Secondary data analysis with a focus upon the needs of older people with acquired hearing and sight loss: An analysis of the ‘Network 1000’ and ‘Cambridge’ datasets

1 August 2007

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Research Report prepared for Thomas Pocklington Trust as part of the research project “Experiences of people with both hearing and sight loss”

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Acknowledgements

We would like to thank a number of people for their help in preparing this report: all the participants from both the ‘Network 1000’ and ‘Cambridge’ studies who freely and willingly gave their valuable time to talk to us about their lives; the Network 1000 Management panel for giving permission for this analysis to take place; the project advisory group for advice and support; Thomas Pocklington Trust for funding this work.

Report overview

This research report forms part of a larger project entitled: “Experiences of People with both Hearing and Sight Loss” funded by the Thomas Pocklington Trust. The work reported here is based upon a secondary data analysis of data collected in two previous studies (the ‘Network 1000’ and ‘Cambridge’ studies). These studies gave the research team access to data relating to 609 people who had hearing and sight loss and were over the age of 50 years.

The report is split into four sections. The first section is the introduction and rationale for the analysis. This section introduces the key aims of the analysis, as well as giving a description of the two datasets and the approaches taken.

The second and third sections present the results from the analysis of each dataset. The Network 1000 dataset is presented first which involves a sample of 205 people who are registered as blind or partially sighted in Great Britain and also reported having a difficulty with their hearing. These people had taken part in a larger telephone survey of visually impaired people in 2005-6. The Cambridge dataset is then presented. This involves 404 participants who were members of Deafblind UK and took part in a postal questionnaire in 2005. Both these sections follow a similar structure, and together they form the majority of the report.

The final section draws together the findings from the two analyses as well considering their implications for methods adopted in the remainder of the project.

Introduction and rationale

In April 2007 Thomas Pocklington Trust commissioned the University of Birmingham to undertake a piece of research "Experiences of people with both hearing and sight loss". The primary aim of the project was to produce knowledge that will increase understanding of the experiences, needs and goals of people with both hearing and sight loss who acquire one or both of these conditions in later life. The main research phase of the project involves case studies of 20 individuals who have both hearing and sight loss, and are aged 50+.

Another phase of the project was to interrogate two existing datasets which we believed contained important information about people with hearing and sight loss - the 'Network 1000 dataset' and the 'Cambridge dataset'. There were two purposes in analysing this data:

- the analysis will generate ideas regarding possible areas for investigation with participants during the case study phase of the project;
- the analysis is an important 'end in itself' because it contains insights into the views, experiences and circumstances of 609 people with some kind of hearing and sight loss who are 50 years of age and over.

Background to the "Network 1000" and "Cambridge" datasets

At the time of writing the research proposal two key sources of data were identified by the research team – the 'Network 1000 dataset' and the 'Cambridge dataset'.

The 'Network 100 dataset' is the outcome of a large-scale survey of the opinions and circumstances of 1007 visually impaired people in Great Britain which has been carried out by members of the Visual Impairment Centre for Teaching and Research (VICTAR). The telephone-based questionnaire was far reaching, exploring many aspects of people's lives including some aspects of health and other disabilities including hearing loss (in the case of some participants, additional support was required to undertake the interview because of their poor hearing). Some 27% (n=254) of the sample described themselves as having difficulty with their hearing, almost half of whom said they wore a hearing aid. The vast majority were over the age of 50 (79%, n=205). The Network 1000 project research team have reported findings from the first survey (see Douglas, Corcoran and Pavey 2006) and are currently undertaking analysis of the large dataset collected in the second survey, due to be reported in 2007.

The 'Cambridge dataset' was collected in 2005 by Sarah Bodsworth and Dr Isabel Clare, at the University of Cambridge, in conjunction with Deafblind UK. A postal questionnaire, adapted to meet the preferred form of communication of each individual member, was sent to the entire membership of Deafblind UK, in order to explore the mental health needs of adults with dual sensory impairment, using an established measure (the GHQ-12, Goldberg, 1972). The 539 useable responses (mean age of respondents: 71.5 years) that were returned were demographically representative of the membership, The findings were presented at the British Society for Mental Health and Deafness 2006 Annual Conference, and are being written up for submission for publication (Bodsworth, Clare, and Deafblind UK, in preparation). Like the Network 1000 dataset, this data has undergone further analysis in order to identify the participants who would fall into the category of acquired hearing and sight loss as set out above (N=404). Additionally, there was also a large amount of accompanying qualitative data related to the participant's circumstances generally, which has been analysed.

Therefore, in total the secondary data analysis gave access to data relating to 609 participants who have acquired hearing and sight loss and are over the age of 50 years. Furthermore, some of the questions in both surveys allow comparisons to be made to the wider population (both those with visual impairment only and the sighted population). In addition, qualitative data collected also provides a different 'unprompted' insight into the issues of relevance to this group. As already argued, not only is this a valuable contribution to our understanding of these issues, but the analysis will also provide a useful backdrop to the case study work and source of information in the design of the methods and sampling used in that phase of work.

Approach and report structure

While this report describes data related to 609 people over the age of 50 years with acquired hearing and sight loss, the 609 is made up of two very distinct samples which must be treated separately. As described above, the 'Network 1000' and 'Cambridge' projects drew from different sampling frames (the registers of blind and partially sighted people in Great Britain, and the Deafblind UK membership respectively). The two projects also used different methods (telephone interview versus postal questionnaire) and collected data against different topics.

For these reasons the analyses of the two datasets were necessarily carried out separately (the Network 1000 analysis lead by Sue Pavey and the Cambridge analysis lead by Sarah Bodsworth) and are presented in separate sections. However, the approach to the two analyses was similar and this is reflected in the similarity in the structure of the report sections. Both sections contain descriptions of:

1) the background of the projects;
2) samples defined in the analyses;
3) parts of the surveys which were analysed;
4) responses to a selection of closed survey questions ('quantitative' analysis);
5) responses to key open questions ('qualitative' analysis).

It is the qualitative analysis which required most careful planning in this process. Both the Network 1000 and Cambridge surveys contained 'open' questions which generated large amounts of qualitative (text) data. In the case of Network 1000 this data had already undergone extensive analysis and been reported elsewhere (see relevant chapter in Douglas, Corcoran and Pavey, 2006). In the case of the Cambridge study no systematic analysis of the data had taken place previously, although all the data had been transcribed into a database from the written questionnaire responses. The task then for the Network 1000 dataset was to isolate the data relevant to people with hearing and sight loss and ‘re-look’ at the analysis. In contrast, the task for the Cambridge dataset was to start the analysis from scratch.

While inter-research reliability is neither possible nor desirable when carrying out these kinds of analyses, it is important for the researchers to have some shared *techniques*, *goals*, and *vocabulary*.

- *Techniques*. Data related to open questions was imported into a qualitative data analysis software package called Nudist Vivo (NVivo) version 2. Each individual response to the question was accompanied by participant details. This varied for the two projects but included information about the participant’s unique ID number, age, and sex.

- *Goals*. The key goal of the analysis was to draw out key issues of importance to the participants. Therefore, the data was 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 a number of themes.

- *Vocabulary*. While the key goal was to draw out the ‘voice’ of the participants from the data, it was also useful to build upon existing literature and frameworks in order to gain a shared vocabulary across the two analyses. The vocabulary from the Department of Health’s Think Dual Sensory report (DoH, 1995) was used as a key framework for the analysis; principally, that combined sight and hearing impairment can cause difficulties with (i) access to information, (ii) communication and (iii) mobility.

Clearly, however, the datasets are different in origin and focus upon different samples. This means the analyses afford different things. In terms of the quantitative data associated with closed questions, Network 1000 was a far reaching survey of visually impaired people’s lives. Therefore it was possible to get a detailed description of the sub-samples lives and circumstances. Importantly, there is a clear comparison group in this analysis in the form of visually impaired people without hearing loss. The section of the report presents some of these comparisons, as well as some description of the sample itself. Again, the choice of which data to present is partly influenced by the DoH (1995) definition which highlights access to information, communication and mobility.

The Cambridge study was a far more focused investigation with a particular emphasis on mental health and the use of the GHQ-12 scale which enabled comparison to the sighted population.

The final section of the report briefly brings together issues identified in the analyses and summarises the findings.

Network 1000 analysis

Background to the Network 1000 project

The Network 1000 project was carried out by the University of Birmingham's Visual Impairment Centre for Teaching and Research (VICTAR), in conjunction with VISION 2020 UK, having been commissioned by the Big Lottery Fund. The aims of the Network 1000 project were to:

- Establish a consultation network of 1000 visually impaired people who could be regularly surveyed on a range of issues affecting them;
- Provide a network for longitudinal studies;
- Provide statistically useful data on the changing views, experiences and needs of visually impaired people which could be used to influence service development and provision.

To date, Phase 1 of the project, which ran from March 2004 to February 2007, has been completed. This involved the recruitment of 1007 participants, the design of two surveys, and subsequent carrying out of two interviews with participants. In summary:

- Survey 1 – sample of 1007 (made up of 960 direct interviews and 47 'key informants'); approximate 40 minute interview about various aspects of their life.
- Survey 2 – sample of 922 (made up of 883 direct interviews and 39 'key informants'); approximate 30 minute interview.

Findings from the first survey have been reported (see Douglas, Corcoran and Pavey, 2006). Analysis of the data collected in the second survey is continuing in 'Phase 2' of the project.

The 1007 participants are split between 960 visually impaired people that 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. For the purposes of this report, only the data relating to participants who took part directly is being presented.

Network 1000 sample and the sampling process

Whilst it was important to select participants at random, the sample was very carefully designed so that we recruited people of different age groups, since otherwise the sample would have been heavily skewed towards older people due to the older age distribution within the visually impaired population. We decided upon five age groups (18-29 years, 30-49 years, 50-64 years, 65-74 years, and 75+ years), and attempted to recruit about 200 people in each, achieving the following composition:

The sample was taken from the population of those who are on the registers of blind and partially sighted people held by 20 social services departments in England (16), Scotland (3) and Wales (1), a total population of approx. 360,000 visually impaired adults (see Douglas et al, 2006). Due to this sampling frame, we know that all participants have a moderate or severe visual impairment, generally best corrected VA<6/18 (though some may have severe field loss). We also have some subjective measures of vision collected during the interviews.

In terms of hearing impairment, however, we know a lot less about the nature and extent of such impairments. We do have subjective data collected during the interviews, which can be seen as *unprompted*, *prompted* or *observed* measures.

- *Unprompted measure of hearing and sight loss.* The unprompted measure is from a question that asked participants “Do you have a long term health problem or disability (other than your VI)? [If yes] Could you describe this / these?”. The participants’ responses were recorded verbatim, and later coded into different categories. In response to this question, only 4% (n=25) volunteered that they had a difficulty with their hearing.

- *Prompted measure of hearing and sight loss.* The prompted measure asked directly about hearing impairment, worded as “Would you say that you have a difficulty with your hearing? [Yes/No]”. Of the 582 participants aged 50+, 35% (n=205) said that they did have a difficulty with their hearing in response to this question, a significantly higher number than those that volunteered the information unprompted in response to the previous question. This suggests that some people do not think of their hearing impairment as a significant health problem or disability, supporting the hypothesis that older people, in particular, attribute it to something that simply happens in old age (Goodwin 1998, Butler 2004), and therefore just has to be accepted.

- *Observed measure of hearing and sight loss*. The third measure is even more subjective, being based upon the interviewer’s observation and interpretation of any difficulties the participant had in taking part in the interview. The question was at the end of the interview, where the interviewer recorded any additional details following the completion of the interview: Question to the *interviewer:* “Did any of the following affect the interview?” followed by a series of options, one of which was ‘Hearing problems’. However, this is a much less useful measure, since the interviewer may have misinterpreted the reason, for example attributing a hearing problem for what was in reality due to a bad telephone line or difficulty in understanding the interviewer’s accent, etc.

