	12%	35%	30%	(180)
Number interviewed	(563)	(397)	-	(960)

* Disabled Person's Component (formerly Disabled Person's Tax Credit / Disability Working Allowance).

In total, 2% said that they received Carer's Allowance, a benefit that is paid to informal carers of people who are severely disabled. There is some ambiguity, however, since some participants may have said that they received Carer's Allowance when in actual fact a relative received the benefit for the care they provided for the participant.

Incapacity Benefit is a weekly payment for people under State Pension age who cannot work due to an illness or disability, although some types of work are allowed (called 'Permitted Work'). Of participants of working age, only 31% of the sample said that they received Incapacity Benefit, the majority of whom described themselves as long term sick or disabled (41%), unemployed (25%), or retired from paid work altogether (25%).

A person can claim the Blind Person's Tax Allowance if they are registered blind, or are unable to perform any work for which eyesight is essential. Of those who said they were registered blind, only 8% said that they claimed the Blind Person's Tax allowance.

Benefits and payments for unemployment

Table 21: Frequencies of those receiving benefits or payments for unemployment (by age group). Base: non-working participants of working age (N=370), weighted.

	Age group			Total weighted %	Total sample (n)
	18-29 %	30-49 %	50-64 %		
Income Support	38%	27%	16%	23%	(97)
Job Seeker's Allowance	3%	6%	1%	3%	(13)
Don't know	7%	1%	1%	2%	(10)
Refused to answer	0%	2%	1%	1%	(4)
No, none of these	52%	65%	81%	71%	(247)
Number interviewed	(119)	(110)	(141)	-	(370)

Of those of working age who were not working, only 3% said that they were claiming Job Seeker's Allowance. In contrast, 23% of working age people who were not working at the time of interview were in receipt of Income Support. A person can claim Income Support if they are aged between 16-59 and are either a lone parent, registered sick or disabled, or caring for someone who is sick or elderly *and* they do not have savings of £8,000 or more and do not work, or work on average less than 16 hours a week.

Family benefits and allowances

Five per cent of visually impaired people have children living in their household who are aged under 16. Of these, 57% said that they received Child Benefit and a further 2% said they received child benefit as a lone parent, whilst 31% received the family component of Working Tax Credit.

Table 22: Frequencies of those receiving family benefits or allowances. Base: Participants with children under 16 years of age living at home (N=109), weighted.

	Total weighted %	Total sample (n)
Widowed mother's allowance	0%	(0)
Child benefit	57%	(76)
Child benefit as a lone parent	2%	(4)
Working Tax Credit – family component *	31%	(44)
Maternity Allowance	0%	(1)
Don't know	1%	(1)
Refused to answer	1%	(1)
No, none of these	32%	(16)
Number interviewed	-	(109)

* Formerly Working Family Tax Credit / Family Credit.

Please note: Due to the low aggregate numbers, no breakdown by age is given for this table.

Housing benefits and allowances

Table 23: Frequencies of those receiving housing benefits or allowances (grouped by people of working/retirement age). Base: whole sample (N=958), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Housing Benefit / rent rebate	22%	14%	15%	(176)
Council Tax Benefit / Allowance	26%	26%	26%	(244)
Heating Allowance	1%	11%	9%	(56)
Don't know	1%	1%	1%	(14)
Refused to answer	1%	1%	1%	(11)
No, none of these	67%	61%	62%	(622)
Number interviewed	(396)	(562)	-	(958)

Twenty six per cent of people said that they receive council tax benefit or allowance, whilst 15% said that they receive housing benefit or a rent rebate or allowance. Of those aged 60 and over (over 80% of the visually impaired population), only 11% mentioned that they receive the tax-free annual heating allowance (also known as the 'Winter Fuel Payment'). This allowance is only available to those who are 60 years old and above. However, this low figure would most probably be higher had participants been prompted about the payment by the researcher.

Other benefits and types of income

A number of people said that they received other benefits that had not been mentioned in the previous questions; examples include:

- transport / travel payments (i.e. Access to Work, Job Centre Plus, free or subsidised public transport, parking permit, free car tax, Motability scheme);
- free/reduced TV licence;
- disabled student's allowance.

Participants were asked whether they received any additional types of income, including: an educational grant; Trade Union or Friendly Society payments; maintenance or alimony/child support payments from a family member not living with them; rent from boarders or lodgers who lived with them; rent from any other property; Foster Allowance; sickness or accident insurance; or any other regular payment. In contrast to the types of income described earlier, these types of income were individually prompted (where appropriate). The most commonly mentioned income type was income from savings and investments (specified in 'any other regular payment') with 13% of the visually impaired population volunteering that they received this type of income. Others included rent from other properties (1%), educational grants (less than 1%), rent from boarders and lodgers (less than 1%) and Trade Union/Friendly Society Payments (2%).

Income of other household members / overall household income

Of the 55% who did not live alone, 28% said that one or more of the other household members were employed or self-employed, whilst 33% said that one or more of the other household members received benefits.

Participants were asked for the total household income for all members of the household, after tax was deducted each week, month or year. Unfortunately, the data collected is problematic as there were a number of unusual outlying figures given, as well as a number of people who did not answer the question, which would skew the average. Therefore, the average (median) household income of £12,000 unweighted or £10,400 weighted cannot and should not be used for any comparison with national data on income.

Savings

All participants were asked whether or not they had any savings; 76% said that they did, and of these, 79% said that their savings were over £3000. The likelihood of people having savings increased with age.

When asked whether they saved on a regular basis or just from time to time when they could, 38% said they saved only occasionally, compared with 31% who saved regularly. A further 23% of people said that they 'don't save', 'can't save' or 'no longer save'.

Thirty-nine per cent who had savings said that their savings were mainly 'long term for the future', compared with 33% who felt they were mainly short term savings for things they needed now or for unexpected events. Twenty-three per cent said their savings were for both the short and long term.

Perceptions of financial situation

All of the participants were asked how well they felt they were managing financially, and were offered five possible descriptions (on an ordinal scale) to choose from to summarise their opinion. The majority felt they were at least 'just about getting by' with only 3% feeling they were finding it quite difficult or very difficult. Forty-three per cent of the population felt they were 'living comfortably', 32% 'doing alright', and 21% 'just about getting by'.

Those aged 75+ were most likely to describe themselves as 'living comfortably'. Whether or not people lived alone did not appear to have an effect upon their perceptions of their financial circumstances.

Participants were asked whether there was anything that they had gone without or had to use less than they needed to because they could not afford it, over the previous 12 months. The researcher did not prompt the participant on any possible answer.

Table 24: Frequencies of goods and services that participants have gone without or used less than they needed to because they could not afford it (by working / retirement age). Base: whole sample (N=960), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
No we haven't gone without anything	63%	78%	75%	(665)
Water	1%	0%	1%	(4)
Gas	2%	1%	1%	(11)
Electricity	2%	2%	2%	(16)
Telephone	1%	0%	0%	(6)
Food	4%	2%	2%	(29)
Clothing	7%	3%	4%	(46)
Holidays	12%	9%	10%	(100)
Visits to friends / family	1%	1%	1%	(10)
Specialist equipment	2%	1%	1%	(16)
Gifts for friends / family	1%	0%	0%	(5)
Hobbies / activities in the home	1%	0%	0%	(5)
Leisure / activities outside the home	6%	2%	3%	(45)
Home improvements	5%	3%	3%	(36)
Other	10%	4%	5%	(75)
Don't know	1%	1%	1%	(13)
Refused to answer	0%	1%	1%	(8)
Number interviewed	(563)	(397)	-	(960)

The vast majority (75%) felt that they had not gone without anything over the past year, although 10% said that they had gone without a holiday as they could not afford it. Four per cent mentioned clothing, and leisure activities outside the home and home improvements were also both mentioned by 3%. Five per cent of people mentioned 'other' things. This other category included statements like "everything" or that they simply had to live cautiously in order to live within their means. It also included more specific personal items such as hairdressing, smoking, private medical insurance, replacing furniture in the home, and costs associated with having a car (e.g. replacing the car with a newer model, or car running costs).

Of the 31% who were paying for their accommodation (via mortgage or rent payments), 7% said that they had found it difficult to keep up with their housing payments over the past year.

Case studies related to finances

The following is an interesting comment on benefits and working, and the participant's perception of his 'position' in the family due to his low income and inability to get a job:

Age 27
Male
Lives alone
Working age (Not working)
Registered blind
Family financially well off, especially younger sister and feels really upset that he can no longer set a good example to her because he isn't working and can't get a job. As far as he knows he can only earn £20-£60 per week. *"If you earn over this much a week you get your benefits taken away."* His idea of a fairer system would be *"if you earn more than the allocated amount a week, you keep half and they take half"*.

Another example about benefits, this time reflecting on how difficult it is to get them:

Age 43
Male
Lives alone
Working age (Not working)
Registered blind
"[I've] tried three occasions for medium DLA but still only receive low rate despite my family helping me with everything. The Department of Works and Pensions just sit behind desk and read a couple of forms to determine my suitability but from that they can't determine how much help I need. [My] brother and sister-in-law are doing a lot and it's not taken into consideration how much they help me."

The following is an example of a participant who reflected upon what she believes are the hidden costs of visual impairment:

Age 64
Female
Does not live alone
Retirement age
Registered blind
"We would probably like to go out to dinner more if somebody was available with a car. Transport is the thing. We haven't been on holiday for years and years, as not only do you need transport, you need a sighted person to come with you, and it's the cost that's prohibitive too. Blind people have a lot more expense than ordinary people realise - you need batteries and things for special equipment, and you can't even borrow these things, and you can't get loans and pay for anything in instalments."

3.8 Independent living skills

Table 25: Difficulty experienced with household tasks (prompted and unprompted questions combined) by working/retirement age. Base: whole sample (N=960), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Difficulty preparing a meal	40%	31%	33%	(381)
Difficulty with household cleaning	40%	44%	43%	(395)
Difficulty with personal care	21%	18%	19%	(188)
Difficulty getting about the home	18%	17%	17%	(150)
Number interviewed	(563)	(397)	-	(960)

Participants were questioned about household tasks they found ‘particularly challenging’. These questions were asked first without prompting and then with prompting. Combining these responses shows that difficulties in preparing a meal and household cleaning were most commonly named (by 33% and 43% of people respectively). Neither age nor registration status appeared to have an obvious link with these responses, with the exception of the 75+ age group and those who were registered partially sighted. Both these groups appeared to have less likelihood of reporting problems when preparing a meal. Those aged 18-29 were less likely to report having difficulty getting around the home (8%) compared to people in the older age group of 50-64 (19%).

For those who lived with someone, 84% received help with these types of daily living skills. This figure was higher for those who were over 50 years of age. People who helped often included the husband or wife (or partner), particularly for those aged 30 and over (although the numbers were lower for the 75+ age group because many lived alone). Similarly, parents often gave support, particularly to those under 30 years old.

Fifty-eight per cent of people (including those who lived alone) reported getting help from people outside the household. Again, these were often relatives, such as parents amongst younger age groups, and children amongst older age groups. A further 17% said that they were helped by their friends or neighbours (the highest being the 30-64 year olds). A significant number of people (52%) reported employing paid help, the likelihood of which increased with age.

Case studies related to Independent Living Skills

The following is an example where a participant lacked self-confidence and described how this was related to some independent living skills:

Age 54

Female

Does not live alone

Working age (Not working)

Registered blind

“Apart from the actual physical frustration of not being able to find the right thing in the cupboard etc, I think self-confidence is hard because I cannot see what I look like in the mirror. I try to put eye make-up on but I have to rely on someone else to tell me whether it looks ok. Also when clothes shopping I don't know what I look like in the mirror. And that affects self-confidence if you can't see what you look like.”

The following is an example of how a participant developed strategies for getting jobs done, but how things were still problematic. She also reflected upon how services and family have supported her:

Age 88

Female

Lives alone

Retirement age

Registered blind

The Low Vision clinic has all different gadgets, which they lend and she finds that wonderful. *“A magnificent service.”* Main thing is when she buys something - for example bubble bath - asks the shop assistant to open it for her before she leaves the shop as she finds them too fiddly and can't see instructions. Relies on scissors a lot for opening packets. Finds people generally very helpful *“if you ask nicely”*. Finds writing on signs / pill boxes / instructions too small and poorly thought out colours. Can't make everything suitable for blind people but could compromise by having slightly larger black print on white background. Has to be organised and know where everything is, which is why she likes being in her own house. Grandchildren are very helpful in assisting with finding lost objects / reading post etc.

3.9 Travel

Participants were asked a number of questions about travel and going out beyond their homes. Forty-five per cent of visually impaired people said that they left their home every day, and this rose to 80% of people who left their home several times a week or more. This was linked with age – older participants were less likely to leave their homes every day (for example, an estimated 67% of working age people left their home every day compared with only 40% of people of retirement age).

This is also reflected in the described purposes of the journeys – 7% left their home to go to work (33% of those of working age). Nevertheless, the most commonly given reasons for leaving the home were shopping and general leisure and hobbies (77% and 47% respectively).

Table 26: How often do you leave your home and go outside (by working / retirement age)? Base: whole sample (N=959)

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Every day	67%	40%	45%	(552)
Several times a week	23%	38%	35%	(270)
At least once a week	7%	15%	13%	(101)
At least once a fortnight	1%	3%	3%	(19)
At least once a month (or less)	1%	4%	3%	(17)
Number interviewed	(563)	(396)	-	(959)

Table 27: What are the main purposes of your journeys? Base: whole sample excluding those who do not go out at all (N=952), weighted.

	Age group					Total weighted %	Total sample (n)
	18-29 %	30-49 %	50-64 %	65-74 %	75+ %		
Work	33%	44%	18%	1%	0%	7%	(191)
To visit family	19%	17%	17%	21%	19%	19%	(174)
To visit friends	37%	23%	22%	22%	23%	23%	(238)
To visit hospital / doctor	7%	13%	13%	15%	17%	16%	(122)
To go to the shops	63%	69%	82%	86%	76%	77%	(716)
Leisure / hobby	41%	36%	42%	48%	49%	47%	(408)
Other e.g.	39%	30%	26%	23%	32%	31%	(285)
Getting out / exercise / walking the dog	(13)	(18)	(22)	(15)	(17)	-	(85)
Education / course / training	(28)	(5)	(3)	(3)	(1)	-	(40)
Number interviewed	(180)	(204)	(222)	(181)	(165)	-	(952)

A variety of modes of transport were described. Fifty-six per cent of people described travelling by private car and 18% by taxi. Nevertheless, public transport was used by many (e.g. 41% told us they used the bus), and walking was one of the most common methods described (46%). Mode of transport appears to be linked to age; private car was more commonly named as a mode of transport by people of retirement age, whilst people of working age were more likely to walk and use public transport.

Table 28: When you leave your home, how do you normally travel (by age group)? Base: whole sample excluding those who do not go out at all (N=953), weighted.