The most useful measure then, is the prompted question that directly asked the participant whether they have a difficulty with their hearing. This question was followed by questions relating to the impairment regarding the use of hearing aids, when they first noticed the difficulty, and whether it had become greater or worse (or was about the same) as a year ago, thus validating the responses to the earlier question. This, then, is the measure used to define the sub-sample for which the data is reported here, and includes 205 people aged 50+ years old (see table below).

Table 1. Whether they have a difficulty with their hearing (prompted). Base: All Network 1000 participants aged 50+ (N=580).

Hearing loss (prompted)?	**Age group**						**Total sample (n)**	**Total % of sample**
	50-64		65-74		75+			
		%		%		%		
Yes (H&SL sample)	58	25%	58	32%	89	53%	205	35%
No (SL comparison sample)	170	75%	125	68%	80	47%	375	65%
Number interviewed	**228**	**100%**	**183**	**100%**	**169**	**100%**	**580***	**100%**

* Does not include two participants for which data is missing.

Description of the survey and analysis

The data collected within the Network 1000 project allows a unique comparison of data relating to visually impaired people with additional hearing loss with those with a visual impairment only (though people in both groups may have other health problems or disabilities). The aim of this section then, is to:

1. describe the sub-sample of visually impaired participants who also have hearing and sight loss (hereafter known as the "H&SL sample", N=205);
2. compare these to a second sample who have sight loss but do not describe themselves as having a difficulty with their hearing (the "SL comparison sample", N=377).

Figures relating to the full Network 1000 sample that have been reported in the Network 1000 Survey 1 report (Douglas et al 2006) were ‘weighted’ so as to aid generalisation to the wider visually impaired population. ‘Weighting’ is a technique which enables an analysis to account for known characteristics of a population (in this case the age profile) – see Douglas et al (2006) for a fuller account in this context. However, the figures that are presented in this report relate to the (un-weighted) percentages of the H&SL sample. This is because this sub-sample is relatively small and also the sub-sample is taken from a limited age range (50+ years) which means weighting by age has less relevance. Nevertheless, throughout we refer to differences across age groups because this proves to be an important variable.

The first Network 1000 Survey included a wide range of questions, most of which sought factual data about the participants’ circumstances, 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. These questions allowed participants to convey their thoughts and opinions in relation to the specific topic about which the questions were exploring, for example independent living skills or travel. Demographic details regarding the Network 1000 participants aged 50+ were re-analysed for this report as well as more focussed analysis on topics that are associated with communication, access to information and mobility, specifically ‘reading and access’, ‘computer use’, aspects of ‘independent living skills’, and ‘travel’.

Whilst these questions generated a wealth of data about a number of important topics, it was important 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. To this end, Network 1000 Survey 1 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; once again the emphasis was on the participant’s visual impairment, as this was the main focus of that survey. With this question, the participant was encouraged to describe any issues that they felt were relevant or important in their own words, rather than being restricted to a pre-defined list of possible responses as in the earlier generative questions used in the survey. 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.

As predicted, a large amount of text (data) was generated in response to this question. As part of the analysis carried out for the Network 1000 project, the data collected from all 960 participants was converted into five Word documents with the responses grouped into the five age groups 18-29, 30-49, 50-64, 65-74 and 75+ and then imported into a qualitative data analysis software package called Nudist Vivo (NVivo) version 2. This helped the research team to make ‘sense’ of the data. A summary of the findings relating to all 960 participants can be found in the final Network 1000 project report (Douglas et al, 2006).

For the purposes of this project, the data relating to a sub-sample of all participants aged 50+ was selected for further analysis, some 580 participants in total; note that this included participants who said that they did *not* have a hearing impairment (n=375) as well as those who did (n=205) – as defined above. This enabled comparisons to be made between the two groups.

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;
- whether or not they had a self-disclosed hearing impairment.

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 a number of themes, including both 'new' issues or themes that had not been covered earlier in the interview schedule and those that had been previously identified.

Some 24 themes were identified and coded in the analysis. These include the following, listed in the order of those most cited by participants with a hearing impairment (the percentage of participants *without* a hearing impairment who talked about the theme is also noted):

Table 2. List of themes identified and coded in the analysis of the open-ended question, by Hearing and Sight Loss sample group (H&SL) and the Sight Loss comparison group (SL). Base: all those aged 50+ (N=580).

Theme	H&SL	SL
1. Travel, transport and mobility	34% (n=70)	41%
2. Independent living skills	24% (n=50)	31%
3. Communication and reading	19% (n=38)	17%
4. Family issues	18% (n=36)	16%
5. Leisure activities - outside of home	17% (n=35)	13%
6. Social and emotional issues	16% (n=32)	15%
7. Counselling, emotional needs and adjustment	15% (n=30)	15%
8. Leisure activities at home	15% (n=30)	13%
9. Agencies and user groups	14% (n=28)	11%
10. Attitudes of others	9% (n=19)	9%
11. Medical/other issues related to visual impairment	8% (n=18)	11%
12. Visual impairment awareness of sighted people	7% (n=14)	10%
13. Other disabilities and health difficulties	5% (n=11)	6%
14. LVAs and lighting	5% (n=10)	5%
15. Technology and gadgets	4% (n=9)	2%
16. Employment	4% (n=8)	7%
17. Laws and policy issues	3% (n=6)	3%
18. Finances	2% (n=5)	3%
19. Education	2% (n=4)	3%
20. ICT and computers	2% (n=4)	2%
21. Housing	1% (n=3)	1%
22. Visually impaired people’s awareness of VI	1% (n=3)	2%
23. Religion	1% (n=2)	1%
24. Voluntary work	1% (n=2)	2%

In terms of reporting style, 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.

General description of the hearing and sight loss sample

In this section we present general descriptions of the H&SL sample. The first sub-section makes some general comparisons between the H&SL sample and the sight loss (SL) comparison sample. The subsequent sub-sections describe the H&SL sample alone focussing upon variables that we think are most relevant.

General comparisons with the sight loss sample

The likelihood of hearing loss increases with age. This is reflected in the mean ages of the two samples (H&SL sample being significantly older than the SL comparison sample). Nevertheless, within given age groups the picture is slightly more complex. For age groups 50-64 and 65-74 years, there is little difference in the ages of those with and without hearing loss. For those in age group 75+ years, those with hearing loss are significantly older than those without hearing loss (mean 84 years compared with 82 years; $t = 2.85$; df 1,167; $p < 0.005$).

In terms of other key characteristics, few clear differences between those with and without a hearing loss were observed. The samples seem matched for subjectively reported levels of functional vision. The same is true for the likelihood of reporting an additional long-term health problem or disability other than visual impairment, the likelihood of living alone, and perception of financial circumstances. Nevertheless, there are indications of some differences between the H&SL and the SL comparison samples across the age groups. In the 75+ age group it appears that people with additional hearing loss may be less likely to live alone (though reasons for this are unclear). Also, those with additional hearing loss are more likely to describe themselves as having long-term health problems or a disability other than their visual impairment in age groups less than 75 years. In part, this could be explained in that younger people (50-74 year olds) are more likely to identify their hearing difficulty as a long-term health problem/disability than older people (75+ year olds) who may see it as an inevitable part of getting older.

General characteristics of the hearing and sight loss (H&SL) sample

The H&SL sample was fairly evenly split between men and women, with 48% male and 52% female. The majority (96%) were born within the UK, and described their ethnic group as White UK (96%). The remainder were from Asian, Black and Other White backgrounds. In terms of religion, 88% of the sample described themselves as having a Christian faith, followed by 10% who said that they did not have any religion. Other religions mentioned were Hindu and Muslim faiths.

Relationships and household

Almost half of the sample were married, with a third describing themselves as widowed (particularly common in the older age group), 9% as divorced and 8% as single/never married. The remaining 4% were either living with a partner as a couple (but not married) or separated. Just over a third of the sample lived alone. Of those who did not, most lived with a spouse or co-habitee, or with their children, the vast majority of whom, unsurprisingly given the age profile of the sample, were not under the age of 16.

Of those who did not live alone (n=134), 14% said that they lived with someone who was sick, disabled or elderly and required special help, and in most cases this was their spouse. Almost all of these participants said that they provided at least some (if not all) of the support that this person(s) required.

Tenure and accommodation

The most commonly reported types of accommodation were detached and semi-detached houses/bungalows (two thirds of the sample), followed by terraced houses/bungalows (15%) and purpose built flats/maisonettes (14%). Only 3% specified living in institutional accommodation, and 2% in sheltered housing. This suggests that this survey may not have tapped into the significant numbers of people with hearing and sight loss thought to be in this type of accommodation.

The majority of the sample (62%) said that they owned their home outright, and perhaps not surprisingly, most were aged 65 or over. Of the remaining sample, 21% were renting their accommodation followed by 9% who were buying it with the help of a mortgage or loan. Of those who were still paying for their accommodation (n=62), the majority said that they did not have any difficulty paying for it over the previous 12 months, with only 7% reporting difficulty. The remaining 11% said that they had received 100% rent rebate.

In terms of overall financial circumstances, participants were asked how well they felt they were managing financially; the vast majority (70%) described themselves as ‘doing alright’ or ‘living comfortably’, with 24% reporting that they were ‘just about getting by’. Only 4% said that they were finding it difficult or very difficult. Whilst this doesn’t give a reliable indication of actual financial circumstances, it does provide a picture of participants’ perceptions of their circumstances. There were no significant differences in the perceptions of participants with hearing loss compared with those without a hearing loss.

Vision, hearing loss and other disabilities/long term health problems

Due to the central focus of the survey upon visual impairment, a significant amount of data was collected about the nature of the participants’ visual impairments. In addition, information was also collected about any additional disabilities and long term health problems that participants’ had, including hearing impairment. Whilst this data is not as detailed as that regarding their visual impairment, it provides an indication of the long term health problems and disabilities that participants live with on a daily basis.

Vision

Due to the sampling strategy, we knew that all of the participants were registered as either blind or partially sighted, though we did not know which category. When asked about their registration status, just over half of the sample said that they were registered partially sighted, with 43% being registered blind. Two participants were not sure of the category, and one was not aware that they were registered at all. Of those who were registered blind, almost half had been registered as partially sighted previously. The participants were asked how long ago they were first registered; the majority, 66%, said they were registered in the past 10 years. This, in part, reflects that many in the sample had late onset of visual impairment (the mean age of onset was 50 years of age), often linked to macular degeneration (39% described having macular degeneration which is usually linked with older age – 62% of those over 75 years reported having this condition). Other conditions that were reported included glaucoma and cataracts (both 12%), diabetes-related conditions (10%), and Retinitis Pigmentosa (7%). Interestingly, some 15% said that they didn't know the medical name of the eye condition which caused their sight problem.

Thirty-eight percent of the sample reported that they first noticed they had a serious problem with their eyes themselves, followed by opticians/optometrists (28%), hospital eye doctors/specialists and other medical personnel (both 9%), a member of the participant's family (8%), and a GP/nurse at a surgery (3%).

A detailed series of questions were asked about participant's functional vision. Some of the key figures are given below demonstrating a wide range of functional vision across the sample:

- 12% had either no vision at all or could, at best, tell by the light where the windows were in a room;
- 32% said that they could recognise a friend if they were across a room or across a street;
- The majority could not read ordinary newspaper without the aid of a magnifier;
- 80% said that they wore glasses or contact lenses at least some of the time, citing distance vision, reading and other close-up uses as the most common reasons for wearing them;
- 53% felt that the difficulty with their sight was greater than it was a year ago, with 39% reporting it as about the same and 8% reporting it as less of a difficulty. Older participants aged 65+ were more likely to report having greater difficulty than those aged 50-64;
- No surprisingly given many had relatively recently lost their sight (and for many it was continuing to deteriorate) just over half said that they worried about their eyesight at least a little of the time (9% said they worried all of the time);
- 47% said they had at least mild pain / discomfort in and around their eyes.

Hearing loss and other disabilities/long term health problems

Thirty-six percent of the sample reported being registered as disabled. Interestingly, younger participants were more likely to be registered than older participants (50% of those aged 50-64 compared with 24% of those aged 75+). When asked whether they had any disabilities or long term health problems other than their visual impairment, 78% of the sample confirmed that they did. Post-hoc coding of the types of disabilities and health problems that participants described reveal a wide range of conditions. The most common were heart problems, arthritis, diabetes, problems relating to the skeletal system, and high blood pressure. As would be expected, some conditions appeared to be linked with age (e.g. heart problems and arthritis more common amongst older participants).

As already noted, it is relatively uncommon for participants to discuss their hearing in the context of this unprompted question (all described themselves has having difficulty with their hearing when asked directly, while only 10% of the H&SL sample described problems with hearing when unprompted). This observation was particularly true for older age groups. As suggested earlier, this may be a reflection of the attitude of older people who are more likely to see it as an inevitable consequence of aging. Alternatively, perhaps other health problems meant that difficulty hearing was not prioritised by older people when answering this question (older people tended to have more health problems / disabilities generally than younger age groups).

Table 3. List of other health problems / disabilities self-disclosed by participants (unprompted), by age group. Base: the hearing and sight loss sample (N=205).

Other disabilities/long term health problems (post-hoc coding)	**Age group**						**Total sample (n)**	**Total % of H&SL sample**
	50-64		65-74		75+			
	n	%	n	%	n	%		
Heart problems	7	12%	12	21%	24	27%	43	21%
Strokes	8	14%	2	3%	5	6%	15	7%
Arthritis	7	12%	14	24%	15	17%	36	18%
Diabetes	8	14%	17	29%	6	7%	31	15%
High blood pressure	7	12%	9	16%	10	11%	26	13%
Circulatory system	1	2%	7	12%	4	5%	12	6%
Skeletal system	11	19%	5	9%	12	13%	28	14%
Nervous system	5	9%	5	9%	5	6%	15	7%
Respiratory system	4	7%	5	9%	5	6%	14	7%
Digestive system	3	5%	4	7%	4	5%	11	5%
Urinary tract/kidney	2	3%	3	5%	2	2%	7	3%
Cancer	0	0%	2	3%	3	3%	5	2%
The ear/hearing (the unprompted measure)	11	19%	5	9%	4	5%	20	10%
Other	11	19%	8	14%	8	9%	27	13%
None	13	22%	8	14%	25	28%	46	22%
Number interviewed	**58**	**100%**	**58**	**100%**	**89**	**100%**	**205**	**100%**

In terms of hearing loss, most of the sample first noticed they had a difficulty with their hearing during adulthood (with a mean onset of 57 years), 44% whilst of working age (17 – 64 years old) and a further 46% whilst of retirement age (65+). Only 10 % first noticed a difficulty with their hearing during childhood. The majority (62%, n=128) of the

H&SL sample first noticed a difficulty with their vision before noticing any impairment of their hearing. Of the remaining participants, 25% first noticed a difficulty with their hearing before any difficulty with their vision, with 10% stating that they noticed difficulty with both their hearing and vision at around the same time.

Half of the sample (51%) said that they wore a hearing aid. When asked if the difficulty with their hearing was greater or less than it was 12 months previously, the majority felt that it was about the same (61%), with 34% reporting that the difficulty was greater than a year ago. Only 3% felt that it had improved.

Department of Health definition of needs

In the following sections we focus upon data related to communication, access to information, and mobility (DoH, 1995). As with earlier data analysis, the data for those with hearing loss has been compared with those who did not have hearing loss (although very few differences were found). Descriptions of findings for the H&SL sample will be presented, along with relevant evidence identified in the analysis of the qualitative responses to the open question.

Communication

Perhaps one of the most difficult barriers to participation and inclusion for people with both hearing and sight loss is communication. Its importance in our social world can not be over-estimated, since an ability to communicate and interact with others helps to form a sense of our self and identity. An inability to do so can lead to isolation and withdrawal, even where a person is living with or in close proximity to others (Butler 2004).

Communication can be seen as either ‘expressive’, as in expressing thoughts and feelings to others, or ‘receptive’, as in understanding what others are saying. Perhaps the latter is the most difficult for people who experience hearing and sight loss later in life (Bagley 1998). As with many older people who acquire hearing and sight loss later in life (Schubotz 2004 and Chapman 2002), the hearing impaired participants in the Network 1000 sub-sample continued to communicate with others largely using speech, and were able to do so successfully as evident by their ability to take part in the telephone interviews. This is, of course, more a reflection of the research method used to interview participants rather than a representative feature of this group of people, since one can assume that people with more profound hearing loss were more unlikely to respond to the invitation to participate.

When we compared the H&SL and SL comparison groups in terms of communication we found few obvious differences. There was one obvious exception to this which, ironically, was in relation to communication using the telephone. The data relating to the researchers’ observation about the interview, collected after the interview had ended, suggests that some of the participants with hearing loss did indeed have difficulty communicating, since the researcher reported that the participant had difficulty hearing the questions in 28% of these cases (compared with only 3% of cases in the SL comparison group). This provides very tangible evidence of how the hearing difficulty affects people's everyday communication.

It is important not only in terms of conversation and verbal communication with others, but also in the ability to keep in contact with friends and family through written communication such as letters, emails and text messaging. When asked how they communicated in writing, just over half of the H&SL sample (58%, n=119) still communicated using handwriting Only 8% said that they used text messaging, perhaps unsurprising considering the age distribution of the participants. Some 30% said that they did not communicate in writing at all, and a further 7% said that someone else helped them, e.g. by dictation.

In terms of computer use, only 25% (n=52) of the H&SL sample said that they ever used a computer (with 22% using one once a week or more) and this was less common in older age groups. Of these, 77% (n=41) said they used it for word processing and 62% (n=33) for sending and receiving email. The use of computers is important not only in terms of communicating with others, but also in accessing information, which is covered later in the report.

Findings from the open ended question revealed that participants experienced a number of difficulties in terms of written and spoken communication. Communicating with sighted people in writing was a common difficulty:

ID 232
Age 66, Male
Lives alone
Retirement age
Registered Partially Sighted
"The biggest problem I have is reading and writing. Form filling and things like that, reading letters is difficult and that's the main concern - the other things don't matter as much."

Many examples were given where participants felt isolated as a result of their sight and hearing loss, even when in close proximity to others, due to the difficulty in taking part in social exchanges.

The following example demonstrates how important the ability to see and read body language is in conversation, and how hearing impairment exacerbates the difficulty:

ID 218
Age 71, Male
Does not live alone
Retirement age
Registered Blind
“I think it's a question of being able to recognise people and being able to see facial expressions and understand body language, and appreciate simple things like whether somebody's smiling - I can hear them, [but] may not be able to hear the undertones… the hearing problem exacerbates that - I can understand things said directly to me but conversations between other people to which I'm not directly involved, I cant participate in - there's a tendency to become isolated in that way.”

The following examples also illustrate the difficulties that people with sight and hearing loss can face when taking part in conversation with others, for example in turn-taking and being able to engage in conversation in noisy environments:

ID 405
Age 82, Female
Lives alone
Retirement age
Registered Blind
“I do get concerned, I suppose, who I am talking to if I am in a room with people, I'm not sure if they are talking to me. I don't know if they are looking at me. I do not open my door at night . . . I have the electricity meter man, he has the code. People have codes for me.”

ID 175
Age 83, Female
Does not live alone
Retirement age
Registered Partially Sighted
“Generally speaking I find difficulty in communication because I can't see the people. I think that's the main thing because you feel somewhat at a loss.”

ID 637
Age 53, Female
Does not live alone
Working Age (Not Working)
Registered Blind
“I don’t go to pubs now because of my hearing and my sight… if there's music on in the pub, or if there's more than two people talking, you lose all sound.”

Feelings of isolation, particularly for those living alone, were all too common:

ID 261
Age 88, Male
Lives alone
Retirement age
Registered Blind
"Well, the most difficult thing that's ever happened is my wife dying - I miss her terribly. It's absolutely shattering when your wife dies and you've got a wife that you love and you like living with - my wife was my life that was my reason for gardening, keeping chickens and keeping all that. When she died I felt like a tube with nothing inside. It's taken me a long time to get over it and I suppose I'm more or less over her but I still think of her and buy little bunches of flowers [or] something and put on the sideboard. I suppose that's the sort of thing lots of people do. One of the main things is that on your own you've got nobody to talk to. If I don't go out I spend all day and apart from cursing myself I don't say a word - I call myself an idiot very often. She died of cancer and it hits you like a bomb and you suddenly find you are alone… "

The following participant felt isolated due to sighted people's attitudes towards people with visual impairment:

ID 191
Age 74, Male
Does not live alone
Retirement age
Registered Blind
"When you are young you are more attractive to younger people and they are attracted to you. When you get older it seems to me that your visual handicap [sic] can lead to greater isolation. An old man is never quite as attractive as a young man. I may be generalising but I feel that poverty and financial stress are much less a problem with visually handicapped people than is isolation - you can be isolated in great comfort."

Access to information

Access to information is a broad term, encompassing issues relating to accessing general information about 'mainstream' services or events in the community, as well as information more specifically related to and aimed at people with hearing and sight loss, for example information about available advice, products and services. Difficulties emerge when information that is available in the community is presented in inaccessible formats, or when people are not aware of organisations that can offer them help and advice.

Participants were asked about the different ways in which they actively read or accessed printed material. Interestingly, the most common method of reading (69% of the sample) was by listening to tapes (e.g. talking books, information on tape), only slightly lower than the 76% of participants without hearing loss. The second most common method was reading large print either with or without a magnifier (62%), followed by 48% who read ordinary print (with or without a magnifier). Forty-two percent of the sample said that they had someone else who read to them. Reading braille or moon were much less common methods, with only 5% and 2% respectively, using it to access information.

A common method of accessing information is via the internet. Participants were asked a number of questions relating to their use of computers; the majority (74%) of participants said that they didn't ever use a computer, and most didn't have a computer in their home (54%). Of the minority who said that they did use a computer (n=53), just over half said that they used it to surf the internet.

When asked whether they would like to use a computer more than they did currently, 37% of the sample said that they would. These participants were then questioned about what they thought would help them and what stops them from doing so; the most commonly cited perceived barrier to using computers more was the participant's visual impairment. This was closely followed by issues relating to the accessibility of computers and related equipment. Other issues that were mentioned include the availability of computers and equipment, and course-related issues, for example a lack of appropriate courses in computing, or difficulties in accessing a course (particularly mainstream courses). Some mentioned a lack of confidence in relation to computing as a barrier to using computers more than they did, whilst some said that they either didn't have the time or didn't see it as a priority.

The 63% (n=129) who didn't want to use a computer more were asked why they said that; 37% simply weren't interested, particularly older participants (i.e. 53% of 75+ compared to just 16% of those aged 50-64). Fifteen percent said that they used a computer enough already, most of whom were in the younger age groups. As with those who did want to use computers more, many of those who didn't (22%) attributed their visual impairment as a barrier or reason why. Perhaps reflecting the older age distribution of this sample, some felt that they were too old, a more common reason amongst the older age group.

Findings from the open-ended question suggest that a number of people struggle with accessing information that is essential on a daily basis, for example reading labels in shops or on clothes, or reading their own mail, often having to rely upon family members to help them. A number of illustrative examples were given.