	Age group					Total weighted %	Total sample (n)
	18-29 %	30-49 %	50-64 %	65-74 %	75+ %		
Private car	48%	47%	53%	67%	57%	56%	(516)
Bus	44%	52%	47%	32%	40%	41%	(416)
Train	21%	21%	15%	5%	5%	8%	(132)
Other public transport (coach / tube / tram)	10%	4%	2%	3%	1%	2%	(40)
Taxi	17%	24%	16%	21%	18%	18%	(180)
Dial a ride	1%	2%	4%	4%	9%	7%	(37)
Walk	52%	60%	59%	47%	42%	46%	(501)
Other	9%	9%	7%	9%	10%	9%	(85)
Number interviewed	(180)	(204)	(222)	(182)	(165)	-	(953)

People were asked ‘If you were able to, would you like to leave your home more often?’ – 43% of visually impaired people told us that they would. People of working age were more likely to say they wanted to leave their home more often than people who were of retirement age (55% and 41% respectively). We asked follow-up questions of these people asking what would help them get out more, and what stops them. The answers to these questions gave an insight into how people explained their situations.

Those who said they would like to leave their home more often were asked ‘What do you think would help you get out of your home more often?’ and ‘Put another way, what stops you from getting out of your home more often?’ This generated many ideas about perceived barriers and enablers to people getting out more often. When these responses were collapsed and combined, some interesting individual, social and economic factors emerged. As would be expected, these are linked to age. For example, people of retirement age were more likely to tell us that their poor general health was a barrier to getting out than those of working age (25% and 15% respectively).

Visual impairment was identified as a key barrier by many (32%), though this did not appear to be linked to age. Other common individual explanations were poor general health and mobility (22% and 29% respectively), both of which were more commonly

expressed by people of retirement age. In contrast, lack of confidence was more commonly identified by people of working age.

A common social explanation given by 29% of the population was related to their perception that they could not go out alone or unaccompanied; this was not linked to age. Similarly, 22% of people considered that general issues relating to transport such as cost and availability, posed significant barriers. This was more common amongst those of working age (33% compared with 19% of those of retirement age).

A number of other barriers and enablers relating to getting out more often were raised, the most common of which related to driving (e.g. missing being able to drive, or being dependent upon other people).

Table 29: ‘What do you think would help you get out of your home more often?’ and ‘Put another way, what stops you from getting out of your home more often?’ (by working / retirement age). Low frequency categories dropped or collapsed. Base: participants who would like to get out more often (N=475), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Individual-based explanations:				
Problem related to visual impairment	32%	32%	32%	(151)
Mobility	16%	33%	29%	(88)
Poor general health / other disability	15%	25%	22%	(70)
Confidence - lack of	18%	11%	13%	(79)
Social-based explanations				
Does not want/unable to go out alone	27%	30%	29%	(133)
General issues related to transport	33%	19%	22%	(136)
For example, other factors (n)				
Issues related to driving	(37)	(12)		(49)
Lack of purpose / motivation	(17)	(9)		(26)
Lack of support networks	(13)	(6)		(19)
Too expensive	(20)	(4)		(24)
Problem in bad weather	(12)	(13)		(25)
Number interviewed	(302)	(173)	-	(475)

Those who said they would *not* like to leave their home more often (or did not know) were asked ‘Why do you say that?’ The overwhelming majority felt that they already went out enough or that they were content with the current situation. Nevertheless, there were some participants who gave other explanations in line with the findings above.

Case studies related to travel, transport and mobility

The following examples illustrate how participants of different ages struggle with different aspects of mobility:

Age 81

Female

Does not live alone

Registered partially sighted

"I'm stuck with it [visual impairment] and so I have to get on with it. But it does worry me. [I] went to shop one time and two youths stopped me and it scared me, I thought they were going to have my bag. I haven't been out since because I feel vulnerable. I can be short changed sometimes in the shop but most people are nice. For example the bank helped me by getting me a bank card where I don't have to punch numbers in, I only ever have to sign."

Age 22

Male

Lives alone

Registered blind

"Things like when you're outside - street furniture, I find that a major problem. The city's pedestrian areas have put in silver bollards - through the research I've done with VI people, people walk into them. Stairs I find a big problem, changes in level especially when they're unexpected and when they don't have handrails and tread markings. Colour and contrast need to be thought about a lot more. Tactile markings - need to be more on the ground. And signage - a big problem - should be at eye level. In places like [railway] stations it's as high as the roof or writing too small to see it. Glass doors are also a problem - I don't see them. I won't travel on buses as I have no idea where I am as there's no audible alerts. That's why I use the trains - they announce it."

3.10 Computer use

**Table 30: How often do you use a computer (by working / retirement age)?
Base: whole sample (N=958), weighted**

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Every day	38%	4%	10%	(257)
Several times a week	14%	3%	5%	(101)
At least once a week	6%	2%	3%	(53)
At least once a fortnight	1%	1%	1%	(12)
At least once a month	2%	0%	0%	(14)
Less than once a month	3%	0%	1%	(26)
Don't use / never use	32%	88%	77%	(471)
Not since onset of VI	2%	2%	2%	(17)
Use with someone else	0%	0%	0%	(2)
Other	1%	0%	1%	(5)
Number interviewed	(561)	(397)	-	(958)

A high proportion of the sample appeared to be split between those who used computers often and those who did not use them at all. This was clearly linked to age - younger participants were more likely to use computers than older participants. The resultant weighted frequencies reflect this: an estimated 77% of the population never use a computer (88% of those of retirement age, 32% of those of working age). The use of computers did not appear to be linked to registration type.

Table 31: What do you use computers for (by working/retirement age)? Base: Those who use computers (N=473)

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Word processing (e.g. writing letters)	80%	63%	73%	(376)
Sending and receiving emails	73%	45%	62%	(347)
Surfing the world wide web / internet	75%	33%	58%	(345)
Spreadsheet work	41%	13%	30%	(177)
Database work	35%	20%	29%	(156)
Anything else – including:	32%	46%	38%	(165)
Games/ leisure/ photography (n)	(53)	(16)	-	(69)
Number interviewed	(402)	(71)	-	(473)

Word processing, emailing, and use of the internet were the most commonly cited uses of computers. Using the internet and emailing was more common amongst the younger age groups.

The majority of people aged 18-29 and 30-49 had a computer at home (82% and 77% respectively). These numbers decreased with age (22% in the 75+ age group). Similarly more people in the younger age groups had access to a computer outside the home.

When we asked participants 'Would you like to use computers more than you do currently?' n=379 said yes (an estimated 34% of the population). Of the people who said they did not use a computer at all (77%, predominantly people aged 50+), 29% wanted to use computers. Those who said they would have liked to have used computers more were asked, 'What would help you use computers more?' and 'Put another way, what stops you from using computers more than you do now?' This generated many ideas about perceived barriers and enablers to people using computers more than they currently did. When these responses were collapsed and combined, some interesting individual, social and economic factors emerged. As would be expected, these were linked to age.

For example, visual impairment was identified as a key barrier by many (43%), and this was more common amongst those of retirement age compared with those of working age (48% and 30% respectively). A more social explanation related to the accessibility of equipment (e.g. inaccessible screen or keyboard) was also seen as a key barrier (26%). In contrast, this perception was more common amongst people of working age than those of retirement age (39% and 22% respectively). These contrasting findings suggest that social explanations of disability (in relation to computer use at least) are more common amongst younger people with a visual impairment than older people.

Nevertheless, there are other social and individual explanations that did not appear to be age related. For example, lack of confidence (9%), time and motivation (7%), financial costs (e.g. of specialist equipment and installation/use of internet connections) (15%), and general issues related to training and courses (e.g. cost and availability) (10%). The general availability of equipment (both specialist and generic) was seen as a barrier by many (21%).

**Table 32: What stops and helps the participant to use a computer (more often).
Base: Those who would like to use computers more than they do currently
(N=378), weighted.**

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Individual-based explanations:				
Problem related to visual impairment	30%	48%	43%	(125)
Confidence - lack of	8%	9%	9%	(28)
Time and priority/motivation	9%	6%	7%	(37)
Social-based explanations				
Cost of equipment	18%	14%	15%	(62)
Availability of equipment	21%	21%	21%	(78)
Accessibility of equipment	39%	22%	26%	(132)
Issues relating to training courses	14%	9%	10%	(45)
Don't know	6%	10%	9%	(34)
Number interviewed	(238)	(140)	-	(378)

Those who said they would *not* like to use computers more (or did not know) were asked 'Why do you say that?' Again, this generated many explanations. Fourteen per cent of people saw age as a key barrier, not surprisingly these were almost entirely people of retirement age. Again, visual impairment was identified as a key barrier by many (20%), and this was more common amongst those of retirement age compared with working age (21% and 12% respectively). People of working age often felt they used computers enough already and therefore did not want to use them any more (52% for this age group, 11% in total).

The most common explanation given for not wishing to use computers more was that people were simply not interested (43%), and this was particularly common amongst those of retirement age (47%).

Case studies related to computer use

The following are examples of how some participants viewed computers and ICT generally as an essential information provider and communication tool:

Age 28
Male
Does not live alone
Working age (Working)
Registered blind
"Computers have been a big source of help in being able to access material on the web and screen reading software and such like."

Age 58
Female
Does not live alone
Working age (Not working)
Registered blind
"I'd be lost without the computer now, as it gives me constant access to friends and family abroad."

However, the use of technology was not without problems:

Age 37
Female
Does not live alone
Working age (Working)
Registered blind
"The internet, websites are difficult - often the computer package I use isn't compatible with the websites – it's frustrating."

3.11 Education

We asked participants a series of questions about their educational qualifications. Inevitably these questions were not mutually exclusive (people often have a number of different qualifications). For ease of analysis, this data was collapsed into five categories of people's 'highest' qualification ranging from no qualifications to degree and postgraduate qualifications (plus an 'other qualification' category which will be further analysed in future reports).

Forty-nine per cent of visually impaired people described themselves as having a qualification and 12% had achieved a degree or higher. Approximately 38% had an ordinary level (or GCSE) or higher qualification.

Table 33: Frequencies of participants' highest educational qualification by age group. Base: whole sample (N=954), weighted.

	Age group					Total weighted %	Total sample (n)
	18-29 %	30-49 %	50-64 %	65-74 %	75+ %		
No qualifications	11%	16%	38%	50%	59%	51%	(328)
Ordinary Level	26%	28%	20%	16%	8%	13%	(190)
Advanced Level	30%	19%	16%	8%	4%	8%	(146)
HE below degree*	7%	11%	3%	7%	4%	5%	(60)
Degree and higher**	24%	21%	14%	10%	11%	12%	(153)
Other qualifications	3%	6%	9%	10%	14%	12%	(77)
Number interviewed	(176)	(204)	(222)	(184)	(168)	-	(954)

* Including 'Nursing and medical qualifications' ** Including post graduate certificates and diplomas.

Taking the population overall, the older the participant was the less likely they were to have any qualifications, for example only 11% of 18-29 year olds did not have a qualification compared to 59% of people aged over 75. This pattern was repeated throughout the sample, although it was more likely that older participants would have a qualification in the category 'other qualifications' than their younger counterparts.

For those whose onset of visual impairment occurred between the ages of 0-16, (n=394, which is an estimated 18% of the wider population), the majority were aged *under* 65 at the time of the interview. This reflects the fact that for the majority of the visually impaired population, sight loss occurs later in life i.e. beyond the age of 65.

We carried out further analysis relating to educational placement and achievement on the data from the sub-sample of participants (n=220, an estimated 5% of the population), who had lost their sight in childhood and had been in compulsory education within the previous 25 years (i.e. under the age of 42 at time of interview). Twenty per cent had attended a special school for those with a visual impairment. The onset of this group's visual impairment occurred at an earlier age. They also tended to be older (reflecting a shift in educational policy of the previous 25 years). Ten per cent had attended a non-visual impairment special school. Forty-nine per

cent had attended a mainstream school with support provided for their visual impairment. They tended to be younger (63% of 18-29 year olds compared with 12% of 36-41 year olds), again reflecting shifts in educational policy towards inclusion in mainstream schools.

In terms of educational achievement, onset of visual impairment at an earlier age was associated with higher educational achievement. While the explanation for this is unclear and warrants further investigation, this may reflect the positive impact of early intervention strategies on educational outcome, or may indicate the detrimental effect of later onset of visual impairment on educational access. It may also be associated with other difficulties including the emotional impact of visual impairment.

Table 34: Education provision by age when visual impairment was first realised. Base: participants whose onset of visual impairment occurred at or before school age, and who were in compulsory education within the previous 25 years (N=220), unweighted.

	Age when visual impairment was first realised			Total sample %	Total sample (n)
	Pre-school (0-4 years)	Primary school (5-11 years)	Secondary school (12-16 years)		
Special school for visually impaired	21%	28%	0%	20%	(44)
Special school for other disability	9%	9%	17%	10%	(21)
Mainstream school with support	54%	43%	26%	49%	(108)
Mainstream school with no extra help	32%	41%	57%	37%	(81)
Special college for visually impaired	14%	22%	4%	15%	(32)
Ordinary college of further education	44%	35%	48%	43%	(94)
Sixth form college	19%	15%	13%	17%	(38)
Adult education classes	3%	0%	9%	3%	(6)
University / polytechnic	34%	43%	9%	34%	(74)
No formal education	0%	0%	0%	0%	(0)
Number interviewed	(151)	(46)	(23)	-	(220)

After school, those who went on to college were more likely to go to a mainstream college than a specialist one (43% and 15% respectively). Thirty-four per cent of the sub-sample went to or were at university.

For participants whose onset of visual impairment was after school age, 13% had since been involved in formal education. The vast majority (74%) had attended adult

education classes, although 17% had also attended some form of higher education establishment, 6% had attended a special college for those with a visual impairment and 5% had attended ordinary colleges of further education.

Fifty-eight participants were studying at the time of the interview, the majority of whom (n=38) were in the 18-29 age group.

We also asked the entire sample "Do you currently want to do any formal education or training?" Eighty per cent of people did not want to do any formal education. Those of working age were more likely (or were unsure) to want to carry out some form of education. In particular 68% of the 18-29 age group wanted to do formal education. In line with this, younger participants were more likely to be in formal education or to have 'clear plans' to do formal education or training.

Case studies related to education

The following is an example of a participant whose visual impairment began in childhood talking about her mixed experiences at school:

Age 20

Female

Does not live alone

Working age (Not working)

Registered partially sighted

Onset of visual impairment during primary education

"I suppose one of the things that wasn't positive was at primary school – [I] used to be sat at the back of the class away from all the other children. At the time I didn't mind but looking back I do. [They] gave me a large thick pen - learning to write with a thick pen is not easy." The learning support teachers wouldn't always believe her when she said she could see things – said she would have to have this enlarged - they didn't listen when she said she could see something. Got bullied a bit in secondary school "some children were not understanding because I used to have someone sat by me. Could be jealousy or lack of understanding. Some didn't believe I couldn't see things. They used to pull faces to test if I could see. Having a disability makes you more understanding of other people and the only thing with a visual disability is unless you have a stick, etc people can't tell and people think you are stupid. For example chip and pin. I think I should have a sign on my head (saying) "I'm visually impaired I'm not stupid."

Another participant reflected upon how well she had done in education and the support she had received, but ultimately was still concerned about getting a job:

Age 26

Female

Does not live alone

Working age (Not working)

Registered partially sighted

"I've got a good education because I've had a lot of help, e.g. from lecturers. I'm happy that I've achieved that. I do find that if you have a disability it's really hard to get employment."