For example, the following participant described a number of situations in which she has difficulty accessing printed information, primarily due to her visual impairment:

ID 902
Age 52, Female
Does not live alone
Working Age (Not Working)
Registered Blind

The thing struggles most with is poor labelling and instructions. Print is so tiny - struggles most with sell-by-dates / best-before-dates - does struggle with food, not with things she knows how to cook, but new things and occasionally (for example when grandchildren come over) wants to cook pizza, has to get help with instructions. Sometimes struggles with sizes on clothes, some people are helpful, some aren't. Toilet signs often not clearly enough marked. Can't use public telephone boxes, so many buttons on the display it is too confusing… Has quite a few friends who live abroad, prior to visual impairment would fly out to visit them but finds travelling difficult now, e.g. at train stations, can't see information screens clearly enough. Gets annoyed by this - one train station she uses is Oxford Road and they frequently change platforms, have to run across, finds this frustrating if not announced. People take it for granted that everyone can see. Has problems with light, confuses her vision, has on occasion walked in to glass doors. Her bank now sends her large print statements which she finds extremely useful. No chance with telephone directory, BTs 195 service which (if you have a pin number) gives you a free directory service.

ID 648
Age 83, Female
Lives alone
Retirement age
Registered Partially Sighted

"There are things I find difficult e.g. shopping - in the supermarket I have an awful job to read the labels and sell by dates and prices. I find it difficult reading labels on food at home."

ID 324
Age 67, Female
Does not live alone
Retirement age
Registered Partially Sighted

"I get frustrated when I'm reading or cooking something and I can't see it even with a magnifier and I have to ask my husband to read it - things on packets I can't see. Frustrated that can't read numbers on hearing aid… Can't see the prices of anything in the shops."

Some participants expressed dislike for having to ask family and friends for help:

ID 1040
Age 50, Female
Does not live alone
Working Age (Not Working)
Registered Partially Sighted
"The hardest thing I find is shopping, the labels are too small. Have to have someone with me. If I go clothes shopping with husband it's hard in the changing rooms as he can't come in with me. Manufacturers should take into consideration that blind people can't see the labels - maybe do them in braille. It's hard always having to ask family/friends to go out shopping, etc. Find it hard to cope with."

ID 10
Age 68, Female
Does not live alone
Retirement age
Registered Partially Sighted
"There's things like reading labels, and things like that on things, I have to keep asking 'will you tell me what this says?', and 'will you help me with this?', I don't like to keep worrying them [her husband and sons] with every little thing, it does get me annoyed. If I try to read the packages and I can't see I've got to keep asking them 'tell me what this is?'. I don't like bothering them. [Researcher: "I'm sure they don't mind though"]. Well, sometimes they do, it's surprising you know, sometimes my sons, without thinking, I know they don't mean anything by it, say things like 'what's the matter, are you blind?' or something like that, just on a spur of the moment. Things like that really hurt, you know. I know they don't mean it, don't get me wrong. But things like that do affect you."

In terms of specialist services for people with hearing and sight loss, some participants felt unsupported due to a lack of advice about what help is available for them:

ID 82
Age 62, Male
Does not live alone
Working Age (Not Working)
Registered Blind
"Authorities never check to see how you are getting on or if you need anything. People don't know what they can have to help them because nobody is telling them. I suppose it is down to money. Left to your own devices. Get fed up of asking."

Another participant felt that she had not received adequate support from a number of opticians, and that there was a lack of places to go to get advice or to complain about services:

ID 535
Age 66, Female
Does not live alone
Retirement age
Registered Blind
"We don't get much help in regard to how to help ourselves. With this sight problem I'm finding I have to keep going back to the opticians because the glasses aren't right or they've got it wrong… You can't seem to get any advice as to what to do to help yourself. It's terrible, it really is bad."

One participant felt that visually impaired people should be consulted more about the services, adaptations and help that they require, since 'one-size-fits-all' solutions don't work:

ID 500
Age 53, Female
Does not live alone
Working Age (Working)
Registered Blind
"The difficulty when I was told about my visual impairment was knowing what it was going to be like and what it would mean. That was difficult and the family didn't even think about it. It was hard for them to understand. But positively, coming out of that, it explained the problems I'd been having and it also opened so many more doors. I found that it didn't worry me talking to people about it. That was really positive. It's made me so much aware of other people's problems, not just VI but other disabilities or difficulties. I've become very much more a people person. 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] people have been told that yellow is the colour that people lose so they've made certain signs yellow but if you put yellow against no contrast we can't see it. Also very 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 and go after information to help but they are given the wrong information, the people who need to be asked aren't being asked."

More positively however, some participants described the help and advice they had received and how it had made a difference to them:

ID 1013
Age 82, Female
Lives alone
Retirement age
Registered Blind
"If I hadn't had help from social services I wouldn't know about what was available, e.g. attendance allowance."

ID 1031
Age 79, Female
Lives alone
Retirement age
Registered Blind
Has had a lot of help from Social Services which she appreciates. Is a member of the Macular Degeneration Society which has been very supportive.

Mobility

The Network 1000 data clearly demonstrates that how often people leave their homes is clearly linked to age (older people leaving their home less often). There is also some evidence that those in the H&SL sub-sample leave their home less often than those in the sight loss comparison group. While this is difficult to tease out with confidence (because those with additional hearing difficulties tend also to be older), this trend seems to be in evidence amongst people over 65 years of age.

In contrast, there were no differences between those with and without hearing loss in terms of reported challenges presented by independent living skills (including preparing meals, household cleaning, personal care and getting about the home).

The following presentation of data relates to the H&SL sample only.

Participants were asked a number of questions about travel, transport and their general mobility. The first question asked "how often do you leave your home and go outside?"; most participants with hearing loss (93%) went out at least once a week or more. Forty-two percent of the sample went out every day, 9% less than participants aged 50+ without hearing loss. Only 3% of the sample (n=7) said that they never went out or went out less than once a month.

In terms of transport, the most popular methods were travelling in a privately owned car (59%), walking on foot (48%), public buses (42%), and taxis (18%). The high use of privately owned cars suggests that people rely on others at least for some journeys (this, of course, is not necessarily a problem in itself, although some of the subsequent quotes suggest it is problematic for some). The most common reason to leave the home was to go shopping (78%), followed by leisure activities or hobbies (49%), visiting friends (21%) and family (20%), and visiting a GP or Hospital (15%).

All of the participants were asked whether or not they would like to leave their home more often than they currently did; just under half (45%, n=90) said that they would. When asked what they thought would help them and what stopped them doing so, the most common reasons cited were the participant's visual impairment (32%), general issues relating to transport (27%), feeling unable to go out alone or unaccompanied (26%), mobility problems (25%), and poor general health or other disabilities other than the visual impairment (21%). Fifteen percent of the sample also mentioned having a lack of confidence that prevented them from going out more often that they did. Of those who said that they didn't want to go out more often than they already did (52%, n=107), many reasons were given including not being able to go out alone or unaccompanied, a lack of confidence, being content with their current situation, problems related to their visual impairment, mobility problems and other health problems or disabilities, and fear of crime.

Participants were asked a series of questions about independent living skills that involve 'micro-mobility' skills, for example preparing a meal, household cleaning, personal care (washing, dressing, etc), and getting about the home:

- 42% of the sample experienced difficulty with tasks involved in household cleaning;
- 36% found difficulty in preparing a meal;
- 24% with personal care tasks;
- 22% found difficulty in getting around their home.

Participants who did not live alone (n=133) were asked whether or not they received help with any of these tasks from anyone that they lived with, and the majority (83%) confirmed that they did. This was most commonly a spouse or partner (75%) or a child that lived with them (20%). All of the participants, regardless of household composition, were asked whether anyone from outside the home helped them with any of these daily tasks. Just over half of the sample (55%) said yes, and this was most often paid help (44%), followed by children (31%), a friend or neighbour (21%), and social services employed workers (13%) including social workers and rehabilitation workers.

Issues relating to travel and independent living skills were the two most common themes that were raised by participants with hearing impairment in response to the open question, substantiating their importance. Comments were almost exclusively negative, focusing upon the difficulties faced in travelling or in carrying out various independent living skills.

Common difficulties cited when travelling on foot were obstacles such as street furniture and people:

ID 264
Age 51, Male
Does not live alone
Working Age (Not Working)
Registered Blind
“Walking on the pavements, especially near town - you get children running in and out of shops and I bump into them. I can see but not to my left at all - have a blank spot. Obviously timetables and things like that, I can't see them at all - bus times or train times. It's just getting around really - mobility's the hardest part. There's no transport in this area at all really.”

ID 159
Age 68, Male
Does not live alone
Retirement age
Registered Blind
“It's quite difficult with any problem a person might have, but up till recently I felt I coped ok, but recently I'm struggling more, have to be more aware of what’s around me when I'm out and about. Biggest problem is in supermarkets and walking, especially young children, it's not their fault, but I'm frightened I'll knock them over when they’re running about. Negotiating the streets when the advertising boards are outside the shops - they're like obstacle courses, even without the people. And the wheelie bins get in the way on the pavements. Don't blame the people as such; they have nowhere else to put them. Used to grow flowers once upon a time, now its bins.”

ID 411
Age 56, Male
Does not live alone
Working Age (Working)
Registered Partially Sighted
“The other two greatest problems of low vision are rubbish and lamp posts - clutter is the worst. Within shopping areas the kinds of things that are not taken into account for visually impaired people like all the signs outside shops, like sandwich boards and the sprawl of stuff outside the shops on the pavement, and dog mess. These are the most difficult bits of being able to cope.”

The need for assistance from others to complete various tasks around the home was often described. The following is an example where the participant depends heavily on her husband for assistance with various tasks requiring mobility that she would otherwise find difficult, both on a micro level (e.g. locating items, reading labels) and a macro level (e.g. navigating new places):

ID 557
Age 72, Female
Does not live alone
Retirement age
Registered Partially Sighted

"If I didn't have my husband I don't know what I'd do. Looking at prices, menus, ingredients, instructions is very hard. Small print (e.g. UP TO half price), people putting things in the wrong place in supermarkets makes it difficult. Going from dark to light (e.g. in restaurants) is difficult. Going anywhere strange is hard because you don't know where the steps are etc. I help myself by having a white lining in my handbag and a bright red purse. I have coloured wine glasses and mugs etc so I don't knock them off the shelves. I have everything brightly coloured so they're easier to see and also more cheerful. Travelling is difficult, I need warning when my husband is going to overtake because I can't see so it's scary. My husband now warns me and tells me what is happening when we're driving. When going to a new hotel I feel embarrassed, I don't use my white stick when I'm with my husband. He is wonderful."

As with the participants without hearing loss, the inability to drive leading to a lack of independence was a common issue that many participants with hearing loss lamented about:

ID 106
Age 84, Male
Lives alone
Retirement age
Registered Blind

"The biggest problem that I've found is not being able to drive - been driving since I was 15 and it broke my heart when I had to give it up. And now 100 yards away I can't see a car coming. That's really upset me. Because I used to be able to go out socially on my own - I can't now."

Many participants talked about independent living skills that involve micro-mobility tasks, such as locating items around the home, maintenance of other health conditions or disabilities, and using appliances and technology in the home, for example:

ID 646
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, for example 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. Operating the television and radio is difficult, I have to remember which button is where. I can break things or drop and spill things when I'm eating. There's very little pleasure.”

The following example demonstrates how a participant has learned to adapt to the difficulties she faced in both micro and macro mobility due to her hearing and sight impairments, with help from her friends and people in the community:

ID 114
Age 70, Female
Does not live alone
Retirement age
Registered Partially Sighted
“I used to find it very difficult that I couldn't see on my right side and kept bumping into people, and because of my deafness. Friends now tell me who they are and where they are. I find that everything's a lot better these days - like my bank, the staff are very helpful - I pushed the wrong numbers when I put my card in - it's only since my field [of] vision went on my left side that things are more difficult, but I compensate for it now, I use my white stick on the other side now. It's the little things like not being able to write properly. I have to say I don't like to be dependent on people even though they say they don't mind. I miss being able to drive, I miss the freedom of being on my own. I miss being able to go and walk along the prom on my own. But all in all I don't feel I have much to moan about. I can't fault the hospital staff or the district nurses - they all went out of their way to help me.”