3.12 Leisure

We asked all participants about the things they like to do in their spare time, both at home and outside of their home. The questions were open-ended (unprompted) and answers were pre-coded into categories by the researcher at the time of interview.

Activities within the home

A variety of leisure activities within the home were described by participants without prompting. The most popular were reading/listening to Talking Books (49%), listening to/watching television, videos or DVDs (41%), listening to the radio or to music (39%), and gardening (35%). Twenty-six per cent mentioned 'other' activities, some of which included socialising with friends and family at home, playing musical instruments, doing DIY tasks, and housework.

Table 35: Leisure activities within the home by working age / retirement age (with prompted and unprompted responses). Base: whole sample (N=960), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
TV and videos / DVDs	48%	39%	41%	(462)
– following prompt	88%	86%	87%	(841)
Listen to radio or music	47%	37%	39%	(425)
– following prompt	93%	90%	91%	(887)
Reading / Talking books	49%	49%	49%	(468)
– following prompt	73%	78%	77%	(712)
Gardening	29%	37%	35%	(287)
Caring for pets	7%	2%	3%	(52)
Arts, crafts and handicrafts	9%	8%	8%	(84)
Knitting and / or needlework	5%	9%	9%	(66)
Crosswords	2%	11%	9%	(48)
Use computers and Internet	13%	3%	5%	(110)
Talk to family/friends on phone	4%	7%	6%	(46)
Playing card or board games	3%	2%	2%	(29)
Cooking	10%	7%	8%	(90)
Rest / sleep	2%	3%	3%	(25)
None	3%	2%	2%	(22)
Other at home activity, e.g.	30%	25%	26%	(283)
Socialising	(43)	(26)	-	(69)
Playing musical instruments	(32)	(10)	-	(42)
DIY	(22)	(14)	-	(36)
Housework	(14)	(14)	-	(28)
Number interviewed	(563)	(397)	-	(960)

Four specific 'at-home' activities were then prompted to participants who had not mentioned it spontaneously in the previous question. These particular activities were chosen as they were both prompted and unprompted in the 1991 RNIB survey, and were predicted to be popular activities. Following these prompts, the most popular at-home leisure activity was listening to the radio or to music (91%), followed by listening to/watching television or videos/DVDs (87%), and reading/listening to Talking Books (77%). The majority of those who had children under 16 said that they spent time being or playing with them.

In terms of the age of participants, there were no particularly significant differences in the at-home activities specified, with the exception of gardening, which was more popular amongst people of retirement age. Similarly, there were no noteworthy differences in relation to the registration status of the participants, though people registered blind were slightly more likely to read/listen to Talking Books than partially sighted participants (83% compared to 72%). As would be expected, people with the lowest functional vision score (i.e. no light perception) were not as likely to say they listened to or watched television as those with some vision. Nevertheless, the percentage for those with no light perception who did listen to the television was still quite high at 75%.

Activities beyond the home

This section should be read in conjunction with Table 36 and Table 37. When people were asked about the things they liked to do outside of their home (unprompted), the most popular activity mentioned was walking (28%), followed by going shopping (17%), having a meal in a restaurant, pub or café (17%), and visiting/meeting friends or family was also commonly reported. Fifteen per cent said that they did not do any leisure activities outside of their home at all, which was more commonly the case amongst people of retirement age. As with the question regarding at-home activities, eight activities were then prompted to participants that had not mentioned them spontaneously (see Table 36). Subsequently, the most popular activities were going shopping (43%) and going for a drink in a pub or club (30%). Younger participants, particularly those in age groups 18-29 and 30-49, were more likely to undertake these activities than older participants were. They were also more likely to go to the cinema (see Table 37).

Conversely, older participants were much more likely to attend meetings for local groups/clubs/voluntary organisations than those in the younger age groups. This amounted to 34% overall (following the prompt). Of these, 37% were of retirement age compared to 20% of those of working age. Thirty-two per cent of the population participated in religious activities, which was more common amongst people of retirement age. Other relatively common activities that were reported by participants included attending meetings or clubs for visually impaired people (16%) and doing unpaid voluntary work (14%) (see Table 36).

Table 36: Unprompted/prompted leisure activities beyond the home by working / retirement age (with prompted and unprompted responses). Base: Whole sample (N=960), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Religion (worship, church, related activities)	5%	17%	14%	(88)
- following prompt	23%	35%	32%	(258)
Go to a shopping centre, other than for regular shopping	19%	17%	17%	(198)
- following prompt	56%	40%	43%	(513)
Take your children (under 16) out for activities	6%	0%	1%	(31)
- following prompt	14%	0%	3%	(77)
Go for a drink at a pub or club	17%	4%	6%	(132)
- following prompt	55%	24%	30%	(432)
Attend leisure activity groups such as evening classes	6%	5%	5%	(63)
- following prompt	12%	12%	12%	(131)
Attend meetings for local groups (not VI specific)	8%	16%	15%	(112)
- following prompt	20%	37%	34%	(255)
Attend meetings for clubs or groups for VI people	3%	7%	6%	(43)
- following prompt	15%	16%	16%	(155)
Do unpaid voluntary work	6%	4%	4%	(52)
- following prompt	25%	11%	14%	(197)
Number interviewed	(563)	(397)	-	(960)

In terms of registration status, people who were registered blind were more likely to attend clubs or groups for visually impaired people than those registered as partially sighted (21% compared to 13%).

The types of voluntary work undertaken by participants varied from fundraising for charities on an *ad hoc* basis (for example, selling raffle tickets, helping to organise jumble sales, coffee mornings and sponsored events), to more long term and time consuming commitments, such as counselling, running an animal sanctuary and

holding key positions within charities, such as Director and Treasurer. Many of the participants said that they sat on committees of voluntary organisations, whilst others helped out with the day to day running of local groups or clubs.

Whilst many of these participants volunteered for organisations that are concerned with visual impairment issues, the majority of participants did voluntary work for non-visual impairment organisations or causes, such as cancer charities, local hospices, mental health groups, and other disability groups. They also participated in community work, religious outreach activities, youth groups, and services/groups for the elderly. Some of these participants did voluntary work in an informal way by helping friends and neighbours in need, for example helping them with gardening tasks or befriending them.

Table 37: Unprompted leisure activities beyond the home by working / retirement age. Base: Whole sample (N=960), weighted.

	Age group		Total weighted %	Total sample (n)
	Working age %	Retirement age %		
Play sport	9%	4%	5%	(77)
Sport spectator	7%	2%	3%	(42)
Go swimming	10%	3%	4%	(80)
Go walking	37%	26%	28%	(305)
Go to the cinema	10%	2%	4%	(88)
Go to a concert, theatre or other live performance	12%	11%	11%	(109)
Go to a museum, heritage site or building	6%	5%	5%	(49)
Visit a theme park, fairground, fair or carnival	0%	0%	0%	(4)
Visit a zoo, wildlife reserve, aquarium, or farm park	1%	0%	0%	(8)
Other outdoor trips – countryside, going for drive	11%	10%	10%	(105)
Go dancing	2%	4%	3%	(27)
Go to bingo	1%	1%	1%	(10)
Go to a library	1%	0%	0%	(3)
Have a meal in a restaurant, café or pub	20%	16%	17%	(183)
None	7%	17%	15%	(90)
Other activities beyond the home, e.g.	39%	33%	34%	(368)
Visit / meet friends / family	(118)	(69)	-	(187)
Holiday	(31)	(14)	-	(45)
Number interviewed	(563)	(397)	-	(960)

Case studies related to leisure

Some people talked positively about the things they do now that they are visually impaired:

Age 42

Female

Does not live alone

Working age (Not working)

Registered partially sighted

"The most positive thing has been learning to use a computer and screen reader - it's changed my life from being permanently bored and get interested in something again. The worst thing has been the complete lack of interesting things to read on tapes, the lack of unabridged works - have to send to away to America to get unabridged stuff - it's terrible. There is a big Right to Read campaign and I'm a big supporter of that one - I write away all the time to book publishers. Radio - you suddenly rely on it - that's fantastic! It's mostly recreational things - not so much gadgets and widgets to make your life better because as you get into a routine you learn to do things yourself. When you lose your sight suddenly, it's boring, your life becomes dull - things that stimulate you are incredibly important. It's wonderful being a mum and being a wife but you have to do things for yourself."

Age 27

Female

Does not live alone

Working age (Not working)

Registered blind

"As for the positive - if it wasn't for my eyesight I wouldn't have swum - I swam at the 1996 and 2000 Paralympics, hoping to ride at the 2012 Paralympics."

Nevertheless, many people talked about things that they could no longer do, and felt excluded from:

54

Female

Lives alone

Working age (Not working)

Registered blind

"I used to thoroughly enjoy my life, be out and about all the time, especially with my son, when he was growing up, and I feel like I've missed out on his life. He has two grandchildren now - frustrated at not being able to spend time with them or do the normal grandparent things. Just enjoying their life. They're not old enough to understand why I can't do things - they're only three and five and a half. Just generally socialising with my friends, I can't go out and lock my door, and go meet them - they have to come and pick me up. [Not being able to go to discotheques or clubs] I sometimes feel like I'm a burden on them. It is hard at times, I don't want to be a burden upon anybody."

4 Analysis of open ended question

4.1 Rationale

The majority of questions in the Year 1 Survey sought factual data about the participants' circumstances, or their experiences and opinions on a variety of pre-determined themes, using a mix of closed and open-ended style questions. (See Pavey, Douglas and Corcoran, 2005, for a detailed description of the design of the Year 1 Survey.) While the questions regarding themes allowed participants to convey what they felt was important, it still restricted them to the specific topic about which the question was exploring, for example employment or travel.

In order to ensure that the interviewee was given an opportunity to talk about other themes of personal importance which were not covered elsewhere in the survey, we included a final 'catch-all' question:

"We have discussed many things about you, and different aspects of your life and hope that the questions we have asked have given you a chance to express things which are important to you. However, I wonder if you could spend a final minute or so telling us about things in relation to your visual impairment that are very important to you - this might be something you have found really difficult now or in the past, or alternatively something that has been very positive."

This invited the participant to talk about any issue that they felt was important to them in relation to their visual impairment, whether this was a negative or positive experience or an observation regarding the past, present or future. Rather than having a pre-defined list of possible responses as in the earlier generative questions, the participant was encouraged to describe this issue in their own words. The interviewer summarised what the participant said, and read the summary back to them to confirm that it reflected the point the participant was making. In short, the question gave the participants an opportunity to emphasise and elaborate upon themes already discussed or to introduce new themes.

4.2 Method of analysis

The research team were aware that such an open-ended 'catch-all' question would generate a significant amount of qualitative data requiring careful and time-consuming analysis. However, providing participants with an opportunity to influence future agendas overrode such pragmatic considerations.

As predicted, a large amount of text (data) was generated in response to this question. The qualitative data analysis tool Nudist Vivo (NVivo) 2 was chosen to help the research team make 'sense' of the data. The data was exported from the statistical analysis package, and converted into five Word documents with the responses grouped by the five age groups 18-29, 30-49, 50-64, 65-74 and 75+, and

were then imported into an NVivo project. Each individual response to the question was accompanied by details of:

- the participant's unique ID number (enabling linking with the main dataset);
- the name of the social services department from which they were selected from the registers of visual impairment;
- the participant's age;
- their sex;
- an indication of whether the participant lived alone;
- whether they were of retirement or working age, and if working age, whether they were working at the time of the interview.

The data was then analysed following a grounded, generative approach, in which the data was coded in order to draw out themes. This involved scrolling through the documents and highlighting text that related to previously identified themes, or 'new' issues or themes that had not been covered earlier in the interview schedule.

4.3 Outcomes

Some 24 themes were identified and coded in the analysis. These include the following, listed in the order of most cited:

1. Travel, transport and mobility (394 participants)*
2. Independent living skills (209 participants)*
3. Family issues (152 participants)
4. Social and emotional issues (144 participants)
5. Communication and reading (140 participants)*
6. Counselling, emotional needs and adjustment (122 participants)
7. Leisure activities - outside of home (120 participants)*
8. Employment (117 participants)*
9. Agencies and user groups (114 participants)
10. Visual impairment awareness of sighted people (103 participants)
11. Attitudes of others (102 participants)
12. Leisure activities at home (93 participants)*
13. Medical and other issues related to visual impairment (87 participants)
14. Education (53 participants)*
15. Other disabilities and health difficulties (49 participants)*
16. LVAs and lighting (35 participants)*
17. Finances (35 participants)*
18. Technology and gadgets (27 participants)
19. Laws and policy issues (26 participants)
20. ICT and computers (25 participants)*
21. Visually impaired people's awareness of visual impairment (21 participants)
22. Voluntary work (14 participants)*
23. Housing (nine participants)*
24. Religion (four participants)*

Fourteen of the themes (denoted with a '*' above) clearly overlapped with previous sections in the interview schedule. We refer to these as "Existing Themes". A number of the often illuminating quotes regarding these themes have been added as

'case studies' to the appropriate sections earlier in the report. Nevertheless, they will also be briefly described in the section below.

The remaining ten themes more clearly stand alone. We refer to these as "New Themes" and describe these with illustrative quotes later in this section.

In terms of reporting style, as with the illustrative examples used earlier in the report, some of the responses are presented verbatim whilst others are paraphrased, dependent upon the method used by the researcher at the time of interview. As described earlier, in all cases, the response would have been checked and confirmed as a correct reflection at the time of interview.

4.4 Existing themes

Travel, transport and mobility (394 participants)

This was the most popular topic with 394 participants mentioning some aspect of travel, transport or general mobility in response to the question. This is not surprising as getting from one place to another is an integral part of people's lives. This theme covers anything relating to moving around, i.e. issues relating to:

- guide dogs, long (white) cane usage, mobility training;
- general mobility issues, e.g. moving around the home or outside on foot, whether difficult due to their visual impairment, other health difficulties or obstacles in the sighted world;
- public transport, including actual use of and locations/facilities within stations, etc;
- experience of driving, and resulting loss or lack of independence;
- lack of/loss of independence due to the need to be accompanied when travelling or lack of flexibility that sighted people (as drivers) can enjoy.

Due to the wide range of issues that this topic covered, it was coded further into four codes relating to:

- Driving
- Independence and flexibility (including loss of or lack of, or where participants feel they *do* have independence/flexibility)
- Mobility on foot (including general mobility issues, guide dogs, mobility training issues, and also confidence about being outside alone, feeling vulnerable, difficulties due to physical obstacles, lack of support from local councils regarding street furniture, safety, etc)
- Public transport

It is important to note that the comments were not always negative, indeed in many cases they were positive. For example, regarding the helpful support provided by staff on public transport or the quality of mobility training provided by social services.

Independent Living Skills (209 participants)

This topic area covers a range of skills necessary for independent living, including housework tasks, meal preparation, personal care and hygiene, getting around the home, basic DIY tasks, and shopping. It also includes general comments regarding a perceived lack of independence and dependence on others, and the need for training or 'gadgets' to facilitate participants' independence. Some 209 participants talked about one or more aspects of independent living.