Cambridge study analysis

Background to the 'Cambridge study'

The Cambridge study comprised a cross-sectional study involving the entire membership of a charity for people with dual sensory impairment, Deafblind UK. A covering letter and two questionnaires were sent out in February 2005 with the regular Deafblind UK newsletter and participants were given one month to respond. Of the full adult membership (2,717 people), 555 returned the survey. The number of viable responses was 539, an overall return rate of 19.8%. Though low, this is a typical response rate for surveys of people with dual sensory impairment.

The aims of the Cambridge study were:

1) to carry out a systematic survey of the mental health needs of these men and women, using the database maintained by Deafblind UK; and

2) to investigate the levels of support which this group of men and women receive in order to inform the development of appropriate services.

The specific hypotheses were:

1) Compared with the general population, older people and people with a single sensory impairment, a higher proportion of people with deafblindness will meet the criterion for 'caseness' (i.e. meet or exceed the threshold for significant psychological distress).

2) There will be a large discrepancy between the level of service provision individuals with deafblindness want and their perceived level of support.

Cambridge sample

As per the aims of the Thomas Pocklington Trust study, the secondary data analysis of the Cambridge dataset focused on a sub-sample of participants aged 50 years and over with both hearing and sight loss. This equated to 404 people: 252 women and 152 men. Participants were divided into three age categories:

- 50-64 year olds, 66 participants;
- 65-74 year olds, 37 participants;
- 75+ year olds, 297 participants.

The sample was representative of the Deafblind UK membership. The mean age of the sample was 80 years.

All participants, by the nature of their membership of Deafblind UK, had dual sensory loss. The survey was tailored to each individual member by Deafblind UK and sent in their requisite format, e.g. large print, braille, Moon, audio-tape and so forth. Stamped addressed envelopes were enclosed for the surveys to be returned free of charge.

The survey provided prompted subjective measures of the participants' hearing and visual impairments – for their hearing loss, participants could select from descriptors such as 'mild', 'moderate', 'severe', 'profound' and 'other'; for their sight loss they could choose from 'partially sighted', 'blind' and 'other'. We also asked about the causes of the participants' hearing and sight losses (unprompted) and the ages at which they acquired these.

The unprompted responses that are most pertinent to the Thomas Pocklington Trust hearing and sight loss study were derived from the following open-ended questions:

- **Q13**: "[If you did not receive help to come to terms with the loss of your sight and hearing] What kind of help [would you have wanted]?"
- **Q15**: "What are the main difficulties of being deafblind?"
- **Q16**: "Is there anything else you would like to tell us?"

As part of the analysis, the responses to these questions have been coded into different categories that will be described in the following section.

Description of the survey and analysis

The survey comprised two questionnaires:

A specially devised self-report questionnaire that requested the following information:

- Demographic details about the participant;
- Causes of their dual sensory losses;
- Ages of onset of their dual sensory losses;
- Subjective measures of their dual sensory losses;
- Whether they received support at diagnosis; if not, what kind of help they would have liked;
- (If yes to the preceding question) details of the support provided;
- The main difficulties of having a dual sensory impairment;
- Anything else the participant wished to tell us.

The General Health Questionnaire (GHQ-12 'How You Feel', see Appendix 1), an established self-report test encompassing 12 questions used to screen for mental distress and psychological ill-health; this measure is a clinically validated and internationally recognised self-report measure that has been shortened from the GHQ-60 (GHQ-12, Goldberg and Williams, 1991). According to Goldberg, Gater, Sartorius, Ustun, Piccinelli, Gureje and Rutter (1997), the shorter GHQ is ‘remarkably robust and works as well as the longer instrument’ (p. 191).

An initial descriptive analysis of the Cambridge dataset was undertaken using Excel in order to ascertain the characteristics of the sample. The data collected from the 404 participants was then exported from Excel into a Word document and subsequently imported into the data analysis software package QSR Nud*ist Vivo (NVivo), version 1.2. The qualitative responses to Questions 13, 15 and 16 of the ‘About You’ questionnaire were then coded in NVivo.

Each individual response in NVivo was accompanied by the following details:

- the participant’s unique ID number;
- the participant’s age;
- their sex;
- cause of their hearing loss;
- cause of their visual impairment;
- age of onset of hearing loss;
- age of onset of visual impairment;
- subjective measure of hearing loss;
- subjective measure of visual impairment;
- question 13 response;
- question 15 response;
- question 16 response; and
- the participant’s GHQ-12 score.

As a starting point, the unprompted responses of Questions 15 and 16 from each participant were coded according to the Department of Health’s (DoH) working description of deafblindness (Think Dual Sensory, DoH, 1995) i.e. persons are considered deafblind if their combined sight and hearing impairment causes difficulties with access to information, communication and mobility.

As for the Network 1000 analysis, the data from the responses to questions 13, 15 and 16 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 a number of themes, using the ‘Network 1000’ topics as a starting point and then broadening these, in addition to creating brand new themes.

The qualitative data was coded into five broad categories: (1) emotional, (2) social, (3) practical, (4) physiological and (5) miscellaneous. These were then sub-categorised, identifying some 40 themes which are described in a later section.

Description of the sample

Characteristics of the sample

The mean age of the 404 participants was 80 years, with the oldest being a female aged 104. Nearly three quarters (74%) fell into the 75 years and over age group. Nearly one in five (16%) were aged 50 to 64 years and one in ten (9%) were 65-74 years. More than 3 in 5 (62%) of the participants were female. A full descriptive summary of the Cambridge dataset, by sex, can be seen in Appendix 2.

Half of the participants reported themselves as having ‘severe’ hearing loss and 62% as being ‘partially sighted’. The main causes of hearing loss were reported as ‘unknown’, ‘old age’ and ‘occupation’. The dominant causes of visual impairment were ‘macular disease’, ‘old age’ and ‘glaucoma’.

On average, both visual and hearing impairments occurred around middle age with the onset of hearing loss occurring at age 51 and sight loss at age 61. More than three fifths of participants (62%) acquired their hearing loss prior to their visual impairment, with an average difference of 24 years between these losses. For those who first acquired sight loss (27%), the average time delay was smaller (18 years). One in ten people acquired both their hearing and sight losses concurrently.

In total, 32 participants indicated that they had other conditions or disabilities in addition to their dual sensory impairment; these included arthritis, Down’s syndrome, heart disease, cancer, brain haemorrhage and autism.

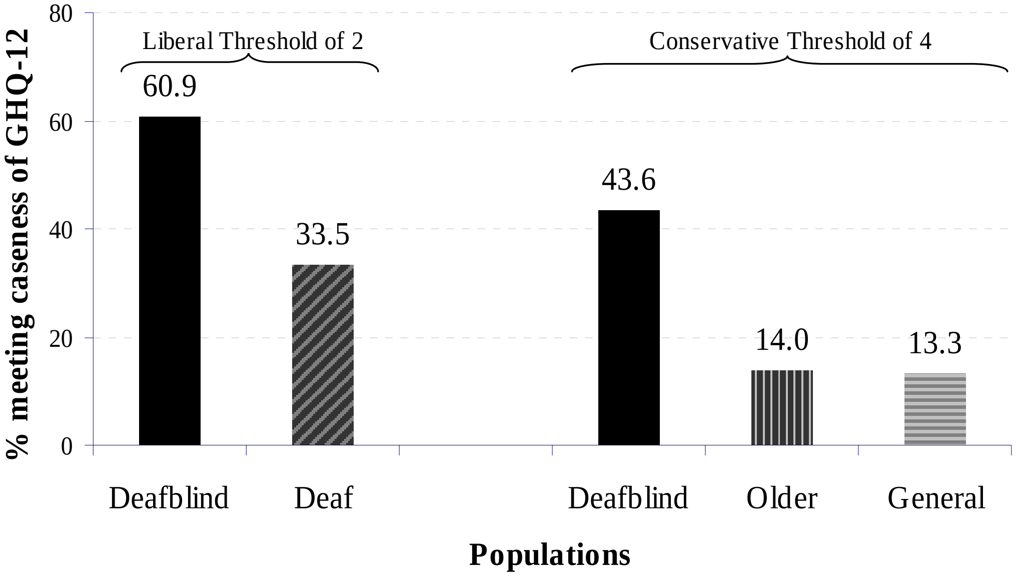
There were 312 useable GHQ-12 responses and the mean score for all persons was 3.8, out of a maximum of 12. GHQ ‘caseness’ is measured via a threshold that indicates whether a participant’s score lies above normal levels of psychological distress and would therefore benefit from further assessment. The higher the score, the more ‘psychological stress’ one is exhibiting. Using the most conservative threshold of ‘4’, 43% of participants indicated psychological distress. With a more liberal threshold of ‘2’, more than 3 in 5 (61%) of the sample reported psychological distress.

Table 4. Mental distress levels of the Cambridge dataset. Base: all participants aged 50+ (N=404).

	Mean age of participants	Mean age of onset - hearing loss	Mean age of onset - sight loss	Mean GHQ-12 score	Caseness ≥2	Caseness ≥4
Males	79	49	59	3.5	59.0%	39.3%
Females	81	52	63	4.1	62.1%	46.2%
All	**80**	**51**	**61**	**3.8**	**60.9%**	**43.6%**

We can compare the level of GHQ-12 caseness within the Cambridge dataset to other groups - older people (Health Survey for England, 2000), the Deaf (De Graaf and Bijl, 2002) and the general population (Health Survey for England, 2003); the proportion of Cambridge survey participants exhibiting mental distress is considerably higher than all the other groups (see graph below).

Table 5. Proportion of Cambridge participants meeting caseness of GHQ-12 in comparison with other populations.



GHQ-12 mean scores were highest among the 50-64 age group. All males and females in this age group had a mean score that was above even the conservative threshold (4.3).

The lowest score was attained by males aged 65-74 years (3.3 out of 12). The average GHQ-12 score of the 75 years and over age group was 3.7.

Men fared better in the GHQ-12 than women. The average female score was 4.1 out of a possible 12, which indicates that caseness is high whether the threshold is liberal (>2) or conservative (>4). The average male GHQ-12 score was nevertheless high (3.5). The proportion of men and women meeting caseness for the liberal criterion was 59% and 62% respectively. Two fifths of men (39%) and nearly half of women (46%) still met caseness for the conservative criterion.

Participants' issues and difficulties

Question 13 relates to participants' perceptions of their needs and services and has thus been analysed separately from Questions 15 and 16. Questions 15 and 16 have been analysed together using Boolean union searches in NVivo.

There were 211 cases where no response was given for Question 13, 29 cases for Question 15, and 170 for Question 16.

Of the 404 participants, nearly three quarters (72%, n=290) mentioned at least one of the three DoH themes in their responses to questions 15 and 16 that concerned the main difficulties they associated with dual sensory impairment and any other issues that they wished to divulge (note that some participants mentioned more than one):

- communication was mentioned by 43% of participants (n=172);
- access to information was mentioned by 36% (n=147);
- mobility was mentioned by 36% (n=145).

The second 'grounded' phase of coding generated a further five broad themes for all questions. These are listed below in order of most cited:

Table 5. Number of participants identifying each theme, by question type. Base: all participants (N=404).

	Total sample (n)	
	Questions 15 & 16	**Question 13**
Practical (P)	264 (65%)	94 (23%)
Social (S)	221 (55%)	37 (9%)
Emotional (E)	154 (38%)	66 (16%)
Miscellaneous (M)	41 (10%)	15 (4%)
Physiological (Ph)	33 (8%)	2 (0.5%)

These five themes were further categorised into 40 sub-themes. These are presented in Table 6 and give an insight into the broad range of topics participants described.

In the following sections the three DoH themes (Communication, Access to Information, and Mobility), as well as the five ‘grounded’ themes are discussed and illustrated with quotes.

Table 6. Themes and sub-themes generated in the analysis of the Cambridge open-ended questions (% based upon answers to question 15 and 16, only figures 5%+ given). N=404.

Theme	% (n)
EMOTIONAL	**38% (154)**
Dependency or loss of independence	23% (91)
Adjustment	9% (38)
Trauma	-
Unhappiness	-
Lack of support	-
Frustration	-
Loss of confidence/self-worth	-
Counselling or talking to someone (*Q13 only*)	-
SOCIAL	**55% (221)**
Isolation and loneliness	26% (106)
Isolation within groups	13% (51)
Communication	30% (172)
Telephone	7% (28)
Lack of awareness	10% (39)
Attitude of others	13% (51)
Contact with people with same/similar condition	-
Holidays	-
PRACTICAL	**65% (264)**
Access to information	36% (147)
Reading	21% (85)
TV	12% (48)
Mobility	36% (145)
Crossing roads/traffic	-
Independent Living Skills	33% (133)
Shopping	11% (46)
Finances	-
Technology	-
Hobbies	13% (52)
Housework (including cooking)	20% (81)
Employment and education	
Thanks and appreciation of help	7% (28)
Formal sources	6% (23)
Informal sources	
Information and advice (*Q13 only)*	
PHYSIOLOGICAL	**8% (33)**
Other conditions or disabilities	7% (30)
MISCELLANEOUS	**10% (41)**
Religion	-
Other people worse off	-
Anything/Everything/Life in general	-
Deafness harder than blindness	-
Blindness harder than deafness	-
Completed on behalf of participant	-

Communication and social issues

Communication was the most cited issue for participants when asked about the difficulties they experience due to their dual sensory impairment – it was mentioned by more than two fifths of participants. Levels of hearing and sight loss varied from person to person. Regardless, communication was a major worry whether the individual had any residual sight and hearing or not. One participant, who required the survey to be completed by a third party and was profoundly deaf and blind, indicated just how difficult communication can be:

> ID 428
> Age 96, Male
> Level of HI: Profound
> Level of VI: Blind
> “He can't communicate at all. He can't listen to the radio, tapes or anything and obviously can't watch television. Conversation is virtually impossible.”

Some participants identified a gap in support services that people with dual sensory loss fall into as their needs are unique and cannot be addressed by organisations that deal with single sensory loss:

> ID 135
> Age 60, Female
> Level of HI: Moderate
> Level of HI: Partially Sighted
> GHQ-12 score: 10
> “If I contact RNIB all solutions are in terms of sound. If I contact RNID all solutions are in terms of sight. I have to say "solutions in terms of touch please" (and we are a society that hates touching strangers). I have some sight/hearing but people hate me leaning into their 'personal space' however much I explain. However people who have no useful sight/hearing manage modern life. I don't comprehend. I dread the day I lose what I have got (do you realise how the TV licence people couldn't believe we have no television!!”

More than half of participants stated that they experienced real difficulties with social issues, often stemming from communication difficulties. These included isolation within social settings, the attitudes of other people, general feelings of isolation and loneliness, and a general lack of awareness of deafblindness amongst the public.

Many participants indicated that conversation in a social setting can be impossible as visual cues can be missed and other people who should make the effort to express themselves clearly often fail to. A problem distinctive to dual sensory loss is the contradiction of being physically present at social occasions but excluded from any conversation involving more than one person. More than one in ten participants mentioned this sense of group isolation. The following is just a selection of the many examples that were given:

ID 286
Age 88, Female
Level of HI: Severe
Level of VI: Partially Sighted
GHQ-12 score: 8
"When I am among people I can hear practically nothing and find most people don't understand or take time to speak to you. I feel very left out and lonely even amongst crowds..."

ID 53
Age 77, Male
Level of HI: Other
Level of VI: Blind
GHQ-12 score: 0
"My greatest difficulties in coping with blind and very hard-of-hearing have related to communication. As stated above I do not normally have any problems in a small group, provided the others in the group speak clearly. Problems arise in bigger groups and particularly in public meetings and lectures and, say, in making contact with someone standing next to me in a pub or other noisy place. There is also communication in a broader sense. I can use a telephone fairly adequately but reading and answering correspondence has been difficult. In the latter case having a computer and being able to email people has been a tremendous godsend."

ID 252
Age 96, Female
Level of HI: Severe
Level of VI: Partially Sighted
"When I am with a number of people I cannot hear and feel isolated."

ID 138
Age 93, Male
Level of HI: Severe
Level of VI: Partially Sighted
GHQ-12 score: 2
"The loss of my independence. I am not longer able to prepare meals and live alone. I could not check the freshness of food in the fridge, for example. Loss of hearing means I cannot hear in a group and find it hard to socialize. This undermines my confidence and increases loneliness."

ID 303
Age 90, Male
Level of HI: Severe
Level of VI: Blind
GHQ-12 score: 11
"An outsider when more than one person is speaking. One tends to live in your own world."

The isolation felt by some appeared to be intolerable:

ID 242
Age 52, Male
Level of HI: Profound
Level of VI: Partially Sighted
GHQ-12 score: 12
"Because I have a lot of problems and all are getting worse and I am stuck here alone [in the] daytime - I cannot guarantee I will be here tomorrow. I think about dying constantly."

ID 232
Age 53, Female
Level of HI: Severe
Level of VI: Partially Sighted
GHQ-12 score: 0
"Blindness does not bother me much - used to it as a child. The severe deafness bothers me a great deal and I feel very lonely and alone in the world."

The kind of isolation cited in the many examples above is often a result of other people's lack of awareness of the unique needs a person with both hearing and sight loss has with regard to communication. Many felt that there needed to be greater awareness raising about issues relating to being dual sensory impaired:

ID 379
Age 52, Female
Level of HI: Severe
Level of VI: Blind
GHQ-12 score: 7
"There is a great need for the public and service providers to understand significances of red and white stick or harness on Guide Dog, or red and white armbands worn by Guide Dog owners. Medical staff need disability awareness training."

ID 442
Age 74, Female
Level of HI: Severe
Level of VI: Blind
“People do not understand about my red and white cane. Distance can be a problem.”

The attitude of other people was the ninth most cited difficulty for participants. This relates to a general lack of awareness of dual sensory impairment and consequent treatment of the individual with hearing and sight loss:

ID 476
Age 62, Female
Level of HI: Severe
Level of VI: Partially Sighted
GHQ-12 score: 1
“People misunderstanding me or thinking I'm mentally ill as well as blind. People not being patient or unable to make me understand what they are saying to me, particularly in noisy surroundings or in dimly lit places. I can't always guarantee if I ask for help that I'll be able to hear what the person says.”

ID 185
Age 57, Male
Level of HI: Severe
Level of VI: Blind
GHQ-12 score: 11
“Number 1, I can't see, Number 2, I can't hear. Number 3, people keep calling me ‘dear’ and asking if I want to go to the toilet. I have dual sensory loss. I am not mentally retarded and don't like being treated as such.”

ID 499
Age 77, Female
Level of HI: Severe
Level of VI: Blind
GHQ-12 score: 6
“Deafness is so misunderstood. Although I am deaf as a post I am not as thick as a plank! When deafness is combined with real sight problems it can be very disabling. Trying to cope all the time can be very stressful”.

Access to information

Nearly 40% of participants cited access to information as one of their main difficulties. This includes reading small print and labels, completing forms, reading bus numbers and so on, as well as accessing information about support that they could receive.

ID 293
Age 84, Female
Level of HI: Profound
Level of VI: Partially Sighted
GHQ-12 score: 0
"Shopping/money. Seeing faces and people. Reading/writing. Recognising people. Electric switches and controls. Signposts. Subtitles on TV. Price labels/sizes. Talking lifts/gadgets not good."

ID 373
Age 58, Female
Level of HI: Profound
Level of VI: Partially Sighted
GHQ-12 score: 11
"The feeling of isolation in the company of normal people, not knowing what is being said and a rude feeling of looking round at their faces. Getting around on my own i.e. bus number - I took a 57 for a 37 and realised I was on a different route, not knowing when fares increase and trouble communicating with the driver." "Chip and Pin - how can a person who is deaf and blind use it unless it can be picked up and held closely? I reckon banking is a big worry for people like myself as technology keeps changing and you can feel embarrassed in a bank or shop with the public all around you. I recently found a nice big cash machine with large clear prints, but they are rare."

ID 114
Age 90, Female
Level of HI: Moderate
Level of VI: Blind
GHQ-12 score: 12
"Reading newspapers and letters, shopping, buses. Seeing labels on almost every single article of clothing. Nightmare. Shop assistants haven't the time to help. I'm coping with my writing I'm sorry to say is awful I cannot see the words I write. Gardening - how does one see the weeds and plants? Holidays one has to be so careful, no stairs, steps, dark corridors."

Over 20% of participants indicated that they miss being able to read – whether as a hobby or in order to access information:

ID 254
Age 88, Male
Level of HI: Moderate
Level of VI: Partially Sighted
GHQ-12 score: 5
"I'm reasonably well, I go out for walks every day, eat properly but miss terribly being able to read."

Mobility and Practical Issues

Many participants talked about practical issues relating to mobility, that fall into both macro and micro mobility tasks (see discussion earlier about macro/micro distinction).

Thirty six per cent of participants cited their lack of macro mobility, including difficulty in crossing the road and being able to see traffic:

ID 382
Age 50, Female
Level of HI: Moderate
Level of VI: Partially Sighted
GHQ-12 score: 2
"Not being able to see cars coming, crossing the roads, always having to move head around to see where going as you know tunnel vision you can only see in front. So you do not know where to put feet, steps, banging into things, lots of bruises on legs. Being deaf is that you cannot have a proper talk with people because you only hear bits and background noise."

ID 114
Age 90, Female
Level of HI: Moderate
Level of VI: Blind
GHQ-12 score: 12
"I wish I'd never had the laser treatment. I could see teletext on the TV and could see very well. Now I have to get inside the box to see and again find the radio my friend. The shock of losing one's eyesight is awful. You don't want to live and feel suicidal. You lose your confidence afraid to go out. I loved going out, I went dancing twice a week, love shopping, painting, any craft I love doing. Now it's all gone."

More than 65% of participants indicated that some of the main difficulties associated with their dual sensory impairment were practical issues. Their main problems often arose with independent living skills including housework, cooking, shopping, hobbies and reading (for both pleasure and house-keeping, etc).

The following are some illustrative examples where participants found shopping very difficult:

ID 28
Age 64, Female
Level of HI: Severe
Level of VI: Partially Sighted
"Being in shops where it is very difficult to hear what people say to you. Also when people ignore you and walk straight across in front of you."

ID 62
Age 68, Female
Level of HI: Severe
Level of VI: Blind
GHQ-12 score: 6
“I try to be as independent as possible but find some people and some shops etc seem to have little patience especially dealing with money. Shopping malls are my biggest difficulty with so many people about with little patience for my seeing disability”.

Others cited housework as something they are unable to do themselves:

ID 467
Age 79, Female
Level of HI: Moderate
Level of VI: Partially Sighted
“Can't do housework, can't mix with people, can't read, close my eyes most of the day.”

Some participants said that they found a variety of micro and mobility tasks extremely difficult with impaired sight and hearing:

ID 270
Age 91, Female
Level of HI: Severe
Level of VI: Blind
GHQ-12 score: 1
“I miss reading. I find social situations difficult and don't go out because I can't hear in a group. I can't see or hear the TV well and I get very lonely. It's hard to hear my family when they phone and I'm scared to cook because I can't see.”