This topic was further coded using the WHO ICF framework (WHO, 2001) which differentiates between individual 'within-person' factors (e.g. the impairment) and 'beyond-person' factors (i.e. barriers to participation), as used within the generative questions earlier in the interview schedule (see Pavey, Douglas, Corcoran 2005). This was used to code descriptions of activities that participants either currently participated in, or that they would like to do, or activities that they had participated in previously but were now unable to. The new codes include:

- *What helps – within-person*; this codes personal qualities that have or would help them to take part in an activity (e.g. having the confidence to ask others for help when shopping, organising oneself and taking more time to carry out tasks, thinking up new strategies for undertaking tasks);
- *What stops – within-person*; this codes personal qualities that have stopped or hindered them in taking part in an activity (e.g. lack of confidence to try and do things or ask others for help, difficulties due to the nature of their visual impairment);
- *What helps – beyond-person*; this codes things beyond the self that have or would help them to take part in an activity (e.g. receiving help from family and friends, having 'gadgets' and devices to help prepare meals and refreshments, various suggestions of how shops/manufacturers could help, such as providing bigger labels and better instructions);
- *What stops – beyond-person*; this codes things beyond the self that have stopped the participant from taking part in an activity (e.g. difficulties with small print on labels and layouts of shops which keep changing, unhelpful shop staff or relatives, expense of special equipment, feelings of discrimination relating to products and services which are designed for sighted people).

The most common code was the more positive 'What helps – beyond-person factors', being cited 49 times, though participants often expressed frustration about their situation at the same time that they described a solution. This was followed by 'What stops – beyond-person factors' (cited 34 times), 'What helps – within-person factors' (21) and 'What stops – within-person factors' (9). This suggests that most participants perceived social barriers or solutions, rather than attributing their difficulty to personal qualities, such as their visual impairment or a lack of confidence.

Communication and reading (140 participants)

One hundred and forty participants talked about issues relating to communication and reading, both positive and negative. Comments were made about print and the use of Low Vision Aids, braille, talking books/newspapers, the management of mail,

the ability to read labels on grocery items, medication and clothes, and the use of technology such as mobile phones for communicating (including text messaging).

Often participants talked in terms of their visual impairment having a negative impact, citing the difficulties they faced in order to read printed mail, communicating with others via text messaging on mobiles due to the small font sizes (particularly the younger participants), and the frustration of having to depend on others to read for them. Others talked positively about their experiences, for example having learnt how to read braille, installing speech software so that they could use text messaging, or how talking books have had a positive impact upon their life.

Leisure activities – outside of home (120 participants)

This topic relates to activities outside of the home that some participants did in the past but are now unable to do for various reasons. It also includes activities that they are currently participating in and issues regarding how easy or difficult such participation is, as well as describing activities that participants would like to do either now or in the future.

The activities mentioned ranged from participating in sporting activities such as football, water sports, bowling, to social activities such as going to the pub, dancing/nightclubbing or going to the cinema. Whilst many participants still enjoyed taking part in these sorts of activities, others said they were unable to do so, due to transport-related difficulties or the need to be accompanied.

Employment (117 participants)

This topic was mentioned by 117 participants, and covers a number of different issues relating to employment. Often comments were simply descriptive, i.e. talking about the work that participants do, whilst others described how they successfully managed to get or stay in a job, or how they have been prevented or had difficulty in attaining/keeping a job. Not surprisingly, participants within age groups 18-29, 30-49 and 50-64 were more likely to talk about employment related issues than those aged 65+.

As with the topic 'Independent living skills', the topic was further coded using the WHO ICF framework (WHO 2001) into four areas including:

- *What helps/has helped to obtain/stay in employment – within-person factors*; this includes perceptions of what has helped or would help participants to obtain or stay in employment, in terms of factors internal to the individual, e.g. improved health/vision, self-confidence, better skills, etc;
- *Barriers to obtaining/staying in employment – within-person factors*; this describes perceived barriers to either attaining or staying in employment, which are internal to the individual. For example, due to their lack of confidence, where they consider their visual impairment or other health difficulty as the problem, rather than external factors;
- *What helps/has helped to obtain/stay in employment – beyond-person factors*; this includes perceptions of what has helped or what would help them to

obtain/stay in employment, in terms of external factors beyond the individual, e.g. employers were aware of and supported their needs, received Access to Work support, etc;

- *Barriers to obtaining/staying in employment – beyond-person factors*; this describes perceived barriers either to obtaining or staying in employment, which are external to the individual. For example: attitudes of employers/other employees etc; lack of practical support to enable them to continue in their job; rules of the benefit system that are a disincentive to getting a paid job or wages which are too low; limited choices of suitable jobs for their visual impairment or health difficulty; or difficulties with transport.

The re-coding was not applied to text where the interviewee was simply stating that they had a job or were looking for a job without elaboration. Also, some people simply stated that they did not work anymore but gave no reason as to why.

Leisure activities at home (93 participants)

This topic relates to at-home activities past, present and future. Participants often talked about activities that they did in the past but were now unable to do for various reasons, or activities that they currently do. They also discussed how easy or difficult such participation is, as well as telling us about at-home activities that they would like to do either now or in the future.

As with leisure activities beyond the home, a variety of activities within the home were mentioned, ranging from watching television, listening to the radio, reading books (often in the context that the participant missed doing this), talking books, board games and puzzles, various hobbies and crafts, and gardening.

Medical and other issues related to visual impairment (87 participants)

This includes a variety of issues relating to participants' visual impairments and their experiences of medical interventions. A number of participants talked about medical research into their eye condition (e.g. hoping for cures, taking part in medical trials). Others commented on the information that they had been given/would like to be given about their condition by medical personnel, or gave descriptions of their eye condition and how much they can see. This topic also includes comments about participants' experiences of medical appointments at hospitals or other locations in relation to their visual impairment, both negative and positive.

Education (52 participants)

This topic covers both past experiences within compulsory education (both mainstream and special schools for the visually impaired), college and university, and present difficulties or experiences within education, particularly regarding the amount of support received and how the participant feels they have been treated in terms of

their visual impairment. In many cases, participants felt they had been treated the same as everybody else by teaching staff and fellow students, which they saw as a very positive thing. Others, however, expressed disappointment due to the lack of support they received, both in terms of encouragement and practical support, which they felt had adversely affected their educational achievement. Younger participants (particularly those aged 18-29) were more likely to mention educational issues than older participants (those aged 65+).

Other disabilities and health difficulties (49 participants)

This includes description of other disabilities or health difficulties experienced by participants (sometimes associated with the visual impairment), which some participants felt presented more of a difficulty than their visual impairment. For example, some participants talked about the fatigue that they often suffered which hindered their everyday life, whilst others talked about medical conditions like Multiple Sclerosis affecting their mobility or difficulties coping with and managing their diabetes.

LVAs and lighting (35 participants)

Thirty-five participants talked about low vision aids and lighting in answer to the question. Some simply gave descriptions of the low vision aids that they used, whilst others mentioned low vision aids that they would like but do not have for various reasons (e.g. due to cost) and the effect of different lighting on their ability to see and get around. Only three participants talked about LVA services in their area, and of those who did, one mentioned that services were few and far between, whilst another praised their local LVA clinic and the help they had received from them.

Finances (35 participants)

This topic covers issues relating to the additional costs that visually impaired people have to budget for compared with sighted people (e.g. medication, expensive technical devices and equipment, help with tasks around the home that many sighted people could do themselves). They also told us about benefits that they currently receive or have failed to qualify for, the cost of transport, and calls for more financial help from the government for people with a visual impairment.

Technology and gadgets (27 participants)

A number of people described how technology and gadgets used in everyday life presented them with difficulties (e.g. mobile phones), as well as talking about specialist equipment designed to enable visually impaired people to be more independent. Whilst a number of people described how specialist equipment had impacted significantly and positively upon their quality of life, there was some discussion about the prohibitive cost of specialist equipment for visually impaired

people. Others hoped for more technological development of gadgets that would help them in their everyday life.

ICT and computers (25 participants)

This covers issues relating to the use of computers and the desire to use computers, including what helps or would help participants to use computers effectively and what stops or has stopped participants (e.g. training issues, specialist software) from doing so.

Voluntary work (15 participants)

Fifteen participants talked about voluntary work that they had either carried out in the past, or were currently involved in. This included descriptions of voluntary work with other visually impaired or disabled people, which enriched the participants' lives.

Housing (9 participants)

Several people talked about housing issues, for example their desire to move to housing which was more suitable for their needs or nearer to family and friends. Others talked about difficulties in maintaining their homes or that they felt lucky in their current situation (e.g. in owning their own home).

Religion (2 participants)

In terms of religion, two participants explained how their religion had helped them to cope with their visual impairment and circumstances.

4.5 New themes

The remaining 10 themes had not been explicitly covered earlier in the schedule, although they may well have been covered incidentally. For example: when talking about what stops the participant getting out of their home more often, people may have mentioned the attitudes of sighted people (see Outcome 11, above). These 'new' themes will now be described in detail, with illustrative quotes.

In addition to the 10 themes listed below, 88 people said that they had nothing further to say or did not know how to answer the question, and 14 people said that everything was difficult due to their visual impairment, and did not feel able to elaborate any further.

Family issues (152 participants)

This topic covers issues relating to participants' family members. Examples include the support provided by participants' families, the changing roles within the family since losing their sight, support for family members to help them cope and adapt to the loss of their loved one's sight, and support for visually impaired parents in caring for their children.

Whilst many participants clearly appreciated the support their families gave them, some lamented how much they missed having independence and the opportunity to be more spontaneous. For example:

Age 70

Male

Does not live alone

Retirement age

Registered blind

"I find it difficult to calibrate my injection equipment (for insulin). I sometimes have to ask my wife for help and can't see the measurements all the time and fill the hypodermic. If no one else was here I would find it very difficult indeed. I find reading difficult and if I put anything down and then turn my head away I have trouble finding it again. I find telling the time difficult. I have a talking watch but it's a bit difficult e.g. changing the time. You have to ask somebody for every little thing that you want. Most things in my life have pretty well stopped. If it wasn't for my wife being around I should really be in trouble."

There were many examples where participants' families helped them through difficult times:

Age 57

Male

Does not live alone

Working age (Working)

Registered partially sighted

"Positive things - all the family treat me normally, my wife chivvies me along and says 'you aren't as bad as you make out'! The family are very supportive and good that way, if there's anything I need or need to go anywhere. I went through a bit of a bad depression stage July/Aug last year - they were very supportive. But I seem to be getting over that now. We plod on."

Whilst many participants relied on the support of their families, they often remarked upon the (negative) impact their visual impairment and circumstances had upon their family:

Age 66

Female

Does not live alone

Retirement age

Registered blind

"I feel very guilty about my visual impairment, as not only has my life changed but my husband's has. I don't have the chance to get more involved with my family now - with my grandchildren. I feel I have robbed him [husband] of time he could have been doing things he wants to do, because he has to spend that time with me now [because she needs his help]."

As described earlier in the report, many of the participants are carers for others, for example sick, disabled or elderly partners requiring 'special' help, or parents caring for children. In particular, participants with young children talked about difficulties in caring for their children and being able to offer them the same opportunities as children with sighted parents, often noting the lack of support services in this area; for example:

Age 37

Female

Does not live alone

Working age (Working)

Registered blind

"My main issues at the moment are being a blind parent to sighted children - my main gripe is that there's no support, I don't fit into any group. You get help if your child is disabled or you have a different disability. Things like taking child to the park - irresponsible not to have someone there, or having curriculum books that I can read to/with them. And generally support for me to help with his homework. There are lots of info sheets, but not enough practical doing, people to help do things."

Social and emotional issues (144 participants)

This includes aspects of visual impairment that people felt impacted upon being able to socialise and communicate with others, being aware of and understanding other people's body language, and social conventions, making it particularly difficult to make new friends as well as sustain established friendships. Others talked about whether they felt able to ask others for help, and having self-confidence.

The 144 participants who talked about these social and emotional issues were fairly evenly spread in terms of age, which suggests that these are fundamental issues regardless of age. The following are some examples:

Age 22

Female

Lives alone

Working age (Not working)

Registered partially sighted

"My major problem is loneliness. If I walk along the street, I can't spot people and smile at them; people have to approach me, so I feel like I'm in a world of my own, which is quite damaging at times. If I did go out to a pub or a club, because I'd never be able to make the eye contact, it would be hard to make more friends, so that's a problem."

Age 43

Female

Does not live alone

Working age (Not working)

Registered partially sighted

"Meeting new people and mixing with them is also difficult. Because I don't wave to people when I'm outside, I think they think I'm miserable or something. It's difficult to take part in conversations when out in a group - I don't know when people are looking at me, so unless they're close I don't know when to speak. Sometimes I don't notice things; it's not that you're stupid, you just can't see. You think other people are thinking that you're stupid."

Older participants described similar experiences:

Age 75

Female

Does not live alone

Retirement age

Registered blind

"I find it very difficult - you feel so lonely sometimes because you can't communicate in the way you did. I feel that I'm losing skills in communicating with people. It's quite traumatic."

Age 97

Male

Does not live alone

Retirement age

Registered blind

"The eyesight problem is a problem and it cuts you off from the outside world."

Counselling, emotional needs and adjustment (122 participants)

A number of participants talked about the emotional needs they currently have or have had in the past, in relation to their visual impairment. Some people reflected on the support that they were given, particularly at time of diagnosis, or the support that

they felt they should have been offered; for example, counselling services or signposting to organisations that could have helped them in some way. Others talked about different strategies that they followed in order to adjust emotionally to their eye sight loss. This theme is in many ways related to the previous theme “social and emotional issues”, as it looks at the psychological well-being of people with visual impairment, and some of the strategies that participants have used or felt they would have benefited from, in order to adjust, cope or come to terms with their circumstances.

The following are examples where participants felt they had received inadequate support:

Age 38

Male

Lives alone

Working age (Not working)

Registered blind

Feels maybe our survey should ask more about the emotional support offered when people lose their sight. When it happened to him he felt stupid and scared and vulnerable and angry (with himself and with the world). People tell you things they think you want to hear but you don't. Need better counselling services to treat the emotions of disability. People always think he wants to be treated normally, he does not. He is aware of his disability and the special needs he has because of it. People are too 'PC' and that leaves them afraid to help. Society needs to be more open about disability in order to support it better.

Age 35

Male

Does not live alone

Working age (Not working)

Registered partially sighted

“[There was a] lack of support once discharged from [hospital]. Felt as if I'd had operation and that there was no support. Even if after the operation I'd have been given contact details of somewhere, e.g. phone no., address.”

Age 65

Female

Does not live alone

Retirement age

Registered partially sighted

"The most important thing to me is the lack of emotional support there is when you are diagnosed with sight loss - I didn't know which way to turn."

Had never been involved with social services, had never had a reason to. Rang RNIB, was crying - but said they could not help and would get back to her - but still haven't called! Left three messages on diabetic retinopathy helpline but never got a reply. Social services said they would send a social worker, but told her it was 6 or 7 weeks wait. Eventually got in touch with a blind lady who helped so much, not due to what she said but her own demeanour. She worked which amazed her as didn't realise visually impaired people could work! Feels really strongly that there should be some sort of helpline to help people when first diagnosed. That is the reason they founded [self-support group] - she was one of founding members.