Enjoyable tasks and hobbies such as sewing, listening to music, reading for pleasure, sporting activities and so on appear to be difficult for many of the participants to undertake. More than one in ten of the participants stated that pursuing their hobbies was difficult, if not impossible, for them. This has an obvious impact on their quality of life:

ID 386
Age 81, Female
Level of HI: Profound
Level of VI: Partially Sighted
“From leading an enjoyable, full and very active life - I am now down to nothing. All my interests, hobbies and friends have disappeared. No driving, golf, sewing, knitting, reading. China painting - (my favourite), entertaining, now I can only watch TV (close seat) and have to make up my own dialogues. Strange, but friends do desert you when you cannot communicate. Hope you can read my writing.”

ID 458

Age 79, Female
Level of HI: Severe
Level of VI: Blind
GHQ-12 score: 1
"As I can't see - I feel isolated. In company I can't see people's faces and don't know if I'm being addressed. Can't eat out socially - at home I feel for food on my plate. Rely on daughter to buy clothes, I cannot see colours. I cannot cook, sew, knit, read - all the things I used to love. I no longer watch TV. I cannot hear without hearing aid and sometimes feel like a social outcast."

In some cases, participants said they had difficulty in gaining employment, despite feeling that they have the capacity to do so:

ID 538
Age 57, Male
Level of HI: Severe
Level of VI: Partially Sighted
GHQ-12 score: 6
"Finding a job. Every time I apply I get the same answer - we have no jobs. When I did not say I am registered or disabled they have jobs. Getting assistance at stations, especially Colchester. No lift or loop. I have difficulty going out in the dark."

Emotional issues

Emotional issues were cited by nearly 40% of participants. Difficulties arose from dependency on others and loss of independence, adjustment to their condition and unhappiness. Counselling or talking to someone about their condition at the time of diagnosis was the second most cited issue for Question 13.

If a person experiences difficulty with communication, access to information and mobility then they may well require assistance with many parts of their life. Nearly one quarter (23%) of participants indicated that dependency was a major difficulty associated with their condition.

ID 397
Age 50, Male
Level of HI: Profound
Level of VI: Partially Sighted
GHQ-12 score: 0
"Can't go anywhere on my own or do many things for myself."

ID 140
Age 64, Female
Level of HI: Profound
Level of VI: Partially Sighted
GHQ-12 score: 2
"Loss of independence. Having to rely on mechanical aids and people to cope."

ID 201
Age 66, Male
Level of HI: Severe
Level of VI: Blind
"To get around by myself and not with my wife all the time. We are always together. We need to have time apart to ease the strain on ourselves."

Adjusting to this level of dependency and a sense of loss can be extremely difficult:

ID 135
Age 60, Female
Level of HI: Moderate
Level of VI: Partially Sighted
GHQ-12 score: 10
"I used to be a teacher in primary school, as I became more disabled my life crumbled in front of me. I could write a book about what happened to me - only no-one would believe it! Practical problems: pin machines at checkouts; banking - explaining what I want; shopping - finding way in big shops; walking in town; just communicating with people. I had a visit from cousin I had not seen for 20 years. The contrast between myself and her - I could not hear her clearly or see photos of her (grown) children - and her joy at being a fit 60 - made my disabilities so much more obvious to me."

Coming to terms with the diagnosis of dual sensory loss can often be traumatic and make people feel depressed:

ID 379
Age 52, Female
Level of HI: Severe
Level of VI: Blind
"Emotional support. I feel like I have suffered a bereavement. It came as quite a shock to be told I have lost over 80% of my hearing."

ID 115
Age 94, Male
Level of HI: Severe
Level of VI: Blind
GHQ-12 score: 1
"Sympathy. Boredom. Being unable to read, see or hear TV, talking books or radio. Unable to do crafts. No longer able to do chores around the house. Difficulty in recognising friends in street. Inability to play card games, join in conversation, to appreciate any music. Sorry but all this makes me depressed."

Some participants indicated that they were frustrated as a result of their dual sensory loss:

ID 82
Age 80, Female
Level of HI: Profound
Level of VI: Blind
GHQ-12 score: 1
"It's a damn nuisance! I get annoyed, frustrated and cross."

ID 303
Age 90, Male
Level of HI: Severe
Level of VI: Blind
GHQ-12 score: 11
"To help with short cuts to make up for the loss of sight and deafness. At an elderly age and chair bound, life can be very frustrating."

Some participants felt that they had not received the support that they needed with their condition:

ID 435
Age 79, Male
Level of HI: Profound
Level of VI: Blind
"In the early days of deafness I received some help. As time went on, and people moved, my help stopped. I am a very proud and independent man and I feel and know if I had been what I call a whinger I would have been receiving more help with deafness. More contact with Deaf Blind would be very appreciated and a few suggestions on how to fill in my long days. I do keep as busy as possible, but not being able to see TV or listen to radio makes some days seem twice as long. I liked doing cane work but now I can't do that because of arthritis in my shoulder."

Twenty per cent of participants who answered question 13 (that explored the kind of support they would have liked at time of diagnosis) indicated that they would have liked more information and advice regarding their condition at the time of their diagnosis.

Many participants stated that they had been provided with only the name of their condition and failed to receive any further details or support afterwards:

ID 66
Age 54, Male
Level of HI: Mild
Level of VI: Blind
GHQ-12 score: 2
“Someone to talk to, explain what is available/where to go etc. Not to feel cut off.”

ID 153
Age 78, Male
Level of HI: Severe
Level of VI: Partially Sighted
GHQ-12 score: 7
“Explanation that went beyond 'go home and live with it'….”

ID 142
Age 78, Female
Level of HI: Profound
Level of VI: Partially Sighted
GHQ-12 score: 3
“More information about what was available and what help I could expect in the future - no info from the eye specialist and even had to ask about being registered.”

ID 2
Age 85, Female
Level of HI: Other
Level of VI: Other
GHQ-12 score: 9
“More information about my condition and to be told in more detail what would happen to me. Some empathy would have been nice.”

Aside from wanting more information and advice, 16% of participants wanted someone to talk to about their diagnosis and provide them with emotional support:

ID 325
Age 86, Female
Level of HI: Profound
Level of VI: Blind
GHQ-12 score: 1
“Someone to read correspondence, magazines, write Christmas/birthday cards. Someone to listen and talk with me who understands the loneliness and isolation.”

ID 176
Age 59, Male
Level of HI: Severe
Level of VI: Blind
GHQ-12 score: 5
"Someone outside the family to talk over the problems, difficulties and frustrations."

ID 216
Age 62, Male
Level of HI: Profound
Level of VI: Partially Sighted
GHQ-12 score: 12
"Counselling - my wife left me saying she didn't want to be married to a deafblind cripple."

Twenty per cent of participants stated that they would have liked contact with other people who were deafblind as a way of coming to terms with their diagnosis:

ID 59
Age 66, Female
Level of HI: Other
Level of VI: Partially Sighted
GHQ-12 score: 4
"Chance to swap notes with similarly affected could have been helpful."

ID 476
Age 62, Female
Level of HI: Severe
Level of VI: Partially Sighted
GHQ-12 score: 1
"It would have been helpful to talk over some of my problems with either another sufferer or other person who could have reassured me that I was able to cope with my life - I felt isolated and afraid as I hadn't realised my hearing was going gradually."

On a positive note, some participants were keen to show their appreciation of the help that they had received in the past or were currently receiving, by both informal and formal sources. This shows that adequate services can be available to people with dual sensory loss and provides some hope that these can be broadened to reach the majority of those who need it:

ID 458
Age 79, Female
Level of HI: Severe
Level of VI: Blind
GHQ-12 score: 1
"I am grateful for phone calls from Deafblind - nice to know someone is happy to contact me and also when my daughter is on annual holiday - someone phones daily - a very good service - thank you."

Miscellaneous issues

Sixteen surveys were completed on behalf of the participant, presumably because the participant's level of sight loss made it difficult to access the survey.

Some participants stated that they found their hearing loss harder to cope with than their sight loss. People do not appear to be as understanding of this "invisible handicap" (participant ID 166) as they are of visual impairment:

ID 11
Age 84, Female
Level of HI: Severe
Level of VI: Partially Sighted
GHQ-12 score: 4
"Deafness more isolating than blindness. People talk about my needs to others rather than address me directly, excluded from conversations due to poor hearing rather than due to sight."

ID 293
Age 84, Female
Level of HI: Profound
Level of VI: Partially Sighted
GHQ-12 score: 0
"Being deaf is worse than being a visually impaired. As a deaf person I suffered being spat and sworn at, ignored and isolated. Now I carry a white stick (the red band not a lot of people recognise), I am treated with help and courtesy wherever I go. Magic!!"

ID 145
Age 85, Female
Level of HI: Severe
Level of VI: Partially Sighted
GHQ-12 score: 10

“In the main I think people are not aware of just how difficult it is to manage every day. I feel more upset and left out regarding my deafness than I do ‘peering around’ trying to see properly. I think people have more understanding of the sight problems than the hearing or lack of it! Perhaps the audiologists in hospitals need more training as in the local hospitals I have not had a good service.”

Summary and conclusions

There were two reasons for carrying out the secondary data analysis:

- to generate ideas regarding possible areas for investigation with participants during the case study phase of the project;
- as an important ‘end in itself’ because it provides an insight into the views, experiences and circumstances of 609 people with some kind of hearing and sight loss who are 50 years of age and over.

In this final section we attempt to bring together the findings from the Network 1000 and Cambridge studies, and map them against these two aims. First, we seek to identify the key themes to emerge from the analyses, and secondly, we consider the implications of these findings for the rest of the Thomas Pocklington research project.

Summary of findings

Both studies had quite different remits and it is therefore useful to consider some of the ‘quantitative’ findings from the analysis of each dataset in turn. This enables differences and similarities to then be made.

Network 1000

The Network 1000 study aimed to collect wide-ranging information about the circumstances, needs and opinions of the 582 participants who were aged 50 or over, enabling unique comparisons to be made between those with additional hearing loss and those with visual impairment only. The following points from the analysis are particularly noteworthy:

- Since the sampling method was random and focused upon people who were registered as visually impaired, the proportion of people with additional difficulties with their hearing is interesting in itself. It is also interesting that few identified it as a disability until they were prompted (particularly older people).
- In most regards, those with hearing loss appeared to differ relatively little to those without hearing loss, with some notable exceptions (i.e. they were older, and left their home less often). Perhaps surprisingly, differences were not particularly observed in relation to the three key issues of access to information, communication, and mobility.
- Even so, a clear difference observed was that those with reported difficulties with hearing did seem to have greater difficulty communicating by telephone. The telephone is an immensely important method of communication both practically and socially – particularly if mobility is a difficulty (as it is more likely to be amongst older people).

- In spite of there being few obvious differences between this sub-group and the comparable group of people with a visual impairment only, the report provides a rich description of the group:
  - they tend to be older (certainly compared with those without hearing loss);
  - a third lived alone, others with a spouse or their (adult) children;
  - the group had a wide range of functional vision;
  - the majority had additional health problems or disabilities;
  - over half wore a hearing aid;
  - most noticed their visual impairment before any difficulty with their hearing;
  - difficulties with travel, transport and mobility were common amongst the group;
  - difficulties with independent living skills followed by communication and reading were also prevalent.

Cambridge study

The key focus of the Cambridge study was to measure the mental or psychological health of the participants as measured by the GHQ-12. This was accompanied by demographic data about the participants, and more qualitative data that described the thoughts and feelings participants have about their hearing and sight loss, and their daily lives. The following points from the analysis are of particular interest here:

- Approaching 50% of the sample were at or above the (conservative) threshold that indicates they are experiencing above-normal levels of psychological distress and would therefore benefit from further assessment;
- Similar to the Network 1000 sample, the participants tended to be older, with a mean age of 80;
- Unlike the Network 1000 sample, the majority had experienced loss of hearing before acquiring their visual impairment, and many felt that their hearing impairment was worse or more ‘disabling’ than their visual impairment;
- Issues relating to communication and the resulting isolation and loneliness were identified as key factors affecting participants, in the qualitative analysis;
- Feelings of loss of independence and resulting dependence upon others were also commonly expressed;
- Many described difficulty due to the lack of awareness and (negative) attitudes of (mainstream) service providers and the general public towards them and their sight and hearing loss.