Others have accepted and adapted to their circumstances, for example:

Age 82

Female

Lives alone

Retirement age

Registered partially sighted

"You have to accept it, that's the main thing. Can't sit in and feel sorry for myself; you have to go out and meet people. I am going to [a centre for the blind] - does help as I realise there are people worse off. You have to go out, can't stay in. I fell the other week but you can't let that stop you. Can't lose your confidence. You have to be positive about things. There's always someone worse off than you."

Agencies and user groups (115 participants)

A number of participants talked about issues relating to statutory and voluntary agencies that support visually impaired people, and self-help or organised groups for visually impaired people. Due to the breadth of this theme, further coding was undertaken to recode the data into the following four areas:

- **Quality of statutory services** (63 Participants); for example, descriptions of the provision of good support from social services (e.g. in mobility, route training using a long cane), or where support had been inadequate in terms of quality and/or quantity. Some participants talked about the recent implementation of the Disability Discrimination Act, and how in their opinion this had not appeared to have had a positive effect upon services for visually impaired people.
- **Voluntary organisations** (VOs) (54 participants); for example, participants talked about the quality of services they received from local voluntary organisations, though some of the younger participants felt they catered more for older visually impaired people. Others mentioned it was difficult and time

consuming to receive any support, and that some of the services offered by VOs were expensive (e.g. talking books like Harry Potter, gadgets to assist independent living). There were also a number of participants who expressed a desire for more volunteers to befriend visually impaired people, to enable them to enjoy social activities.

- **Information provision** (22 participants); participants talked about a variety of different information needs, for example parenting with a visual impairment, employment issues, mobility and independent living skills, computing, and more or clearer information about their visual impairment. Sometimes the coding for this overlapped with other themes since statutory or voluntary services were (or should be) the providers of related information.
- **Visual impairment or other social groups** (13 participants); there were a number of contrasting views expressed about these groups. Some participants did not want to join visual impairment specific groups as they preferred to mix with sighted people or felt that the atmosphere was too 'negative', while others had joined such groups and felt it had been a positive experience.

The participant in the following example talks about the poor quality and coordination of services following registration:

Age 50

Female

Does not live alone

Working age (Not working)

Registered blind

"Well on the negative side I've found the help you get after your initial registration is appalling and I think it's very bad in [county] as a whole. I had an 18 month wait for mobility training which, if I hadn't had family about me, I would have been housebound. I think it's about time they had a national policy that kicked in, that when you were registered you all got the same help on a national scale. What I found was when you are registered you are automatically entitled to a blue badge and a bus pass, mobility training and all the information on groups, but to get all those things you have to apply to each office in turn and give the same information each time and you have to show your registration papers each time which I think is stupid. It should be when the County get your registration from the hospital why don't they give you a box where you get your blue badges in it, your stick, your bus pass and all the leaflets and information all in one pack. Simple! Instead you've got to traipse here and traipse there, and post this and show all of these different officers all the same stuff. It's so inefficient - if it was all done in one place for all disabilities it would be a lot better. There isn't any aftercare at all here [in county]. I haven't had any contact with any of the Council disability officers from at least the late 80s. I could have died by now!"

The following is an example where the participant felt they had received good support from statutory services, both personally and for her son:

Age 47

Female

Does not live alone

Working age (Not working)

Registered blind

"My mobility trainer does all sorts of things, he is brilliant. I've been so lucky through social services. That link for me has been so important and he really has opened up my world. My son has the same eye condition and he is 18, also has Aspergers. Social services input has been very good."

The following participant talked positively about support they had received from a national voluntary organisation, though she laments at the lack of volunteers for befriending:

Age 60

Female

Lives alone

Retirement age

Registered blind

"Best thing that's happened is a listening support group, when you speak over the phone to others. I don't have contact with people except on the phone for that hour when I speak to other people in the support group. It's nice having the company. It's the RNIB 'Talking Support', when people in similar situations can chat to one another. It's really positive and makes a big difference. Big disappointment is the lack of volunteers - want someone to befriend me, in which I could meet them in town."

Whilst some participants talked positively about going to clubs and groups for visually impaired people, others did not want to join groups aimed at visually impaired people; for example:

Age 80

Female

Lives alone

Retirement age

Registered blind

"I don't join groups as people aren't welcoming. I don't want to join a blind club due to the stigma, but I may as a last resort."

Visual impairment awareness of sighted people (103 passages)

Many participants commented on the awareness of sighted people (e.g. work colleagues, service industry staff, the general public) about issues relating to visual impairment and how it can affect visually impaired people. This theme was particularly common amongst the first four age groups, with participants aged 75+ less likely to comment about it.

The majority of the participants who commented felt that the level of awareness of the sighted people was very low, often resulting in negative consequences for them. The following are examples:

Age 29

Male

Does not live alone

Working age (Not working)

Registered blind

“Things that are difficult are stopping a bus. I can’t see the number of the bus. I have been removed from a train for not having a ticket because I couldn’t see the ticket machine and the details of what ticket to buy. The general awareness of other people is poor - just because I don’t have a white stick and guide dog doesn’t mean I don’t have a disability.”

Age 29

Female

Does not live alone

Working age (Working)

Registered blind

“I think one thing I’ve found that is embarrassing, is the way people treat disabled people as if you’re different - have an interpretation of what a visually impaired person needs, but don’t ask you - make assumptions - like [my] mother-in-law who assumes [I] can’t look after the house[...] It’s general awareness really.”

Age 53

Female

Does not live alone

Working age (Working)

Registered blind

“One of the disadvantages is people telling you what you need without asking because we’re all very different and need different things, can’t be lumped altogether. For example [...] few people read braille compared to those who don’t, but they put signs in braille - people should ask what we would like, rather than us being told what we would like. There should be something for everybody. I know they do try hard [but] the people who need to be asked aren’t being asked.”

Attitudes of others (102 participants)

This theme includes participants’ descriptions of incidents where they encountered positive or negative attitudes regarding their visual impairment and circumstances from other people (e.g. from family and friends, work colleagues, medical and other agency staff, service industry staff, and the general public). This theme overlaps with the previous theme “Awareness of sighted people”, since many participants attributed negative attitudes of sighted people to their lack of awareness about visual impairment issues.

In many cases participants described negative incidents where people were rude or unthinking towards them, though in some cases participants felt that many people demonstrated more positive attitudes towards them.

Age 43

Female

Does not live alone

Working age (Working)

Registered blind

“Work - sometimes if you tell a client you are deaf and partially sighted they won’t always take you seriously - think you are thick. Twenty years ago was different. When doing law degree in 1993, disabled people would never have been allowed to represent in court. Today I can - has to challenge judges to get support worker in with her - if they don’t they are discriminating. Employment tribunals are good - they will make adjustments. There are more disabled people going into the legal profession - hard profession for people to get into. Stigma of disability, not what they know. Didn’t want to be segregated at school, so pushed to get into mainstream school. It’s not about being clever it’s about having access to education, the back-up of your family. I still see disabled children today being segregated. At work, am trying to get staff to use darker pens so I can read... Society’s attitudes, because you are disabled they think you are thick. Not my disability I can’t cope with, it’s society’s attitudes. I think people need to be aware that people with disabilities have a useful role to play in society.”

Age 42

Female

Does not live alone

Working age (Working)

Registered partially sighted

“I do think people need to be more aware. Sometimes people’s attitudes are bad. One time I went to a shop – couldn’t see something so asked girl behind counter to help me and she told me to put my glasses on. People can be ignorant. People don’t have a lot of respect for disabled people. I manage at work but sometimes think that there’s a problem - no one ever checks that I can see well enough to do a job - they don’t take into consideration that I’m partially sighted. I just think people need to be more aware and have more respect for disabled people.”

Age 53

Male

Does not live alone

Working age (Working)

Registered blind

“Dealing with other people’s ignorance at times is challenging - they see you struggling to read something and you get the usual unhelpful comments like ‘Shouldn’t you get your eyes tested or something?’ - but I guess it’s the usual sort of things people with disabilities come across. Most people who are aware of my condition are supportive and helpful. Someone who’s completely blind, like David Blunkett for example, with his guide dog - people are instantly aware he’s blind. When you’re registered blind but have some sight you don’t stand out in the crowd fortunately - sometimes you want to stand out, sometimes you don’t.”

Laws and policy issues (26 participants)

This covers a wide variety of issues including discrimination against people with visual impairment. Examples include participants unhappy about having to buy expensive specialist equipment in order to simply get by on a daily basis. Participants gave descriptions of both good and poor service from a variety of statutory and commercial services such as local councils, banks, shops, and perceived treatment by the government generally. Opinions were given about these organisations’ awareness of visual impairment issues, communication (via letters, statements, signage) in accessible formats; ensuring physical access to buildings and discussion about policies such as the Disability Discrimination Act and its effectiveness.

Examples include the following:

Age 43

Female

Lives alone

Working age (Not working)

Registered blind

“I think this DDA needs to kick in a bit more. Apart from the fact people are obliged to give us information in a particular format, you have to ask and push all the time to get it. I’ve just got information from the Blind Housing Association which is specifically for visually impaired people - but info about AGM is in print so majority of tenants wouldn’t be able to read it, so won’t be able to vote. Basically, the only thing I’m quite dissatisfied with, is the way the DDA isn’t taking off.”

Age 69

Female

Does not live alone

Retirement age

Registered blind

"I find problems with banks that do not send me large print correspondence - bank statements are in large print but not anything else and they say nothing can be done. Marks and Spencers are very good. You have to badger companies."

Visually impaired people's awareness of visual impairment (21 participants)

This covers a range of different themes regarding the participants' perceptions about themselves and others with impaired vision. Some participants felt that visually impaired people generally need to be more informed about sight loss and the support that is available. Others talked about their self-perception, e.g. whether they see themselves as a visually impaired or disabled person, sometimes resulting in an avoidance of showing that they have a visual impairment to others. Other participants described how, due to becoming visually impaired themselves, they felt much more aware and tolerant of other people with disabilities and the problems they might experience. This was often cited as being a positive outcome of becoming visually impaired.

Here is one example of comments made:

Age 24

Male

Lives alone

Working age (Not working)

Registered blind

"I'd like to say that I'm currently training to be a visual rehab worker [...]. One thing that I think is very important is the need for awareness training for visually impaired people - not just knowing about your rights and benefits but also knowing what it means to be visually impaired and how to make best [use] of your sight. For example, just because it takes longer for you to do something doesn't mean that you do it any worse. Awareness training is important for the non-visually impaired but equally important for visually impaired people. I've discovered more things about my condition since doing this course as well as the need to be on the lookout for new things and to keep up-to-date. Since doing this course, as well as getting training for the actual job, I have been learning new things about me... I think it is very important that people with visual impairment know how to articulate their visual problems and get the right kind of help. You hear people say 'Oh he's just pretending to be blind' because they don't realise that there are different kinds of visual impairment. It is important that visually impaired people know how to articulate their visual impairment to service providers."

5 Findings from the key informant interviews

5.1 Rationale

As described earlier in the report, all participants were sent information packs about the project inviting them to participate. Consent forms were enclosed, which enabled the addressee to indicate whether or not they wished to take part in the project. The majority of the consent forms returned were straightforward, i.e. the addressee was able personally to indicate their preference. However, a number were returned with annotations from a third party indicating that the addressee was unable to take part in the project due to additional health or learning difficulties.

As the underlying philosophy and framework of the project is one founded in participation, aiming to 'minimise exclusions' (Ferrucci, Gualnik, Studenski, Fried, Cutler and Walston 2004, p.628), the research team was prompted to devise an alternative approach that would ensure this group of people were included in the project. (See Corcoran, Douglas and Pavey forthcoming, for a full account.)

It was decided to invite a third party who was 'close' to the visually impaired person, to speak for and on their behalf; this could be a relative, friend, or someone who was caring for the participant in a professional capacity. We were then able to use their knowledge of the visually impaired person to include details of their lives and circumstances within the project.

We refer to this third party as a key informant (KI) and to the visually impaired person that they are speaking on behalf of as the 'co-participant'.

5.2 The KI survey instrument

The survey instrument used for this part of the Network 1000 project was very similar to the non-KI survey, although the questions were re-worded to allow the KI to give their opinion of the needs and circumstances of the co-participant. In order to try and replicate the main survey further, we also added questions that gave the KI the opportunity to reflect on whether they felt that the co-participant's opinion would be the same as theirs. As a result of this more reflective position, the KI survey had more open-ended questions than in the non-KI survey.

Whilst the research team were aware that inviting a third party to be a key informant was not a perfect solution, it nevertheless enabled these participants to be included in the project as their 'voices' would not otherwise have been heard. Consequently, the data from this survey has been analysed separately, although comparisons with the main survey are made where possible.

5.3 Method of analysis and reporting protocol

As described above, the data generated from the survey is more qualitative due to the small numbers of participants involved (a total KI sample of 47 key informants on behalf of 47 co-participants). There is also a likelihood of a response bias in terms of sampling (i.e. there may have been many more potential participants unable to take part personally, whose carer did not contact us or indicate why they would not be taking part). It is also important to note that much of the data collected is more subjective, reflecting the KI's opinion regarding the co-participant's views or opinions on a topic in particular, but also regarding other information, e.g. what the co-participant can or cannot see.

For these reasons, the findings relating to the key informants and co-participants are *not* statistically generalisable to the wider visually impaired population. Therefore, the following description of the findings restricts itself to reporting numbers only and has adopted a more qualitative style than that relating to the main sample. The terms 'population' and 'people' have been avoided within the text to reinforce the concept that these findings should not be applied to the wider visually impaired population.

5.4 Details about the KIs and the co-participants

In all but 6 cases, the KI was related to the co-participant, most commonly one of their parents (n=26). In 12 cases the KI was the child of the co-participant. Two of the KIs were partners of the co-participant, another a sibling. The remaining 6 KIs were either professionals (n=5) involved with the co-participant, or a friend (n=1).

The co-participants were unable to take part in an interview directly due to various learning and/or communication difficulties. These included various conditions and syndromes, for example Down's syndrome, Moyamoya syndrome, memory loss, and dementia, among others. The KIs told us that whilst the majority of the co-participants could communicate with others using speech to some extent (n=32), 14 of the co-participants communicated solely or additionally in other ways, for example using body language (n=5), sounds (n=5), signing (n=3), finger spelling (n=1), and the use of switches attached to a wheelchair (n=1). It was reported that six co-participants did not communicate in any obvious way.

Learning and/or communication difficulties were acquired by the co-participants at various stages of their lives. These were collapsed into two key groups: those whose onset of their learning and/or communication difficulty was congenital or post-natal (i.e. in early childhood), and those whose onset was as an adult. A key variable was thus created that separated the co-participants into one of these two key groups:

- thirty co-participants' learning and/or communication difficulty was congenital or post-natal, most of whom (n=28) were aged 18-49 at the time of interview;
- seventeen co-participants acquired their learning and/or communication difficulty as an adult, all of whom were aged 50+ at the time of interview.

This variable is a useful guide to the complex needs and circumstances experienced by these co-participants beyond their visual impairment, and may be of use to policy makers and service providers when planning for care at different stages in the life cycle. Where appropriate, this variable is used throughout this section to illustrate the data collected. It would have been preferable to produce tables splitting the data by this, and other, key variables (as with the n=960 sample), but the low numbers of key informants and co-participants in the sample does not allow this.

In terms of age at the time of the interview, most of the co-participants were distributed in either the younger age group 18-29 (n=21) or the oldest age group 75+ (n=17). Seven were aged 30-49, one was aged 50-64 and one was aged 65-74. At the time of interview, co-participants ranged in age from 19 through to 100 years of age.

Unlike the main sample, the co-participants were not evenly split in terms of sex; 29 were female, 18 were male. There was an uneven distribution of age, with the majority of males (n=13) aged 18-29, whilst the females were aged 75+ (n=15), or between 18-49 (n=13). Interestingly, the majority of males (n=15 of 18 in total) had a congenital/post-natal onset of learning and/or communication difficulty, whilst the females were more evenly split between onset in childhood (n=15) and onset in adulthood (n=14).

In terms of registration status, 29 were registered as blind and 15 as partially sighted, whilst the KIs were unsure about the status of the remaining 3 co-participants. Of those who were registered blind, seven were thought to have been previously registered as partially sighted.

Twenty-seven of the co-participants were single and had never been married, all of whom acquired their learning and/or communication difficulty congenitally or during early childhood. Four were described as married or living with a partner, with a further 13 who were widowed (of whom all but one was aged 75+), and two who were divorced. Ten of the co-participants had children, none of whom were under the age of 16. As would be expected, all of these co-participants acquired their learning and/or communication difficulty during adulthood, and were now aged 75+.

Other key variables include ethnicity, country of birth, their first language, and religion. As with the main sample, the ethnicity of the majority of the co-participants was described as White UK (n=44); the others were described as White Chinese, White European, and Caribbean African. All but one of the co-participants were born in the UK. English was the first language of all but two of those who could communicate via speech (n=32); the first language of the two other co-participants was French and Welsh respectively. In terms of religion, the majority (n=40) were described as Christian, whilst five were described as not having a religion.

5.5 Detailed survey findings from KI interviews

Details about the co-participants and their homes

When asked whether the co-participant had more than one home or place of residence, only five KIs said that they did. In all five cases, the two places of residence included the family home for either part of the week or a period of time, with the second place of residence being accommodation offering respite care, boarding at an educational establishment or a residential home for people with disabilities.

Over half (n=25) of the KIs lived with the co-participant about whom they were being interviewed, and in all but two of these cases they were related, most commonly the parent (n=19) of the co-participant.

In terms of tenure, only four of the co-participants owned their home outright, all of whom were aged 75+. Three were living in a home with the KI that was being bought with a mortgage or loan, whilst 12 co-participants were renting, the majority (n=9) of whom rented from a housing association, co-operative or charitable trust. In most cases the rented accommodation was provided unfurnished. Twelve further co-participants were living in their family home, of whom all but one was aged 18-29.

The majority of co-participants lived in either a detached, semi-detached, or terraced house (n=26) or institutional accommodation (n=13). The co-participants who lived in institutional accommodation were fairly evenly split between those whose onset of learning and/or communication difficulty was congenital or post-natal and those whose onset was during adulthood (n=6 and n=7 respectively); these co-participants tended to be older (65+, n=9). The institutional accommodation was provided either by local authorities (n=2), charities (n=4) or private organisations (n=2), though in five cases it was unclear.

In terms of household composition, only six of the co-participants lived alone, three of whom lived in sheltered accommodation with some support for daily living provided. The others lived with family members (n=24), or non-relatives (n=16, all of whom lived in institutional accommodation with other residents).

Just over half of the KIs (n=27) described themselves as the main carer of the co-participant, most of whom acquired their learning/communication difficulty congenitally or post-natal (n=21 compared to six who acquired it during adulthood). When asked approximately how many hours per week they cared for the co-participant, the majority stated that it was 24 hours a day, seven days per week. These KIs tended to be related to the co-participant. Some of the KIs described that they and the co-participant received respite care, but this was often for short periods of time or sporadic. Additionally, some of the co-participants attended day centres or day courses without the KI.

The five KIs who described themselves as professionals who worked with the co-participants, included a support worker employed by a charity for visual impairment, a

Matron of the residential home in which the co-participant lived, and other employed carers (employer not specified).

Of the 20 KIs who were not the main carer, the majority (n=16) described the main carer as being a professional involved with the co-participant. These main carers were described as staff in residential homes or supported accommodation, or professionals who visited the KI in their home to assist them with daily living skills, such as preparing meals and personal care tasks.

Vision and visual impairment

It is important to note that, whilst similar, the questions relating to visual impairment in the KI survey sought the KI's *opinion* about the co-participant's vision, since they would not be in a position to give a first-hand account.

Just over half (n=26) of the co-participants wore glasses or contact lenses at least some of the time. The reasons given included reading at near distance (n=6) and other close-up uses (n=13), distance vision (n=13), cosmetic reasons (n=2), and in some cases simply out of habit (n=3). As with the main sample, there were no notable differences in terms of age.

The six functional vision questions were also posed to the KIs, again with the qualifier "in your opinion". The six questions enabled the 'scoring' of the participants' level of functional vision on a seven-point scale (0-6) which is summarised below:

- (level 0) no light perception – four co-participants;
- (level 1) can tell by the light where the windows are – 12 co-participants;
- (level 2) can see the shapes of furniture in a room – 13 co-participants;
- (level 3) can recognise a friend if close to their face – five co-participants;
- (level 4) can recognise a friend at arm's length away – three co-participants;
- (level 5) can recognise a friend across a room – five co-participants;
- (level 6) can recognise a friend across a road – four co-participants.

Fourteen of the KIs mentioned that it was difficult to tell whether the co-participant could see at certain levels, one of whom said they were unable to say for certain with regard to any of the levels (i.e. was unsure whether the co-participant had even light perception).

In terms of eye conditions, as would be expected, the co-participants were reported to have an array of conditions, though in some cases (N=11) the KI did not know. Macular degeneration was relatively common (N=10), and in all cases this was associated with co-participants whose learning and/or communication difficulties were acquired in adulthood (this makes sense given this group is made up of people who are generally over the age of 50). Another commonly reported condition was cataracts (N=14).

Commonly (N=33), KIs provided additional information about the condition. Post-hoc analysis of this data again revealed an array of specific conditions as well as symptoms and signs (e.g. nystagmus and field loss). Not surprisingly a number of

childhood and genetic conditions were described for co-participants whose learning and/or communication difficulties were acquired in childhood (e.g. related to premature birth, rubella, birth injury and near cot death).

The KIs were asked how old the co-participants were when it was realised that their sight problem was affecting everyday things. For the majority of those whose learning and/or communication difficulty developed congenitally or post-natally (n=26 of 30 in total), their visual impairment was first realised during childhood (i.e. under 15 years old). Of the remaining four co-participants with a congenital/post-natal onset of learning/communication difficulty, the visual impairment was first noticed during adulthood (n=2), or the KI was unsure about the time of onset (n=2). Of the 17 co-participants whose learning and/or communication difficulty was acquired during adulthood, the visual impairment was also first noticed when they were an adult in every case.

The KIs were most commonly the person who first noticed that the co-participant had a serious problem with their eyes (n=17), particularly where the co-participant had a congenital/post-natal learning and/or communication difficulty (n=15). In eight other cases it was reportedly first noticed by an optician or hospital eye doctor / specialist, a medical professional (n=7), or by the co-participant themselves (n=5, all of whom acquired their learning/communication difficulty in adulthood). In 6 cases the KI was not sure or could not remember.

The majority of KIs (n=34) felt that the co-participant did not suffer any pain or discomfort in or around their eyes at all, and of those who did, it was described mainly as mild or moderate (n=9), though two KIs felt it was 'severe'. Similarly, the majority (n=30) felt that the co-participant's difficulty with their vision was about the same as it was a year earlier, whilst 11 felt that their visual difficulty had worsened (all of whom were aged 75+, and had acquired their learning/communication difficulty during adulthood).

Reading and access (including Low Vision Aids)

The KIs were asked whether, as far as they could be aware, the co-participant could read different sizes of print without using low vision aids other than regular glasses/contact lenses, if applicable:

- only two co-participants could see well enough to read ordinary newspaper print;
- seven co-participants could see well enough to read a newspaper headline (but not ordinary newspaper print);
- one could see well enough to read large print but not the smaller sizes of print;
- six KIs were not sure, and 13 said the questions were not applicable as the co-participant could not read at all due to their learning and/or communication difficulty.

When asked about the different ways that the co-participant actually read in practice, KIs reported the following:

- the most popular method was listening to tapes, with 21 doing so;
- this was followed by having someone to read to them, n=20;
- 13 co-participants read print (ordinary or large);
- only three read braille, one used a form of computer speech output, and none read Moon;
- 15 KIs said that the co-participant did not read using any of these methods.

There were no significant differences in terms of registration status or time of onset of the co-participants' learning/communication difficulties.

The eight co-participants who used low vision aids, whose onset of learning/communication difficulty was mainly in adulthood (n=6), mainly used hand-held magnifiers with or without a light (n=7). With regard to lighting, 12 were reported to use better lighting for any reading tasks that they did.

In terms of communicating in writing with sighted people, the vast majority of KIs (n=33) reported that the co-participant did not communicate in writing at all. A few communicated in handwriting (n=7), by computer (n=1), or by text messaging (n=1). Most of those who did write used it for specific short tasks.

Health and hearing

Just over half of the co-participants were registered as disabled (n=24) the majority of whom were in the 18-29 age group (n=14). Ten KIs were unable to say with certainty whether or not the co-participant was registered as disabled. For the majority of those who were registered disabled the onset of their learning and/or communication difficulty occurred in childhood (n=19).

Twenty KIs told us that the co-participant had a hearing problem, about half of whom were in the 75+ age category (n=11). There were no significant differences between co-participants in terms of their age of onset of learning and/or communication difficulty (n=10 for both). Nine of the co-participants with a hearing impairment had a hearing aid and again the majority of these (n=7) were in the 75+ age group.

As in the main survey, we asked the KIs whether this difficulty with hearing was greater or less than a year earlier. About half (n=10) thought that the co-participant's hearing loss was about the same, although six KIs felt that the co-participant's hearing difficulty was greater.

As would be expected, the co-participants had a range of additional health problems other than their visual impairment and all of the KIs reported at least one other health issue. Some of these were age-related e.g. arthritis (n=9) and heart conditions (n=5) occurring mainly in the 75+ age group and were also more closely linked to those whose learning and/or communication difficulty had occurred as an adult. Other health issues included the following:

- skeletal system (n=19), mostly those in the youngest age group of 18-29 and whose onset of learning and/or communication difficulty was as a child;
- nervous system (n=25), mostly those in the youngest age group of 18-29 and whose onset of learning and/or communication difficulty was as a child;
- digestive system (n=11), no distinction between age or time of onset of learning/communication difficulty;
- cancer (n=3) was only reported by those aged 75+ and whose onset of learning and/or communication difficulty was as an adult;
- learning difficulties (n=30), in all but one case, the co-participant's learning and/or communication difficulty occurred at or near birth;
- dementia (n=8), in all but one case participants were aged 75+.

Employment

The KIs were asked to describe the employment status of the co-participants:

- 18 were described as retired from paid work altogether, all of whom were of retirement age at the time of the interview;
- 14 were described as long term sick or disabled, of whom all but one had acquired their learning/communication difficulty at birth or post-natal;
- seven were described as unemployed;
- four were students;
- of the four KIs who described the co-participant's status as 'something else', three said that the co-participant would never really be able to work, certainly not unsupervised, and the other worked unpaid for a religious charity that employs people with learning difficulties;
- none of the co-participants were in paid employment or self-employment.

The KIs told us that of those who were described as unemployed, the majority (n=6) were 'not seeking paid work and did not want to work'. When asked why this was the case, four of the KIs said that nothing would help the co-participant get a job, one of whom felt that the co-participant had no concept of work or working. Other reasons given were: the visual impairment (n=3); general health problems/other disabilities (n=2); and mobility difficulties (n=1). The KIs were asked whether they thought the co-participant would share their opinion; in response to this, four of the KIs explained that the co-participant would not understand the concept of work or working, and would not therefore have any opinion about it.

The remaining unemployed co-participant was described as not seeking paid work, but would like to work. The KI felt that the main barrier to working was a lack of education/training, though when asked whether they thought the co-participant would share that opinion, they said, as before, that they would not have any concept of what employment means.

All of the KIs (n=7) felt that it was unlikely or very unlikely that the unemployed co-participant would begin paid work in the next 12 months.

Seventeen of the co-participants had worked in paid employment in the past. As would be expected, these were all participants who acquired their learning and/or communication difficulty during adulthood. The types of employment that participants had been involved in varied from clerical, retail and factory positions to self-employment in the construction industry or owning and running small retail businesses. The most commonly cited reason for leaving their last paid job was to take retirement (n=6), followed by health reasons (n=4), to look after family/other person (n=2), following marriage (n=2), and moving from the area (n=1). In the remaining cases, the KI did not know the reason.

Finance

As with the main sample, the KIs were asked about the different types of income that the co-participants received. Once again the actual number receiving different income types may well be higher than that reported, since the interviewees were not prompted on individual types of income. Additionally, the KIs might not have been aware of the co-participant's financial circumstances (particularly if they were not the main carer or were not involved in overseeing their financial affairs), and thus would have been unable to answer these questions accurately.

As would be expected, all of the co-participants of retirement age received the State Retirement Pension. Only two of these received a pension from a previous employer, and seven were also in receipt of a pension from a spouse's previous employer. Five participants were reportedly receiving Pension Credit.

All the co-participants under the age of 68 (n=30) were reportedly receiving one or both components (mobility and care) of the Disability Living Allowance (DLA); all but one of these co-participants had acquired their learning/communication difficulty during childhood. A further 11 participants were receiving Attendance Allowance, all of whom were aged over 75. Nine co-participants aged between 18-49 received Incapacity Benefit, seven received the Severe Disablement Allowance, and one received the Blind Person's Tax Allowance. According to the KIs, five of the co-participants did not receive any disability allowances, benefits or tax credits at all.

None of the co-participants were receiving Job Seeker's Allowance, despite KIs describing the status of four of the co-participants as "unemployed"; this probably reflects the fact that these co-participants would be unable to independently participate in paid employment due to their learning and/or communication difficulties. Eighteen of the co-participants were in receipt of Income Support, all of whom were in the two youngest age groups and acquired their learning/communication difficulty congenitally or post-natally.

The majority of co-participants (n=28) did not receive any housing benefits or allowances. Of those who did, 15 received council tax benefit/allowance, 6 received housing benefit or a rent rebate, and five received the annual heating allowance (all of whom were aged over 75).

A number of other benefits and types of income were mentioned by the KIs. For example, six of the co-participants received a contribution towards the cost of their

care (whether living in a residential or care home, in supported housing, or their own homes) from their local authority. This was usually paid for by social services though in one case it was jointly funded by health and social services. Two KIs mentioned that they received free car tax for the family owned vehicle that they used to transport the co-participant. Finally, five KIs mentioned that the co-participant received income from investments that they held, e.g. interest on stocks and shares or building society accounts.