Discussion of findings

Much of the qualitative data in both studies reflects the difficult circumstances that people experience due to their hearing and sight loss (whether directly or indirectly). In the case of the Cambridge study, the qualitative data, to some extent, provides likely explanations for their high levels of psychological distress, which were much higher levels than found with general or older populations; this has far reaching implications for service providers who aim to meet the needs of people with hearing and sight loss. Although the Network 1000 study did not include a measure of mental health, the qualitative data presented from that study also provides many examples of difficulties that participants face on a daily basis. In both studies, issues relating to communication, mobility and access to information were prevalent, supporting the DoH definition (DoH 1997). Perhaps unsurprisingly, social and emotional issues relating to time of diagnosis and coming to terms with hearing and sight loss and its consequences were also common across the samples, as well as reflections about the attitudes and awareness of the general (sighted/hearing) population about dual sensory loss and its consequences.

Perhaps an important reflection is how the two samples differ. Again, the lack of overlap between the two studies means that this is difficult. Nevertheless, it is likely that participants of the Cambridge study (who were all on the Deafblind UK membership) had more severe hearing impairment than the Network 1000 study sub-sample. Many of the Cambridge sample described their hearing impairment as severe or profound (59%), and the sample appeared to have an earlier onset of hearing impairment compared with the Network 1000 sample (though the onset of visual impairment was younger in the Network 1000 sample). This suggests the aetiologies of both the hearing and sight losses are different for the two samples – the hearing loss in the Network 1000 sample is more associated with age-related conditions than the Cambridge sample; similarly the sight loss in the Cambridge sample is more associated with age-related conditions than the Network 1000 sample.

Nevertheless, there is likely to be an overlap between the samples (e.g. some of the Cambridge sample are likely to be registered as blind or partially sighted). It is possible that the order (and age) of onset of each impairment as well as the severity of the condition dictates how people define and describe themselves (e.g. ‘deafblind’ more likely amongst the Cambridge sample compared with ‘visually impaired with some hearing loss’ in the Network 1000 sample).

The qualitative data presented from the two studies offers very powerful and rich insights into the participants’ lives. Although the data generated from the two surveys is in response to different and non-standard questions it is striking that the themes identified by the analyses are similar. Of course this partly reflects the shared broad approach by the researchers (in particular using the DoH definition), but the evidence provided by both analyses is very persuasive that access to information, communication, and mobility (both macro and micro) are key challenges for both groups. Of additional relevance to both groups were consideration of support offered at time of diagnosis and beyond (e.g. information about their conditions(s), counselling, sign-posting to further support and information), and awareness-raising about the needs and circumstances of people with hearing and sight loss with the general (sighted/hearing) population.

Implications for the Pocklington study

The findings from the secondary data analyses have two broad implications for the remaining case study phase of the project; these include implications for the topics that we explore with the participants, and implications for the way that we communicate and work with the participants.

The design, collection and analysis of detailed studies is the key aim of this study. Our planned approach is to use methods over a period of eight months to enable 20 people with acquired hearing and sight loss to tell us about their lives. Through them, we also intend to speak to a variety of people around them (who may be the source of formal or informal support). The collection of personal stories of people with both hearing and sight loss are proposed in order to gather deep and rich information without depending too much on the point of view or leading of the research team. Participants will be given the opportunity to talk about their past, present and future lives through the use of techniques for gathering the participants' life-stories. In terms of the topics and issues that could be explored with the case study participants, it is important to note that the chosen method of the life story interview aims to encourage the participant to steer the interview and decide upon the areas of their life that they wish to focus upon. However, in light of the findings from the secondary data analyses outlined above, it seems highly likely that issues relating to communication, mobility and access to information will be touched upon by the participants to some degree. Therefore the DoH framework seems a useful way to help the researcher conceptualise the challenges and barriers that people face in their daily lives. Additional themes which were particularly evident and might also give the researcher points of discussion are issues of support offered at the time of diagnosis of either condition, general feelings that the general population do not understand the needs and circumstances of people with hearing and sight loss, as well general feelings of mental distress (a clear finding from the Cambridge study).

In terms of the implications for the way in which we approach and communicate with participants, the secondary data analyses has highlighted a number of practical challenges that the research team are likely to encounter; in terms of communication, there are likely to be some participants with whom communication will be very difficult, particularly where their hearing impairment is severe. It is expected that participants will find receptive communication more difficult than expressive communication. Expressive communication is more likely to be in speech with this particular 'target' group; this certainly appeared to be the case with many of the participants in both the Network 1000 and Cambridge studies. Baring in mind the challenges of communicating *to* participants, considerations such as care with the environment (lighting, background noise) and speed and approach to communication will be more important for many than technical or interpreting aids. However, additional support may include the use of finger spelling from an interpreter, the use of enlarged print or text as a main means of communication, or the use of devices to enhance hearing.

There are also likely to be more profound challenges to navigate, for example where participants are feeling and experiencing loneliness and isolation, and depression. People in this group can be very vulnerable, and a sensitive approach will be key. Of particular importance will be efforts to build trust and rapport between the researcher and participant, before interviews take place. Establishing a relationship with each participant is crucial. It is also important to be cautious about the language and terminology that we use when talking to participants about their hearing and sight loss due to their differing self-identities, depending in part on their ‘journey’ to their present circumstances; thus ‘don’t hear and see well’, ‘difficulties with eyes and ears’, may be preferable to terms such as ‘deafblind’.

In conclusion then, the analysis of secondary data has given much food for thought for the research team, in terms of both content and approach, and will help to ensure that the case study phase is carried out sensitively and efficiently, and enable the successful collection of data relating to 20 people with hearing and sight loss that will help to inform service provision within the UK to the wider population.

References

Bagley, M., (1998). "Acquired deafblindness network of deafblind international" IN Report; *Expert meeting on older people with vision and hearing loss, Copenhagen Denmark 18-24 March 1998.* Accessed online at: http://www.deafblindinternational.org/papers/elder.htm in May 2005.

Bodsworth, S., Clare, I., and Deafblind UK (in preparation). *Deafblindness and mental health: The mental health needs of adults with dual sensory impairment.*

Butler, Sarah (2004). *Hearing and sight loss: A handbook for professional carers.* England: Age Concern.

Chapman, C., (2002). "A Deafblind person's response." Zurich: EDBN Seminar. Accessed online at: http://www.sense.org.uk/professionals/research/papers/norway/cchapman.htm on 13th July 2007.

De Graaf, R. & Bijl, R. V. (2002). 'Determinants of mental distress in adults with a severe auditory impairment: differences between prelingual, and postlingual deafness', *Psychosomatic Medicine* 64, 61-70.

Department of Health (1997). *Think Dual Sensory: good practice guidelines for older people with dual sensory loss.* London: DoH.

Douglas, G., Corcoran, C., Pavey, S. (2006). *Network 1000. Opinions and circumstances of visually impaired people in Great Britain: Report based on over 1000 interviews.* Birmingham: Visual Impairment Centre for Teaching and Research, School of Education, University of Birmingham (mimeo). ISBN 0704426048/9780704426047.

Goldberg, D. (1972) *The Detection of Psychiatric Illness by Questionnaire,* Maudsley Monograph 21, Oxford: Oxford University Press.

Goldberg, D. & Williams, P. (1991) *A User's Guide to the General Health Questionnaire* Nfer-Nelson Publishing Company Ltd.

Goldberg D. P., Gater R., Sartorius N., Ustun T. B., Piccinelli M., Gureje O. & Rutter, C. (1997) The validity of two versions of the GHQ in the WHO study of mental illness in general health care *Psychological Medicine*, 27, 191-197.
Goodwin 1998,

Department of Health Survey, (2000). *Psychosocial well-being among older people.* London: The Stationery Office.

Department of Health, (2003). *Health Survey for England 2003.* Published 17th December 2004 . London: The Stationery Office.

Schubotz, D., (2004). *Survey of the needs of people with dual sensory loss in Northern Ireland.* Northern Ireland: Office of First Minister and Deputy First Minister.

Pavey, S., Douglas, G., Corcoran, C. (2005). *Network 1000: a guide to the design and content of the Year 1 survey.* Birmingham: Visual Impairment Centre for Teaching and Research, School of Education, University of Birmingham (mimeo).

Appendices

Appendix 1: ‘How you feel’ questionnaire

Here are some questions regarding the way you have been feeling over the last few weeks (since Christmas). For each question please circle the answer that best suits the way you have felt. Have you recently ...

1. Been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2. Been losing confidence in yourself	Not at all	No more than usual	Rather more than usual	Much more than usual
3. Felt that you were playing a useful part in things	More so than usual	Same as usual	Less useful than usual	Much less useful
4. Lost much sleep over worry	Not at all	No more than usual	Rather more than usual	Much more than usual
5. Felt capable of making decisions about things	More so than usual	Same as usual	Less so than usual	Much less capable
6. Felt constantly under strain	Not at all	No more than usual	Rather more than usual	Much more than usual
7. Been able to face up to your problems	More so than usual	Same as usual	Less able than usual	Much less able
8. Felt that you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
9. Been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
10. Been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
11. Been feeling reasonably happy all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual
12. Been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual

Appendix 2: Descriptive Summary of Cambridge Dataset (Males, Females and Persons)

Males *n* = 152

Mean age of participants	(minus 2 ‘999’ cases)	79 years
Mean age of onset of hearing loss	(minus 25 ‘999’ cases)	49 years
Mean age of onset of sight loss	(minus 25 ‘999’ cases)	59 years
Hearing loss severity	(minus 1 ‘999’ case)	
	Mild	3%
	Moderate	26%
	Severe	50%
	Profound	21%
	Other	1%
Sight loss severity	(minus 1 ‘999’ case)	
	Partially Sighted	56%
	Blind	41%
	Other	3%
Mean GHQ-12 score	(minus 35 ‘999’ cases)	3.5
% Caseness with threshold of 2	(minus 35 ‘999’ cases)	59.0%
% Caseness with threshold of 4	(minus 35 ‘999’ cases)	39.3%

Females *n* = 254

Mean age of participants	(minus 2 ‘999’ cases)	81 years
Mean age of onset of hearing loss	(minus 31 ‘999’ cases)	52 years
Mean age of onset of sight loss	(minus 31 ‘999’ cases)	63 years
Hearing loss severity	(minus 4 ‘999’ cases)	
	Mild	4%
	Moderate	24%
	Severe	51%
	Profound	18%
	Other	4%

Sight loss severity	(minus 4 ‘999’ cases)	
	Partially Sighted	65%
	Blind	30%
	Other	5%
Mean GHQ-12 score	(minus 57 ‘999’ cases)	4.0
% Caseness with threshold of 2	(minus 57 ‘999’ cases)	62.1%
% Caseness with threshold of 4	(minus 57 ‘999’ cases)	46.2%

Persons *n* = 404

Mean age of participants	(minus 4 ‘999’ cases)	80 years
Mean age of onset of hearing loss	(minus 56 ‘999’ cases)	51 years
Mean age of onset of sight loss	(minus 56 ‘999’ cases)	61 years
Hearing loss severity	(minus 5 ‘999’ cases)	
	Mild	4%
	Moderate	24%
	Severe	50%
	Profound	19%
	Other	3%
Sight loss severity	(minus 5 ‘999’ cases)	
	Partially Sighted	62%
	Blind	34%
	Other	5%
Mean GHQ-12 score	(minus 92 ‘999’ cases)	3.8
% Caseness with threshold of 2	(minus 92 ‘999’ cases)	60.9%
% Caseness with threshold of 4	(minus 92 ‘999’ cases)	43.6%