When asked whether the co-participants had any savings, 27 of the KIs confirmed that they did, most of whom were aged 75+ (n=15, plus seven in age group 18-29 and five in age group 30-49). Of these, 15 had savings of at least £3000 or more. Only seven of the co-participants were said to save on a regular basis, whilst eight reportedly saved from time to time. Six co-participants had savings but did not add to them anymore, and in one case, they were being used to fund the co-participant's residential care.

When asked whether the co-participant's savings were mainly long term for the future or short term, most KIs described them as being for either the short term (for things that they needed now or unexpected events) (n=12) or for both the long and short term (n=11).

As with the main sample, the KIs were asked their opinion as to how well the co-participant was managing financially. Twenty-one KIs described the co-participant as "living comfortably", followed by 12 who said they were "doing alright", and a further 11 who described their situation as "just about getting by". When asked whether or not the co-participant (or their family, if living together) had gone without anything or had to use anything less than they needed to within the previous year, the majority (n=31) said that there was not anything. Of those who specified something, the most common was holidays (n=6), followed by specialist equipment (n=3), home improvements (n=3), and utilities such as gas/electricity in the home (n=2). Other things that were mentioned included clothing, hobbies/activities, leisure/activities outside the home, physiotherapy, replacing an old vehicle, and respite care.

In relation to accommodation, only two co-participants (and/or their residing families) were described as having had difficulty paying for their accommodation within the previous year.

Independent Living Skills

As with the main sample, the KIs were asked whether the co-participant found any daily or household tasks particularly challenging. The most common response was that the co-participant did not really do any such daily or household tasks (n=18). However, following prompting, 16 of the co-participants were described as having difficulty getting around their home, 15 experienced difficulty with preparing a meal, 12 found general household cleaning tasks difficult, and 12 had difficulty with personal care tasks.

In terms of support, the majority of co-participants (n=37) were reported to receive help with these daily and household tasks from somebody that they lived with, most

commonly from a family member (n=24), though 13 received support from a professional live-in carer (most commonly staff in residential homes). Similarly, a number of the co-participants (n=31) received support for their daily living from people living outside of their home. Once again this outside help was often from family members (n=13). Support from other individuals was also common, however. Thirteen co-participants received paid help (e.g. home-help funded by social services, privately employed individuals), six received help from people working/volunteering for charities, five received direct help from social services employees (e.g. social workers, rehab officers), and four were helped by friends or neighbours.

Travel, transport and mobility

The KIs told us that 33 of the co-participants went outside their homes at least once a week, most of whom had acquired their learning/communication difficulty at birth or during their childhood. Nine people went out less than once a month and three people, all aged over 75, never left their home. Unsurprisingly those that went out the most were at the younger ends of the age groups.

As in the main survey, by far the most used mode of transport for all age groups and regardless of onset of the learning/communication difficulty, was private car (n=30), followed by a minibus (n=8) provided by, for example, a local authority, day centre or college. Other modes of transport reported by the KIs were relatively rare and included:

- use of public buses (n=7);
- walking regularly (n=5);
- being taken outdoors in a wheelchair (n=5);
- adapted van for use with wheelchair users (n=5);
- ambulance for hospital visits (n=2);
- taxis (n=2).

We asked the KIs what were the main purposes of the co-participants' journeys. For most, the main purpose was to participate in some form of leisure or hobby activity (n=35), followed by visiting the shops or going shopping (n=22). Other common reasons for travelling included visiting friends (n=7) and the hospital or doctor (n=5). As would be expected frequency of travel were greatest for those in the youngest age group of 18-29. As the majority of co-participants lived with their families (n=23), it was to be expected that visiting family was reported as an activity by only a few KIs (n=3), all of whom were aged 50+.

We also asked the KIs if they thought that the co-participant should leave their home more often. Although 25 KIs felt that they should, 17 KIs felt the co-participant should not go out more often. When we asked the KIs why they said this, 10 felt the co-participant went out enough already (five of whom were in the youngest age group). Other KIs identified some within and beyond person factors that mostly related to the KIs perception of the co-participant's needs (n=8). For example:

"We've asked her and she doesn't want to. She feels safe there [at home]."
A friend of the co-participant who was aged 91, female, with an adult acquired learning/communication difficulty.

"[The co-participant] has dementia and doesn't really know whether she would like to go out or not."
A child of the co-participant who was aged 100, female, with an adult acquired learning/communication difficulty.

"If anything, [the co-participant] would like to go out less!... Judgements like this are really hard – when he goes out he does enjoy it and I think his quality of life is enhanced by when he goes out."
A professional involved with the co-participant who was aged 37, male, with a congenital/post-natal learning/communication difficulty.

To help them to consider their responses, the KIs were asked "As far as you can tell, does [the co-participant] think the same?" Of the 21 people who responded, just over half (n=12) felt they would feel the same, although there was some interesting reflection:

"I would think that's his view. Difficult to tell – if he really doesn't want to go out he doesn't go out. We don't follow the time-table at all costs."
A professional involved with the co-participant who was aged 37, male, with a congenital/post-natal learning/communication difficulty.

"I think so – if you ask him he'd say, "Yes" and [the co-participant's family] would take him, but [he] doesn't sit there and complain about wanting to get out more."
A parent of the co-participant who was aged 19, male, and had a congenital/post-natal learning/communication difficulty.

We asked the 25 KIs who felt the co-participant *should* go out more often, what would help them to do so; 11 KIs said that an important factor was the need for the co-participant to be accompanied. This outweighed other factors such as the co-participant's visual impairment (n=1), their mobility (n=1), or their general poor health (n=5). However, when the question was rephrased to "Put another way, what stops [the co-participant] from getting out of his/her home more often?", the KIs were more likely to indicate that poor general health was the greatest barrier (n=10), followed by the need to be accompanied (n=7). Related to the frailty of some of the co-participants, the weather was an important factor dictating whether the co-participant went out or not:

"She can't take the cold, so would need an improvement in the weather."
A parent of the co-participant who was aged 19, female, and had a congenital/post-natal learning/communication difficulty.

"The weather would need to be warmer. He has his heating on at home all the time."
A child of the co-participant who was aged 92, male, and had an adult acquired learning/communication difficulty.

Other important social influences beyond the person that were perceived as a barrier to going out more often, were the cost and availability of services and activities (n=6). Within-person barriers were very individual and related specifically to the circumstances of the co-participant, for example:

"[The co-participant] must learn to control [his] behaviour."
A parent of the co-participant who was aged 19, male, and had a congenital/post-natal learning/communication difficulty.

"She has lost the incentive to go out – [I] wonder if she is slightly agoraphobic."
A child of the co-participant who was aged 95, female, and had an adult acquired learning/communication difficulty.

In keeping with the reflective nature of the survey used with the main sample, we asked the KIs to consider their own responses to the earlier questions by asking *"We've discussed what you think about the [co-participant] getting out more often. As far as you can tell, does [the co-participant] think the same?"* Most of the key informants felt that the co-participants would agree with their thoughts relating to getting out more often, though three were not sure what the co-participant would think. Some of the comments are presented below:

"Yes I do. She always shows such pleasure. If she's a little down and you take her out it lifts her spirits so it's lovely for her to get out, but it is difficult."
A parent of the co-participant who was aged 19, female, and had a congenital/post-natal learning/communication difficulty.

"I don't know – she's never really said 'I want to do so-and-so' – she doesn't really bother."
A parent of the co-participant who was aged 24, female, and had a congenital/post-natal learning/communication difficulty.

"No, I think he's quite happy – we're out every day. The days he's home he falls asleep in the chair. Sometimes he gets restless and bored but he wouldn't know what he wanted to do."
A partner of the co-participant who was aged 50, male, and had an adult acquired learning/communication difficulty.

Computer use

As with the main sample, we asked the KIs to tell us about the co-participants' use of computers. The majority (n=30) reported that the co-participant did not use or had

never used a computer. Of the 16 who did, they mainly used computers for word processing (n=7), games or fun activities (n=10), surfing the net (n=2) or for photographs (n=1). All of the computer users were aged under 50 and had acquired their learning/communication difficulty either at birth or post-natally. Nearly half of the co-participants had access to computers either in their home (n=22) or elsewhere such as at the library or in a day centre (n=24).

We asked the KIs if they felt that the co-participant could use computers more than they did currently. The majority (n=29) felt that they could not, although some (n=7) were unsure. When we asked why they felt this, the most common reasons given were as follows:

- problem with general health or other disability (n=14);
- problem related to visual impairment (n=13), most of whom were in the 75+ age group (n=11);
- co-participant would not be interested (n=7);
- accessibility/availability of equipment (n=4).

The 10 KIs who felt the co-participant could use a computer more were asked what they felt would help or what stopped the co-participant; the reasons given were mainly focussed on the cost, availability and accessibility of equipment (n=5).

We asked the KIs if they thought that the co-participant would agree with their opinion. Four felt they would think the same way, whilst the remaining seven answers were rather ambiguous, for example:

"He wouldn't be able to tell me that – I just feel it would be another activity for him to do."

A parent of the co-participant who was aged 19, male, and had a congenital/post-natal learning/communication difficulty.

"Hard to tell."

A parent of the co-participant who was aged 19, male, and had a congenital/post-natal learning/communication difficulty.

Education

KIs were asked a number of questions relating to the past educational experiences of the co-participants. The KIs of 26 co-participants whose onset of learning and/or communication difficulty had been in childhood were asked about the type of educational establishments they had attended in the past (note that more than one response was possible):

- two had been to schools for visually impaired pupils/students (avoid The visually impaired);
- 20 had attended special schools for other children with other disabilities;
- four attended classes in mainstream schools with support;
- two went to a mainstream school with no extra help;

- four attended or currently attend a special college for visually impaired students;
- six attended a mainstream college of further education;
- two had no formal education.

Of those co-participants whose learning/communication difficulty and onset of visual impairment was during adulthood, only three had been in education since their sight loss.

The majority of co-participants (n=29) did not have any qualifications from school, college or university. Six people whose onset of learning and/or communication difficulty occurred in childhood received some form of certificate of achievement or award relating to life skills or in recognition of participation in activities. One co-participant had achieved an NVQ.

Of the remaining eight co-participants with qualifications (whose learning and/or communication difficulty occurred in adulthood):

- two had first degrees;
- one a teaching qualification;
- two a nursing or other medical qualification;
- five had other qualifications, e.g. shorthand, engineering qualifications.

Where applicable, the KI was asked whether the co-participant was currently doing (or likely to do) any other courses (formal or otherwise). Of the 15 KIs that were asked, nine co-participants were currently studying on courses that covered various 'life skills' that were often designed for people with special needs; the subjects currently being studied included:

- Gardening
- Looking after animals
- Computing
- Cooking/catering
- Work experience in a café
- General living skills (e.g. handling money, learning letters and writing, cookery, art, P.E.)

Leisure

In this section we asked the KIs to tell us how the co-participant spent their spare time both at home and beyond the home.

With reference to activities within the home, as in the main survey, multiple responses were possible and included some prompted and unprompted responses relating to listening/watching TV, listening to the radio or music, and reading or listening to talking books. For ease of reference, the unprompted and prompted responses have been combined and are reported below:

- 35 co-participants listened to or watched TV and videos/DVDs, mostly by those aged under 50 (n=23);
- 39 co-participants listened to the radio or to music, once again mainly by those under 50 (n=24);
- 24 co-participants reportedly read/listened to talking books.

Further activities within the home that were reported by the KIs included:

- talking with family or friends either in person or on the telephone (n=15);
- resting or sleeping (n=6);
- using the computer or internet (n=4);
- playing card or board games (n=4);
- gardening (n=3);
- arts, crafts and handicrafts (n=3);
- knitting and/or needlework (n=3);
- cooking (n=3).

Other activities within the home included engaging in 'pampering' or playing/being alone, singing, or looking at the Christmas lights (n=13). One co-participant reportedly did not do any activities within the home.

We also asked the KIs to tell us what the co-participants did in their spare time outside of their home. Overall, activities that required some mobility or were conducted away from the co-participant's home or place of residence were generally experienced by those aged under 50, and those who acquired their learning/communication difficulties during childhood. When reporting this section, the prompted and unprompted responses have once again been combined, and include the following activities:

- going shopping (n=26);
- attending meetings for local groups/clubs/voluntary organisations (not VI specific) (n=21);
- going for a drink at a pub or a club (n=21);
- attending leisure activity groups such as evening classes, keep fit, yoga (n=8);
- religious activities (n=13);
- attending meetings for clubs or groups for visually impaired people (n=2);
- only two of the co-participants participated in some form of voluntary work.

Further popular activities included:

- swimming (n=15);
- having a meal in a restaurant, café or pub (n=15);
- outdoor trips (n=14);
- walking (n=13);
- going to the cinema (n=9).

Seventeen KIs mentioned other activities, which included sport or social activities such as bowling or visiting friends. Eight co-participants, who were almost exclusively

in the 75+ age group (n=7), reportedly did not take part in any activities outside of the home.

5.6 Summary of survey findings from KI interviews

The visually impaired co-participants in the sample were from a variety of backgrounds and different ages. All had some form of visual impairment that met registration criteria. A variety of different levels of functional vision were reported by the key informants. All of the co-participants also had some level of learning and/or communication difficulty. Again this varied across the sample. Nevertheless, the co-participants tended to fall into those whose onset of learning and/or communication difficulty was congenital or post-natal (i.e. during childhood) and those whose onset was in adulthood.

The co-participants whose age of onset of learning and/or communication difficulty was in childhood tended to have the following characteristics:

- were younger (generally between 18-49 years old);
- onset of visual impairment was in childhood;
- had a range of childhood and genetic conditions that caused their visual impairment;
- often lived with a parent (who usually provided at least some of the care, if not all);
- sometimes lived in individual, supported accommodation;
- were often described as being single/never married;
- were often registered as disabled;
- had a variety of additional health problems or disabilities including (in particular) hearing impairment, and conditions related to the skeletal and nervous system;
- in terms of employment status were often described as long-term sick or disabled, or unemployed, or sometimes as students;
- were sometimes studying on courses for people with special needs covering various life skills;
- usually received one or both components of the Disability Living Allowance (DLA);
- received additional special educational needs support at school;
- usually went outside their homes at least once a week;
- sometimes used a computer, mainly to play games or fun activities;
- often took part in a variety of activities beyond the home.

Co-participants whose age of onset of learning and/or communication difficulty was in adulthood tended to have the following characteristics:

- were older (50+ years of age, and usually older);
- onset of visual impairment was usually in adulthood;
- often had age-related visual conditions;
- often lived in institutional accommodation, for example a residential home;
- sometimes lived with a spouse or grown-up child (who usually provided at least some of the care);

- were often widowed;
- had a variety of additional health problems or disabilities which were often age-related (e.g. arthritis, heart condition, hearing impairment);
- were sometimes described as having dementia;
- a distinct exception was a co-participant whose learning/communication difficulty and visual impairment were the result of an accident;
- were often described as retired from paid employment (though had worked in the past);
- were often in receipt of the Attendance Allowance;
- never used a computer;
- did not leave their home very often, if at all;
- rarely took part in activities beyond the home.

5.7 Open question: what is important to the co-participant?

As with the main sample, the majority of questions were based upon pre-determined topics, and encouraged the KIs to express their personal opinions about the co-participant and their circumstances, and then consider whether they thought the co-participant would share their view. A 'catch-all' question, similar to that used with the main sample and reported earlier in the section "Analysis of open ended question" was posed to the KIs, which asked them to try and describe the co-participant's thoughts regarding their visual impairment and how it affects their life:

"We have spent some time talking about [the co-participant], and different aspects of his/her life. I wonder if we could spend a final minute or so to talk about things in relation to [the co-participant's] visual impairment that he/she thinks is important - it could be something positive or negative in the past or something that's happening now. I realise this is difficult, but we are trying to get [the co-participant's] take on things. So importantly, it's what [the co-participant] thinks."

A variety of illuminating responses were given, some of which will be presented as verbatim quotes (presented in *italics*).

A number of KIs talked about the practical difficulties that the co-participants faced, for example in getting around and avoiding obstacles, or carrying out everyday tasks around the home. In some cases, this led to frustration for the co-participant, for example:

"It's like we've been doing Christmas cards – she gets frustrated as she can't write envelopes as the postman couldn't read it... She says she wishes she was normal. Even like wrapping Christmas presents, she can't do it neatly so gets frustrated. She needs help but doesn't want you to help her."

A parent of the co-participant who was aged 24, female, with a congenital/post-natal learning/communication difficulty.

Some of the co-participants who acquired their learning and/or communication difficulty in adulthood also appeared to experience frustration due to their circumstances; for example:

"That she cannot look after herself; that she can't do what she used to 25 years ago. That's on her mind all the time. That she cannot see. She tells us that, in fact she tells us every time we see her that, "Do you realise that I cannot see?"... She doesn't like it one little bit".

The child of a co-participant who was aged 92, female, with an adult acquired learning/communication difficulty.

Many of the co-participants who acquired their learning and/or communication difficulty and visual impairment in adulthood were also said to miss doing various things they had been able to do before these changes in their life, for example reading and other activities like knitting.

Some of the KIs talked in a much more positive way, for example that the co-participant coped very well with their sight problem and seemed very happy in themselves. One KI talked about the things that her daughter enjoyed that were relevant to her and her visual impairment, for example having a variety of tactile possessions to handle.

A number of the KIs, however, found it very difficult to answer the question, since the co-participant did not ever express their feelings about their visual impairment and circumstances due to their learning and/or communication difficulty; for example:

"Oh gosh, that's a rough question. What do I think would be important? I haven't got a clue. The only way you can do this is to watch [the co-participant] closely – she talks to herself all the time [by signing], but I still don't get it."

A parent of a co-participant who was aged 32, female, and had a congenital/post-natal learning/communication difficulty.

"Hmm... I can't really answer that one. I can't imagine what she would find difficult about it. I know that, like most elderly people, she needs the comfort of routine and things have to be done in the same way, the same every day. It's the security thing."

A friend of the co-participant who was aged 91, female, with an adult acquired learning/communication difficulty

A number of other KIs also commented that avoiding any change to their routine was important to the co-participant, and this appeared to be of importance regardless of whether or not the learning and/or communication difficulty was acquired congenitally/post-natal or later in life.

In some cases where the co-participant's onset of learning/communication difficulty was congenital/post-natal, the KI felt they could not answer the question since the co-participant had never experienced life without their difficulties. For example, one KI said his son (aged 19) had *"never really known anything different"*, so therefore could not *"miss"* anything that he would once have been able to do. A number of other KIs

commented that the co-participant had learned to accept their circumstances over time, and therefore did not really talk about how it affected them.

5.8 Open question: effect of the co-participant's circumstances upon the KI

The analysis of the open-ended question posed to the main sample (see section 4. Analysis of open ended question) suggests that visual impairment and its consequences can affect not only the life of the visually impaired person, but also the lives of their family members. The emerging theme of "Family Issues" demonstrated that the roles of family members can significantly change when a member of the family loses their sight, and that family members are often in need of support, both in practical and emotional terms.

The effects of the visual impairment and additional learning/communication difficulties experienced by the co-participants would arguably have far greater impact upon their relatives and carers, due to their greater level of dependence upon them. Therefore, in cases where the key informant was either related to or the main non-professional carer of the co-participant, the research team felt it was important to allow them to describe how the co-participant's circumstances had affected their own life, and in some cases, that of their family. The following question was posed to all key informants who were not involved with the co-participant in a purely professional capacity (n=42):

"Could you briefly describe how [the co-participant's] visual impairment and circumstances have affected your life?"

A number of the key informants who had dedicated much of their lives to caring for their children with congenital/post-natal onset of learning/communication difficulties felt that it had affected their lives a great deal. In some cases they spoke of the negative effect that caring for their child had had, upon themselves and family members. The following are some examples:

"Umm, hugely. It's because of his profound disability that I'm as unwell as I am, I think, and I have to struggle so much and find life so difficult because of the difficulties he has."

A parent of a co-participant who was aged 19, male, with a congenital/post-natal learning/communication difficulty.

"Well, it's not fair to say it's stopped me doing things but I suppose in some ways it has. You always have to be there to look after him and you have the worry of the future, who is going to look after him. I just go from day to day. It's always ongoing. It does affect the rest of the family. Sometimes this is to the detriment of the other family members because of the extra attention given to the person with the disability."

A parent of the co-participant who was aged 37, male, and had a congenital/post-natal learning/communication difficulty.

"You don't have a normal lifestyle, and his brother and sister didn't have a normal childhood as you work and focus on him really. [...] You can be tied at times, you haven't the same freedom. For instance if I go out today I have to be home by 3.30pm. That's the only time I have. Can't go anywhere with my husband unless I have respite care."

A parent of the co-participant who was aged 26, male, and had a congenital/post-natal learning/communication difficulty.

"Terribly. I cry over it all the time and that's why I feel as though I am to be blamed as to what's happened to [the co-participant]. That's why I don't go out, I stay with her all the time. I say to my friends 'don't forget about [the co-participant]'. [The co-participant] has been in my thoughts completely all the time... I wonder what if something happens to me, who will take her and who will understand what she wants to do. I just have to stop thinking at times, otherwise I would go mental."

A parent of the co-participant who was aged 32, female, and had a congenital/post-natal learning/communication difficulty.

In fact, one of the main concerns expressed by many of the key informants who were related to and the main carers for the co-participant, was about arrangements for the care of the co-participant if they were unable to care for them. This was particularly the case for the younger co-participants with congenital/post-natal learning/communication difficulties. In one case the co-participant's parents had already made plans for the future by allowing him to move into supported accommodation so that he adjusted to life without the constant support from his parents earlier than he might have otherwise had to.

Whilst a number of comments were negative, positive comments were also made by the KIs. For example, one parent felt that, whilst it had affected her life, she was not unhappy about the situation:

"It's affected my life in one way but in a way I don't mind. I'd miss her if she wasn't here. It's affected me not being able to work full time. If you go out for a night you have to make sure someone is here. You're worried she might let a stranger in, you tell her to look out the window but then she can't see. But doesn't bother me at all... She's like a best friend to me. My husband does his own thing so we spend a lot of time together."

A parent of the co-participant who was aged 24, female, with a congenital/post-natal learning/communication difficulty.

Others felt that, whilst difficult, caring for the co-participant had also enriched their lives:

“Well initially I have to say I thought it was the end of the world – we were told he wasn’t going to live very long – and he’s still with us and it changes your life quite severely. But after a while his personality takes over and you love him from the start. It’s enriched our lives because we’ve met some amazing people. His carers are just wonderful.”

A parent of the co-participant who was aged 22, male, with a congenital/post-natal learning/communication difficulty.

“He has had a huge impact on our life with all the worry... But [the co-participant] has been the cement that has kept our family together. [The co-participant] is hugely important to his brothers, in a very positive way they say there is no way they would forget about him, even when Mum and Dad are gone. We don’t see him as a disability or liability to the family.”

A parent of the co-participant who was aged 22, male, with a congenital/post-natal learning/communication difficulty.

A number of parents of co-participants whose learning/communication difficulty was congenital/post-natal expressed the opinion that because they had always had to deal with their child’s difficulties, it was not really an issue for them. The following are some examples:

“Again, because it’s always been there – I guess the only effect is that he can’t be independent and go out on his own, always has to have someone with him, so there are times... I’m in a slightly unique position having a daughter with Down’s too, so we go out as a group. The only thing is having two of them when we go out, shops aren’t very accommodating having three of you linked arm in arm. But it’s not really a problem, that’s how life has always been.”

A parent of the co-participant who was aged 19, male, and had a congenital/post-natal learning/communication difficulty.

“We never sit and think about, we just treat it... we never think we can’t do something because [the co-participant] is in a wheelchair. It’s the norm to us and we just get on with it – I always feel where there’s a will there’s a way and if someone says it’s impossible I’ll prove them wrong.”

A parent of the co-participant who was aged 25, female, and had a congenital/post-natal learning/communication difficulty.

Many of the parents expressed their appreciation of having respite care for the co-participant so that they could spend time alone or with other family members, though in many cases they wished they could get such respite care more often.

Other comments made by key informants demonstrated how they felt incredibly protective of the co-participants. For example, one parent of a co-participant described how he went to great lengths to defend his son’s rights:

"It's affected me 100%. I have to deal with social workers, the Day Centre. I can give info out but can't retrieve any. [Then described situation where he got into a fight with a café owner that was rude about the co-participant]. I'm not the best Dad in the world, I'm not the worst but I'll fight for his rights and use every trick in the book. A lot of people get upset with me; I see something [and] if it's wrong I can't stand back, I'll use anything to try and put it right. I let myself down by effing and blinding, but I want to be true to myself and [the co-participant] – I won't change for no one."

A parent of the co-participant who was aged 24, male, and had a congenital/post-natal learning/communication difficulty.

Similarly, another key informant felt that caring for her friend (aged 91, who acquired a visual impairment and learning/communication difficulty later in adulthood) had made her feel very protective of her and aware of the difficulties she faces, such as when people carelessly leave obstacles in her path. Other co-participants described how one of the major impacts upon their life was that they had to constantly plan for any activities that they did and ensure that the home was kept clear and tidy, so that there were no practical obstacles in the co-participant's way. For example:

"How we arrange our home and the equipment in our home – the furniture, safety measures, lighting. It's all tied up with [everything else that she has to contend with]. I always put the visual impairment first, but the learning difficulty really does affect it so much, I know she could do more without the learning difficulty."

A parent of the co-participant who was aged 39, female, and had a congenital/post-natal learning/communication difficulty.

"Umm, it means you have to think a lot about where you are going and what you are going to do. [Her non-disabled daughter] would probably say that he upset most of our holidays because of his ill health or you can't get around the castle and places like that... A big impact on my daughter though. She gave a talk about being the sibling of a disabled person and I was amazed at what she said. She said she would go to bed as family of four and wake up with just her and her dad, as [the co-participant] and I had gone to hospital. She always worried about whether she would see her brother alive again."

A parent of the co-participant who was aged 23, male, with a congenital/post-natal learning/communication difficulty.

Whilst many of the comments reflected on the emotional impact that caring for the co-participant had brought about, many talked about more practical implications. These included having to move nearer to the co-participant (particularly in cases where the co-participant acquired their learning/communication difficulty in adulthood), never having holidays, or financial implications. One KI felt that they had been penalised for having a child with learning/communication difficulties, through being unable to work full time and thus build up a full pension for their retirement.

The practical implications of caring for the co-participant upon the key informant were often substantial even when the co-participant did not live with them. This was often the case for KIs who were the children of co-participants who had acquired their learning/communication difficulty in adulthood; for example:

“Well, it’s just meant that I’ve had to take over, even when she lived alone I had to organise ‘meals on wheels’, and take her shopping and anywhere she went. So my life, there hasn’t been a week, where twice a week, I’ve not had to take her somewhere. Having no family, it all seems left to me really.”

A child of the co-participant who was aged 84, female, and had an adult acquired learning/communication difficulty.

“Well, quite a bit really. It’s one of the reasons I took early retirement. Worked part-time when Mum was still living at home so I could keep an eye on her. It’s just taken up an awful lot of my life. I’m the one who has to negotiate with doctors, the [residential] home – even things like making sure she has had enough fluid which I shouldn’t have to do!”

A child of the co-participant who was aged 92, female, and had an adult acquired learning/communication difficulty.

6 References

- BRUCE, I., MCKENNEL, A., and WALKER, E. (1991). *Blind and partially sighted adults in Britain: the RNIB survey*. London: RNIB.
- CORCORAN, C., DOUGLAS, G., MCCALL, S., MCLINDEN, M., and PAVEY, S. (2005). "Network 1000: Surveying the changing needs and lifestyles of 1000 visually impaired people – indicative results from generative interviews." Conference Proceedings: *Vision 2005*, 4th-7th April, RNIB, London.
- CORCORAN, C. DOUGLAS, G. and PAVEY, S. (2004). *Network 1000 policy document – participant involvement, description of the mechanisms of involving participants in the project*. University of Birmingham, unpublished.
- CORCORAN, C., DOUGLAS, G., and PAVEY, S. (forthcoming). "Research ethics and participation. Network 1000: the changing contexts and processes of gaining 'consent to access'" (Submitted for consideration to the *International Journal of Social Research Methodology*).
- CORCORAN, C., DOUGLAS, G., PAVEY, S., FIELDING, A., MCLINDEN, M. and MCCALL, S. (2005). "Network 1000: the changing needs and circumstances of visually impaired people: project overview". *British Journal of Visual Impairment*, 22, 93-100.
- DEPARTMENT OF HEALTH (2003). *Registered Blind and Partially Sighted People: Year ending 31 March 2003*. London: Department of Health. ISBN: 1 84182 7983.
- DIRECTGOV (2006). "Money, tax and benefits". Accessed online at: <http://www.direct.gov.uk/MoneyTaxAndBenefits/PensionsAndRetirement/StatePension> (Accessed 09 August 2006).
- FERRUCCI, L., GUALNIK, J., STUDENSKI, S., FRIED, L., CUTLER, G. and WALSTON, J. (2004). "Designing randomized, controlled trials at preventing or delaying functional decline and disability in frail, older persons: a consensus report." *Journal of the American Geriatrics Society*, 52, 625-641.
- NATIONAL ASSEMBLY FOR WALES (2003). *SSDA900.1: Disability Register 2001-02, Version: 1 Released: 29/05/2003*. Processed by the Local Government Data Unit - Wales.
- NATIONAL STATISTICS (2006). "Standard Occupational Classification 2000 (SOC 2000) Volume 2." Available online at: <http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=6460&More=Y> (Accessed 15 August 2006).
- PAVEY, S., DOUGLAS, G. and CORCORAN, C. (2005). *Network 1000: A Guide to the Design and Content of the Year 1 Survey*. Birmingham: University of Birmingham (mimeo). ISBN: 07044 25327.

SCOTTISH EXECUTIVE (2003). *Registration of Blind and Partially Sighted Persons 2003*. Unpublished statistics.

WHO (2001). *International classification of functioning, disability and health*. Geneva: WHO.

WHO (1980). *The international classification of impairments, disabilities and handicaps*. Geneva: WHO.